



Transition to adulthood for individuals with autism spectrum disorder: current issues and future perspectives

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Practice points

- The transition to adulthood represents a particularly vulnerable time for youth with autism spectrum disorder (ASD), as the entitlements of the children's service system end and families encounter fragmented systems of care.
- Poor outcomes for this population across multiple domains – education, vocational training and employment, social support, housing and healthcare – suggest that current models of school-based transition planning are not meeting the needs of youth with ASD.
- While there is a continuing need for supportive services, therapies and medical care throughout adulthood, recent research has shown high rates of service disengagement.
- Policies are needed to monitor and enforce the seamless coordination of support across service delivery systems.
- There is a limited empirical base for current practices during the transition period. An aggressive, evidence-based and well-organized program of research, policies and service system changes will be necessary to achieve more favorable transition outcomes for the ASD population.

SUMMARY Rising autism prevalence rates have lent urgency to efforts to improve outcomes for individuals with autism spectrum disorder (ASD). Stakeholders have focused, in particular, on the transition to adulthood that can occur over a range of ages, typically between 18 and 22 years, and often corresponding to when the youth finishes secondary school. This represents a particularly vulnerable time, as the entitlements of the children's service system end and young adults with ASD and their families encounter fragmented and underfunded systems of care. Research across multiple domains – education, vocational training and employment, social support and community involvement, housing and healthcare – reveals poor outcomes for this population during the transition to adulthood, suggesting that the current models of school-based transition planning are not meeting

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the needs of youth with ASD. This article highlights findings from some of this literature, examines financial aspects of the transition process, and offers our perspectives on current practices and recommendations for future study. An organized program of research coupled with aggressive policy and service system changes are needed to achieve more favorable transition outcomes for the ASD population.

Garnering attention in both academic publications and the popular media, rising autism prevalence rates have mobilized families, professionals, the federal government and other stakeholders into action. The CDC has estimated that one in 88 children aged 8 years have the disorder, reflecting a 78% increase from 2002 to 2008 [1]. Autism spectrum disorder (ASD) are heterogeneous and pervasive, and the growing rates will have far-reaching public health consequences. The increasing prevalence has lent urgency to efforts to improve outcomes for individuals with ASD and focused attention on the transition to adulthood, when the entitlements of the children's service system end. This represents a particularly vulnerable period, as young adults leave the school system and encounter fragmented, strained and underfunded systems of care. From employment to housing, healthcare, income and social supports, the transition process requires individuals with ASD and their families to navigate multiple systems to create a customized service plan that suitably blends their preferences and the available resources with their needs.

This article will provide an overview of transition outcomes research conducted in the USA in several domains, including education, vocational training and employment, social supports and community involvement, housing and healthcare. These domains were selected on the basis of their significance for public policy and the allocation of public resources. This article was informed by an exhaustive search of the existing research on outcomes for youth and young adults with ASD, which was scant. We highlight findings and trends from major papers and also discuss financial aspects of the transition process. In the absence of studies specifically focused on transition-age youth, we cite relevant research on the outcomes and experiences of children, adolescents and/or adults with ASD. We conclude with our perspective on current practices during the transition to adulthood and provide recommendations for future study.

Education

According to the US Department of Education, 378,000 students with ASD, aged 3–21 years,

received special education services under the Individual with Disabilities Education Improvement Act (IDEIA) during the 2009–2010 school year [101]. IDEIA requires school districts to provide children with disabilities with a free and appropriate public education, and special education services are developed and implemented through a coordinated individualized education program (IEP). The last reauthorization of IDEIA also requires schools to address transition planning by a student's 16th birthday through the identification of post-secondary goals and related transition services. As defined by the statute, transition services are intended to be results oriented and enable students with disabilities to successfully leave secondary school and enter the adult worlds of post-secondary education, vocational training or employment [102].

The National Longitudinal Transition Study-2 (NLTS2), which followed a nationally representative sample of more than 11,000 youth with disabilities, has greatly enhanced our knowledge of the transition to adulthood for this population. At the start of the study, participants were between the ages of 13 and 16 years and receiving special education under one of 12 federally designated categories (e.g., autism, learning disability, mental retardation or hearing impairment). NLTS2 provides some data on the transition planning process. Approximately two-thirds (66%) of students with ASD had an IEP that identified a course of study to meet transition goals, while 70.6% had received instruction on transition planning [103]. For IEP team meetings focused on transition planning, IDEIA stipulates that the student is invited to attend, as well as representatives from any agencies that are likely to be involved with providing transition services. Despite these requirements, 67.4% of youth with ASD did not attend their transition planning meetings or attended with minimal participation; only 2.6% led the planning [103]. Other participants, such as vocational rehabilitation counselors, agency personnel and advocates, actively participated in transition planning for 49% of youths with ASD [103]. In interviews with parents, 28.1% rated transition planning as 'very useful', 48.4% as 'somewhat

useful,' and 23.5% as 'not very' or 'not at all useful' [103]. These data highlight the need for increased student and family engagement in the process, as well as greater collaboration between schools and outside agencies as transition plans are developed and implemented.

There is widespread evidence that current transition planning efforts are uneven and do not succeed in preparing young adults with ASD to join the adult worlds of either post-secondary education or employment [2–6]. Empirical research has revealed poor secondary and post-secondary educational outcomes for the ASD population. One study found that youth with ASD enrolled in secondary school were, on average, 4.2 years below grade level in reading and 4.9 years below grade level in mathematics [104]. Of the 4876 students with ASD who exited special education in the 2005–2006 school year, 57.1% graduated with a diploma, 26.6% earned a certificate of attendance, 9.1% dropped out, 6.7% reached maximum age and 0.5% died [105]. Compared with individuals in other disability categories who had been out of secondary school for up to 8 years, young adults with ASD had among the lowest rates of post-secondary school enrollment in NLTS2. Approximately a third (32.3%) of young adults with ASD had ever enrolled in a 2-year or community college, 17.4% in a 4-year college, and 21.0% in a vocational, business or technical school [106]. Students with ASD had a 38.8% completion rate from their most recent post-secondary school, which did not differ significantly from the completion rate for other disability types [106].

Shattuck and colleagues have found that positive employment and post-secondary educational outcomes are elusive for many young adults with ASD. In a nationally representative sample of young adults with autism, more than half of the subjects with ASD had not participated in either employment or post-secondary education 2 years after leaving secondary school [7]. Within 6 years of leaving secondary school, just over a third of young adults with ASD had attended any college and slightly more than half had been employed [7]. Furthermore, those individuals from lower income families had poorer outcomes. These data highlight the shortcomings of current transition planning practices.

Vocational training/employment

Persistent unemployment for people with disabilities is an entrenched problem in the

USA. The Department of Labor estimates that in 2011 just 27% of adults between the ages of 16 and 64 years with disabilities were employed compared with 70% of adults without disabilities [107]. Low-employment rates are a constant over the life course of individuals with disabilities. For individuals with ASD, the vast majority are unemployed and those who are employed tend to work in sheltered employment or voluntary jobs [8,108]. When they do work, they switch jobs frequently and have difficulty adjusting to new job settings [9,10].

Poor outcomes in employment should not be construed as evidence that individuals with ASD cannot work. An extensive body of research has demonstrated that with appropriate supports, individuals with ASD can work in a variety of businesses and industries [11]. Supported employment, in particular, has increased employment rates and has been associated with improved quality of life and cognitive performance [12–14].

More recent research has focused on strategies designed to increase employment retention by matching the individual to a complimentary job. A variety of strategies have been successful in yielding an appropriate match, including offering choices, using assessments to determine task preferences, evaluating social and communication needs, and adding necessary modifications and adaptations [10,15–17]. Furthermore, comprehensive, system-level interventions that develop customized employment opportunities have been successful in improving retention [18,19].

Social supports/community involvement

ASD is characterized by significant impairments that affect social functioning. These include stereotypical gestures, difficulty with eye contact, limited emotional and social reciprocity, and an inability to correctly perceive or 'read' faces [20,21]. Furthermore, aggressive behavior is common among children and adolescents with ASD. In one study, nearly half of the sample of children and adolescents exhibited aggression toward noncaregivers, and well over half were aggressive toward family caregivers [22]. Self-injurious behavior is also highly prevalent in children, adolescents and adults with ASD, with reported rates ranging from 25 to 50% [23–26].

In addition to these behavioral and social challenges, communication deficits are a core feature of ASD despite having unclear etiologies [20,27].

These communication problems often correlate with an inability to develop high-quality social relationships [28,29]. Together, these ASD characteristics and maladaptive behaviors collectively impede the formation and maintenance of social relationships with peers and others outside the family [30,31]. They also prevent individuals with ASD from fully engaging in their communities [32,33].

A substantial body of research has found children and adolescents have significant difficulty making and sustaining friendships, as well as engaging in social activities with same-age peers. Many youth with ASD report having either no friends at all, or characterize their friendships as lacking responsiveness, reciprocity or overall quality [33–40]. The existing research related to integration, friendships and quality of life paints a picture of extreme social isolation and loneliness for many adolescents with autism.

Despite early stereotypes about people with ASD seeking to avoid social relationships, research has shown adolescents with ASD express interest in having social relationships and meaningful friendships [41,42]. However, this desire is often accompanied by limited skills and insights needed to acquire or sustain such relationships. In longitudinal studies, researchers have observed that social and friendship gains occur as children age into adolescence and as adolescents age into adulthood [41–44]. However, social isolation remains profound and persists through late adolescence and into adulthood.

While poor social function is a defining characteristic of ASD, researchers have worked to understand which adolescents with ASD are at elevated risk for poor social relationships [20]. Correlates of social isolation, loneliness and a lack of friends include limited social support networks, communication deficits and more severe ASD symptoms [36,38,39,45,46]. In one study of adolescents living at home with family caregivers, Orsmond and colleagues reported that half of their sample had no peer relationships beyond those at school or work [33]. Moreover, these researchers found that age and level of social impairment predicted social relationships, but environmental characteristics (e.g., number of services received, mother's activities and school inclusion) did not. These findings, in particular, have important implications for the design and implementation of interventions and programs to build the social relationships and full community inclusion of young adults

with autism. Targeted interventions have been developed to enhance the social relationships of children and adolescents with autism, often by enhancing their communication abilities and/or offering training in socially appropriate behavior [47–49]. There remains, however, a critical need for evidence-based interventions to address the social inclusion of youth with autism.

Housing

The proportion of adults with disabilities living in their families' homes is growing, prompted by lengthening wait lists for out-of-home placements in most states [50]. This trend has implications for transition-age youth with disabilities, including those with ASD. Young adults with disabilities have made few gains in accomplishing a common marker of adulthood – that of moving out of the family home and into an independent living situation. Although research on the living situations of youth and adults with ASD is somewhat limited, several studies have found that the majority of youth in their post-secondary school years continue to live at home and fewer than 10% live independently [32,51,108].

Well-documented difficulties in executive functioning among individuals with ASD contribute to the challenges they face in gaining the skills needed to live independently or with lower levels of supervision and support [52]. Specifically, individuals with ASD have difficulty dealing with new situations and processing complex information as well as problem-solving through planning [53,54]. These skills are necessary for managing everyday occurrences. Research has identified interventions that improve independence in the home environment. These efforts have focused on increasing self-help skills, reducing inappropriate behaviors and increasing participation in activities of daily living [55,56]. Video modeling is one technique that has been found to be effective in teaching these skills, but implementation has, thus far, been limited [57,58]. It is critical that these types of training sessions take place beginning in the adolescent years [59]. Family involvement in the training is also important, as many young adults need ongoing support and supervision [8].

Healthcare

Transitioning from the pediatric to the adult healthcare system can be a challenge for any youth and especially so for youth with special healthcare needs, such as those with ASD [109]. Despite efforts by the Maternal and Child Health

Bureau and the American Academy of Pediatrics to heighten awareness of the need for transition services, existing research confirms that many youth with disabilities do not receive any support in planning for or making this transition [60–62].

Healthcare transitions can be complicated for youth and young adults with ASD due to their increased need for specialized care for common co-morbidities, such as mental and behavioral health disorders, epilepsy, gastrointestinal problems, and respiratory, food and skin allergies [63–65]. The prevalence of such secondary health issues heightens this group's need for continuous healthcare through adulthood and suggests that a lapse in care may be especially detrimental to their well-being. In addition, compounding transition challenges for many youth with ASD are their unusual sensory responses to some environmental stimuli, as well as their increased anxiety associated with entering new and highly stimulating environments [66,67]. Sensory sensitivity has been noted across all primary modalities (i.e., auditory, visual, tactile, olfactory and oral) [68,69].

Practice adaptations, such as scheduling appointments during less busy times and organizing preappointment visits to foster comfort and familiarity, may be necessary to help youth with ASD move smoothly into adult healthcare practices [66]. A recent study conducted in-depth interviews with 19 healthcare professionals from 15 care sites across the USA and Canada that primarily serve children and youth with ASD and other developmental disabilities. Five strategies were already in use by some sites to help the transition from pediatric to adult care. These consisted of creating a medical summary to pass on to the adult provider, keeping an informal list of adult providers who would accept referrals for ASD patients, using various care coordination strategies such as conducting teleconferences between pediatricians and adult providers, setting up transition-specific appointments and using checklists to help guide youth through the process [KUHLETHAU KA ET AL. TRANSITION TO ADULT HEALTHCARE FOR YOUTH WITH AUTISM SPECTRUM DISORDER: ISSUES AND PROMISING NEW DIRECTIONS (2013), SUBMITTED]. Other interventions that were identified as needed included creating care binders or workbooks to help organize materials, providing education and training sessions for youth and families, and giving adult providers and medical students more formal training about transition issues and disabilities in general.

Financial considerations

Children and youth with ASD require a diverse array of medical, therapeutic, behavioral and educational services, typically at a high level of intensity [70–73]. Direct medical expenditures are incurred as a result of an elevated need for hospital and emergency services, outpatient, physician and clinic services, medications, behavioral therapies, complementary and alternative therapies, specialized equipment and supplies, and home health services. Beyond these medical costs, many families utilize non-medical services, including specialized childcare, respite, educational services and modifications to the family home [74]. These needs make ASD exceptionally expensive to the public health, social welfare and educational systems. For example, Liptak and colleagues found that the combined healthcare costs of children with ASD were seven-times higher than the healthcare costs of nondisabled children [70]. In another study, total healthcare spending for children with ASD was four- to six-times greater than spending for nondisabled children [71].

Health insurance does not adequately cover the costs of far-ranging, intense service needs of children with ASD [110]. This gap translates into high out-of-pocket spending for families, which can lead to significant financial burden. In one nationally representative study, a third of families that reported any out-of-pocket spending for their children with ASD spent at least 3% of their gross annual income on these health expenses [75]. Furthermore, parents' ability to work is often compromised due to the dynamic and extensive nature of children's care needs. Montes and Halterman reported that families of children with ASD had an average annual loss of 14% of total income [76]. In another study, family income was 28% below that of families of nondisabled children [77]. High out-of-pocket expenditures, coupled with reduced employment, increase the likelihood that having a child with an ASD creates significant financial problems, including bankruptcy and forfeiture of later-life financial security [76–79].

The extent of families' financial burdens depends not only on their own income and resources, but also on the relative generosity of coverage provided by insurance. Families living in states with greater per-capita Medicaid coverage experience lower financial costs related to the healthcare of their children with ASD [75].

Inadequate private insurance coverage has led families to advocate for state parity legislation, which compels private insurers to cover ASD services at comparable levels to other healthcare. To date, families and advocates have been successfully securing various versions of ASD coverage mandates in 32 states [110]. There is promising evidence that families living in states that have adopted these private insurance coverage mandates experience reduced financial burden related to the healthcare costs of their children with ASD [80].

Importantly for our purposes, the costs of ASD services do not end with childhood. Ganz estimated the additional lifetime costs for each individual with ASD exceed US\$3,000,000, which includes medical and non-medical service expenditures [74]. Cidav and colleagues found that the costs of medical and supportive services for children with ASD rise as children enter and progress through adolescence [81]. This trend persists for nearly all types of medical care, including inpatient hospitalization, psychotropic medications, outpatient services, occupational therapy, behavioral health services, respite and personal assistance. Only the costs of speech therapy and diagnostic/assessment services were lower for youth aged 12–17 years than for younger children with ASD [81].

The limited body of research that has investigated the well-being of adolescents with ASD as they age into adulthood has generally found that some individuals demonstrate modest gains in the range of ASD symptoms and some individuals realize improvements in verbal and social skills [44]. Approximately 10–15% of individuals diagnosed with ASD during childhood ultimately become symptom-free during adulthood [44]. However, most individuals with autism, including those whose symptoms and skills improve, do not achieve normal ranges of functioning in adulthood, and their ASD symptoms persist in impairing their daily living [44]. These findings indicate a continuing need for supportive services, therapies and medical care throughout adulthood. Recent research, however, shows alarmingly high rates of service disengagement. Shattuck and colleagues documented decreased service use – including medical care, mental healthcare, case management and speech therapy – for individuals with ASD after leaving secondary school. In their study, 39.1% of subjects had not received any services, and the odds of service disengagement

were higher for African–American individuals and those from low-income families [82].

There are several reasons for the challenges families face as individuals with ASD transition from secondary school into adult services. The participation of youth with ASD in special education services is usually a prerequisite for parental employment, because these youth need supervision and support and cannot necessarily be left alone during the day while a parent works. Parental employment is, in turn, imperative for family financial well-being. Upon exiting secondary school, individuals with ASD enter the adult service system, in which there are no entitlements beyond the safety net provided by Medicaid and Supplemental Security Income. Both programs have strict asset and income caps, and Supplemental Security Income, in particular, has limited take-up and viability in assisting adults with ASD to become independent [111].

Another financial implication of the entitlement to educational services is the fact that schools generally pay for a range of ASD services, including speech, occupational and physical therapies, as well as behavioral interventions. Families frequently contest educational quality, and extensive litigation has resulted from parents seeking court intervention to secure services for their children with ASD [83–87]. This body of case law has not always favored parents, but the courts have clearly established that the provision of an adequate education to children and youth with ASD typically requires schools to provide behavioral and therapeutic services [85,87]. These services are often expensive. For example, applied behavior analysis, which has been rated as an evidence-based practice by the Centers for Medicare and Medicaid Services environmental scan and has been deemed an established treatment by the National Autism Center's National Standards Report, costs an average of \$40,000 annually per child [88,112,113]. Clearly, the need for these frequently costly services does not end when youth with ASD exit the schools, although schools no longer have an obligation to pay. The positive relationship between increasing child age and rising costs for health services and the lack of significant diminution of symptoms as children enter adulthood provide stark evidence that families are probably bearing significant financial costs for their young adult children with ASD [44,81]. Further research is needed to understand these costs and their implications, but we speculate that the financial burden for

families increases as children leave secondary school.

Conclusion & future perspective

Observational studies, such as NLTS2, have helped to map pathways for young adults with ASD and identify areas of need. In order to improve transition outcomes for this population, however, research must shift to developing, implementing and evaluating empirically informed interventions. Commissioned by the Centers for Medicare and Medicaid Services, an environmental scan investigated psychosocial supports and services for individuals with ASD across the lifespan, published in the literature from 1998 to 2008. The research group evaluated the methodological rigor of more than 200 studies and identified evidence-based interventions based on the number and quality of studies supporting their use. Only one out of 15 interventions for transitional youth and three out of nine interventions for adults were rated as evidence-based [112]. The Agency for Healthcare Research and Quality conducted a recent review of behavioral, educational, vocational, adaptive/life skills and allied health interventions for adolescents and young adults with ASD. Of the 32 studies included in the analysis, none were found to be of good quality, five were deemed to be fair quality and the remainder were categorized as poor quality [114]. Clearly, much work needs to be carried out to strengthen the empirical base of effective practices during the transition period.

In the education realm, we believe accountability systems for post-secondary school outcomes and effective secondary school transition planning are urgently needed. Further efforts should focus on reducing the achievement gap between secondary students with ASD and their typically functioning peers. Through higher levels of academic achievement, individuals with ASD will have access to a greater range of post-secondary schooling and employment opportunities. Innovative education strategies and curriculum design will be critical in serving a population with wide variability in cognitive skills and learning profiles. To promote college and career readiness, the Common Core State Standards, currently adopted by 45 states, have established content standards for English language arts and mathematics for all ages from kindergarten through grade 12. New assessments and more challenging performance benchmarks

tied to the Common Core State Standards are under development. How students with ASD and other disabilities will fare in this changing landscape remains to be seen. In particular, schools and families will have to determine how to strike a balance between academic and vocational training.

As conceptualized by IDEIA, transition services aim to enhance students' preparation for life beyond secondary school. Yet the outcomes data cited above suggest that the current models of school-based transition planning are not meeting the needs of youth with ASD. In our opinion, schools must increase student and parent engagement in the planning process, helping families to define their goals, identify the necessary action steps and access resources. Furthermore, schools must work more collaboratively with vocational and employment service organizations. If these efforts are undertaken early and allow sufficient time for preparation and implementation, we believe that the dismal outcomes in post-secondary education and vocational training and employment could start to improve. Hagner *et al.* investigated a transition planning intervention, which included parental training sessions and individualized planning. The active group had significantly greater youth and parent expectations for the future, as well as higher measures of student self-determination and career decision-making ability [89]. The authors suggest that this model could be financed through a reallocation of existing funds.

For residential services, however, the increasing prevalence of ASD necessitates an infusion of funds for system expansion. Nearly all residential services for people with ASD and other developmental disabilities in the US are supported by Medicaid, but states have cut their Medicaid spending in order to balance their budgets [90]. While the federal government added billions to protect Medicaid during the recession, those funds ended in Fiscal 2011, leaving states in a weak position even as the economy improves [91]. It is wholly unclear how states will be able to address the growing waiting lists for residential services without a significant influx of new federal finances. Given the current situation and the years it will take to address the deficit, such an expansion appears unlikely. The federal government, however, has an existing mechanism that could be used to stimulate state spending to increase community-based residential supports for people with ASD and other developmental

disabilities. The Home and Community-Based Services (HCBS) Waiver, which permits states to use Medicaid funds for various support services, has been the most important driver of the growth of the community (as opposed to institutional) residential service system since its passage in 1982 [90]. We feel that enhancing the Federal Medical Assistance Percentages (the funds provided by the federal government to each state for Medicaid) for new HCBS residential services would likely be effective in encouraging states to expand their residential service systems.

Evidence of significant racial and income disparities in diagnosis, treatment utilization, and access to educational interventions and healthcare services can contribute to deleterious outcomes over time for those disadvantaged individuals [82,92–95]. We need assertive action to redress this situation, designing research to more fully understand the determinants of these inequalities and formulating policies to monitor and reduce these disparities. One proposal would be to establish financial incentives for service providers (e.g., academic institutions, social service agencies and healthcare providers) that achieve benchmarks in quality and equal access for all.

The current fragmentation of the educational, vocational, employment and residential support systems bears significant responsibility for the negative outcomes achieved by youth and young adults with ASD. Hampered by long waiting lists and limited funding, adult programs often cannot serve all eligible clients. Families

often must pay for supports previously covered by school or health insurance themselves. Some individuals may be too high functioning to qualify for services from developmental disability or vocational agencies, yet their communication and social impairments, in particular, limit their ability to successfully navigate the transition on their own. Resources should promote increased access to services for all transitioning youth with ASD, with a particular focus on those subgroups currently falling into service voids. In addition, we believe that policies are needed to monitor and enforce the seamless integration of support across service delivery systems. This will require greater collaboration and coordination among service providers, which should begin during the transition planning process in secondary school.

The balance of research across these domains indicates that an aggressive, evidence-based and well-organized program of research, policies and service system changes will be necessary to achieve more favorable transition outcomes for the ASD population.

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