



Transitioning from Adolescence to Adulthood with Autism Spectrum Disorder

An Overview of Planning and Legal Issues

Nanette Elster, JD, MPH*, Kayhan Parsi, JD, PhD

KEYWORDS

• Autism • Transition • Planning • Adolescence • Adulthood • Legal • Ethical

KEY POINTS

- Transition from adolescence to adulthood presents a variety of challenges to individuals with autism spectrum disorder (ASD).
- A variety of legal mechanisms exist to help support the interests and autonomy of individuals with ASD.
- Individuals with ASD who are transitioning will need a variety of supports (financial, housing, education, transportation, health care).
- A potential solution to improving transition to adulthood is supported decision-making.

INTRODUCTION

The transition to adulthood is complex. It is defined by many objective milestones, including going to college, obtaining employment, moving away from parents, and building a family.¹ Transition is also defined by subjective milestones, including being able to care for oneself, make important decisions, and manage one's finances.¹ Transition from adolescence to young adulthood is challenging for neurotypical individuals as well as individuals with autism spectrum disorders (ASD). However, for autistic individuals, this transition is even more complicated and poses a range of legal and ethical considerations. This article discusses how existing legal and social constructs may exacerbate rather than diminish barriers and access for autistic adults and

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Neiswanger Institute for Bioethics, Loyola University Chicago Stritch School of Medicine, 2160 South First Avenue, Maywood, IL 60153, USA

* Corresponding author.

E-mail address: nelster@luc.edu

Twitter: [@kayhanparisi](https://twitter.com/kayhanparisi) (K.P.)

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identifies current and potential legal and policy solutions to reducing current systemic barriers.

BACKGROUND

The transition from adolescence to young adulthood is challenging not only for individuals with ASD but also for their parents and caregivers. Parents report many obstacles and barriers in trying to get needed services for their children. For example, in 1 study “parents of individuals with ASD (20.83%) and CP [cerebral palsy] (18.18%) reported greater barriers in navigating the service delivery system compared to parents of adults with DS [Down syndrome] (10.87%).”²

The study goes on to report that

[p]ost hoc tests revealed that parents of adults with CP and ASD had significantly greater future planning barriers with respect to a lack of information (0.46 and 0.48, respectively) compared with parents of adults with DS (0.17). Parents of adults with DS (vs ASD and CP) also reported significantly less future planning barriers with respect to financial barriers ($F = 6.15$, $P < .001$, partial $\eta^2 = 0.06$). Post hoc tests revealed parents of adults with ASD had significantly greater financial barriers (0.61) compared with parents of adults with DS (0.29).²

The literature is clear that compared with individuals with DS, parents of young adults with ASD face greater challenges when it comes to a variety of markers of adulthood. Many parents refer to this transition of their adolescent children into young adults as “falling off the cliff”; experts in transition planning refer to this as the services cliff.³ This cliff metaphor powerfully reflects the new reality wherein services for which young adults with ASD were once entitled to now become services for which they are merely eligible.

OVERVIEW

This article considers several factors related to transition planning from adolescence to young adulthood for autistic individuals:

1. Legal mechanisms to protect the interests of autistic individuals
2. Capacity
3. Needed supports
 - a. Financial
 - b. Housing
 - c. Education
 - d. Transportation
 - e. Health care, including mental health care and oral health care
4. Eligible support mechanisms
5. Shared decision making: A potential solution to improving transition to adulthood

CURRENT LEGAL CONSIDERATIONS IN TRANSITION PLANNING

Transition planning is very individualized. Physical, psychological, and intellectual abilities will all influence how to best support autistic individuals in moving toward adulthood. These same factors will be considered in determining who should make decisions and how. A range of legal mechanisms exist to support or control decision making for individuals with disabilities, including guardianship, conservatorship, power of attorney for health care, and power of attorney for finances. Many of these

mechanisms have state-specific eligibility requirements; therefore, this article discusses the concepts generally.

Because capacity to make decisions may wax and wane or may exist for some decisions but not others, determining which legal mechanism or mechanisms are most appropriate can be challenging. Making such a determination, however, is necessary in moving forward with any transition plan. Some transition plans may involve more than 1 mechanism or may require a periodic readjustment regarding decision making because circumstances of the individual with ASD will change as will those of the decision maker or makers. What follows is a brief description of some of the most commonly used mechanisms for decision making for individuals who lack or have limited capacity to make decisions in one or more areas of activities of daily living (ADL).

Guardianship

Guardianship is a legal proceeding whereby a court grants an individual or individuals certain rights and authority with regard to another individual.⁴ Guardianship is typically pursued when a person is of the age of majority but is unable to manage various aspects of their lives. (Guardianship of children also occurs, but discussion of this is beyond the scope of this article.) A court of law must deem that adult individual to be incompetent to enter into certain kinds of activities. Guardianship can have different levels of authority. Partial guardianship may grant an individual with certain rights and responsibilities. For instance, a partial guardian may be able to make financial and health care decisions for a person with ASD, but leave other decisions to him or her. Adolescents with ASD who are in transition should be included in the discussion as to whether a full, partial, or no guardianship situation is indicated. Part of this discussion will necessitate what if any ADLs the adolescent has trouble managing, and most importantly, what the person for whom guardianship is sought desires.⁵ Kirby and colleagues¹ recommend that “youth are engaged throughout this process so that their perspectives about their own interests, abilities, and limitations are considered as well as situational characteristics that are appealing to them.”

For individuals at majority age with ASD who also have an intellectual disability, most commonly other concerned parties (typically parents) seek out guardianship. Guardianship can be fraught with challenges, even when pursued with the best of intentions. An adult in guardianship relinquishes a great deal of legal rights. Parents (and other interested parties) who seek guardianship for a young adult with autism should give careful thought about the gravity of their decision. As one commentator has observed, “Adults in guardianships often have fewer rights than convicted felons, and the process is rarely reversible.”⁶ In addition, once a guardian is appointed, making changes to that relationship is very arduous, and again, requires court intervention.

Conservatorship

Conservatorship is a slightly different legal category compared with guardianship, depending on the jurisdiction. Conservatorship grants legal rights to an individual to control the financial affairs of another person.⁴ Guardianship grants broader legal authority over another (although a limited or partial guardianship can be created that limits one's authority over another's legal affairs. In this case, conservatorship and guardianship would be synonymous). Conservatorship may be indicated in young adults with ASD who have challenges with regard to managing finances. Other mechanisms, such as power of attorney or representative payee, that is discussed later, may also be implemented to manage finances.

Differences between Guardianship and Conservatorship

Both guardians and conservators are appointed by a court. Such appointments are only made after an individual is determined, by a court, to lack legal capacity. In order for appointment of a guardian and/or conservator, a court must determine that the person for whom guardianship is sought cannot

- Meet essential requirements for physical health, safety, or self-care because the respondent is unable to receive and evaluate information or make or communicate decisions, even with appropriate supportive services, technological assistance, or supported decision making; and
- The respondent's identified needs cannot be met by a protective arrangement instead of guardianship or other less restrictive alternative.⁷

Although this is a "model law" and has not been enacted in every jurisdiction (the above language is from a Washington state statute), it provides a helpful reference point given that laws related to guardianship and conservatorship differ from state to state.

Conservatorship typically refers to decisional authority over the property of another. The National Conference of Commissioners on Uniform State Laws in the Uniform Guardianship, Conservatorship, and Other Protective Arrangements Act defines a conservator as "a person appointed by a court to make decisions with respect to the property or financial affairs of an individual subject to conservatorship."⁴ A guardian has broader authority and is defined as "a person appointed by the court to make decisions with respect to the personal affairs of an individual."⁴ Guardians can make decisions about health care, housing, and even personal associations. Ultimately, guardianship and conservatorship are formal legal proceedings that involve a court of law. They should be viewed as a "last resort" when other legal mechanisms prove to be inadequate in protecting the interests of an adult with ASD.⁶

Power of Attorney

Less formal legal mechanisms exist to help support young adults with ASD, including a power of attorney for health care and power of attorney for finances. For instance, the power of attorney for health care is a legal document whereby a principal grants an agent or proxy authority to make health care decisions for the principal (typically if the principal loses decision-making capacity). This kind of power of attorney is usually associated with older individuals who may eventually lose decision-making capacity and want to have a trusted individual (typically a family member) make critical health care decisions. This kind of authority to make health care decisions is typically triggered when the principal lacks decision-making capacity. However, a durable power of attorney for health care can be executed that grants an agent decision-making authority for health care decisions immediately. This kind of durable power of attorney for health care may be indicated in situations whereby a young adult with ASD needs greater support for health care decision making.⁸

The power of attorney for finance limits an agent's authority to financial decision making. Similar to the power of attorney for health care, this power of attorney can take effect immediately, allowing an agent to make financial decisions for the principal.⁹ In either instance, the selection of a decision maker is often based on that individual's ability to make a decision that is one that the incapacitated person would have made if able to do so. This concept is known as substituted judgment. If the individual not only currently lacks capacity but has had limited or no capacity before the designation of the power of attorney, then decisions should be made that are in the

best interests of the incapacitated individual. Both standards can pose challenges in practice. The substituted judgment standard presumes that a principal who had capacity but no longer possesses it has shared their views and preferences with their agent. The best interest standard, which is typically what is used with pediatric patients, is often interpreted as an objective standard. However, as anyone who is familiar with controversial pediatric cases can attest, not everyone subscribes to the same views regarding what is in a person's best interests.

Representative Payee

Another possible mechanism for managing financial concerns is the appointment of a representative payee. For example, if a person is receiving benefits under Social Security or Supplemental Security Income (SSI), the Social Security Administration can "appoint a suitable representative payee (payee) who manages the payments on behalf of the beneficiaries."¹⁰ The designee is often a friend or family member but may also be an organization.¹¹

Privacy Protections

An important consideration is assessing how and by whom decisions should be made for an adult with ASD, because considerations of privacy are critical. Certain legally mandated privacy protections exist for adults. Two areas of federal regulation that governs what information can be shared by whom and with whom are in the areas of health privacy and educational privacy. The Health Insurance Portability and Accountability Act (HIPAA) is the federal law that governs the privacy of personal health information.¹¹ The Family Educational Rights and Privacy Act (FERPA) is the federal law that protects access to educational information about a student.¹²

Both HIPAA and FERPA are necessary considerations because adults with ASD do not relinquish their privacy rights because of their autism or any related intellectual disability (absent a guardianship arrangement). Privacy protections for those older than 18 without a guardian or conservator can only be waived in writing by the individual.

NEEDED SUPPORTS

Like neurotypical young adults, adolescents with ASD who are transitioning to adulthood require several supports. These supports include but are not limited to the following:

1. Financial
2. Housing
3. Education
4. Transportation
5. Health care (including mental and oral)

Other supports might include a range of social supports, including engaging in recreational activities, dating, alcohol use, and social media use. Because young adults with ASD represent a variety of capabilities, the level of support provided must be tailored to the needs of each individual.¹³

Financial

Financial support may mean providing a personal finance course for someone with ASD who lacks an intellectual disability but has challenges with managing personal finances. Another young adult with ASD may require a trusted person (typically a

parent) be the financial power of attorney for the individual. Given that some benefits are income dependent, having a basic understanding of finances can ensure that one continues to be eligible for those supports.

Housing

With regard to housing, many young adults with ASD live at home with parents. Others may live in group homes. The deinstitutionalization movement started in the early 1970s facilitated adults with intellectual disabilities to live in more intimate settings. This trend culminated in the late 1990s with the US Supreme Court Decision, *Olmstead v L.C.*, 527 U.S. 581 (1999). The Court rendered its holding under the Americans with Disabilities Act (ADA) finding that “public entities must provide community-based services to persons with disabilities when (1) such services are appropriate; (2) the affected persons do not oppose community-based treatment; and (3) community-based services can be reasonably accommodated, taking into account the resources available to the public entity and the needs of others who are receiving disability services from the entity.”¹⁴ Although the holding was not specific to persons with ASD, it has influenced housing for those with ASD.

Recently, a new movement has emerged that has specifically examined this question of appropriate housing for young adults with ASD.¹⁵ Some are arguing for more campuslike environments for individuals with ASD. Such settings could potentially offer more services and opportunities for cultural and recreational activities compared with traditional group home settings. This setting would allow for adults with ASD to become more integrated into their communities.

Education

Education also poses interesting challenges. Once an individual has aged out of the public education system (typically by the age 22), they no longer are entitled to educational services. They may be eligible for services and may receive some accommodations, but cannot be discriminated against in educational settings. The previous entitlement regimen, however, is gone. Essentially, this becomes a shift from the Individuals with Disabilities Act, which is an entitlement protection, to the ADA, which only requires reasonable accommodation.¹⁶

Young adults with ASD may opt for a variety of educational opportunities. For instance, some traditional colleges and universities have special curricula for students with ASD (National Louis University and Elmhurst College). Other schools are specifically geared toward individuals with ASD and other learning disabilities (Beacon College, Landmark College). Also, many community colleges offer students with ASD specialized courses and curricula. Not all of these options, however, will result in a traditional bachelor’s or associate’s degree. In addition, vocational opportunities may also exist.

Transportation

Transportation is one of the major markers for emerging adulthood. Many adolescents acquire a driver’s license when they turn 16. Because of deficits in executive functioning, adolescents with ASD may either delay or never acquire a driver’s license. Many will depend on family members or ride-sharing services. If they live in a major city with a well-developed transit system, they may be able to navigate the various transit and bus lines. Almost every community offers some kind of transportation assistance for individuals with disabilities. Mobility provides a certain level of freedom and independence for young people, impacting employment, access to health care, and social integration.¹⁷

Health Care

Health care poses special challenges for young adults with ASD. As pediatric patients, these individuals typically relied on their parents to make health care decisions. As young adults, they may no longer see a pediatrician and are relying on internists and other adult care professionals who may have much less training and experience treating individuals with ASD. Such care is also not as coordinated once a young adult with ASD moves from pediatric care to adult care. Importantly, many individuals with ASD can still make health care decisions for themselves (absent guardianship). A recent movement away from guardianship has been supported decision making (as discussed later). This kind of model allows an individual with ASD to make health care decisions with the support of another trusted person, as opposed to completely relinquishing their decision-making rights under a guardianship model.

ELIGIBLE SUPPORT MECHANISMS

Adults with ASD may be eligible for a range of supportive services through state, federal, and local sources. Some of the most common services are discussed later, but what follows is in no way exhaustive.

One source of support available to adults with ASD is SSI through Social Security. This program “pays benefits to disabled adults and children who have limited income and resources.”¹⁸ SSI is income dependent, and thus, if income increases, SSI financial benefits may be diminished. Other sources of support, however, may still be available, including Medicaid benefits to cover health care expenses. The income eligibility requirements can be an impediment, however, to pursuing satisfying employment and perpetuates payment of the legally sanctioned subminimum wage.

Medicaid is a key source of support for noninstitutional housing for individuals with ASD. Although Medicaid does provide federal funding, this funding is a match of state funding rather than an independent stream of funding by Home and Community-Based Service Waivers under Section 1915(c) of the Social Security Act is an example.¹⁹ The Centers for Medicare and Medicaid Services offers incentives to encourage states to develop programs supporting provision of noninstitutional services (**Box 1**).

Because these are state and federal partnerships, the contours will differ from state to state and therefore are beyond the scope of this discussion. For a robust discussion of residential options under Medicaid, please see Cooper R, “Medicaid Residential Options for People with Autism and Other Developmental Disabilities.”²⁰

Box 1

Home and community-based service waiver program basics

To qualify for a Home and Community-Based Service waiver, states must:

- Demonstrate that providing waiver services will not cost more than providing these services in an institution
- Ensure the protection of people’s health and welfare
- Provide adequate and reasonable provider standards to meet the needs of the target population
- Ensure that services follow an individualized and person-centered plan of care

From Medicaid.gov. Home & Community-Based Services 1915(c). Available at: <https://www.medicaid.gov/medicaid/hcbs/authorities/1915-c/index.html>. Accessed Sept 30 2019.

Achieving a Better Life Experience Accounts (ABLE)

Some have argued that the strict asset and income caps on SSI and Medicaid have “limited take-up and viability in assisting adults with ASD to become independent.”²¹ One recent development that may counteract these earning thresholds is the creation of an Achieving a Better Life Experience (ABLE) Account. With the 2014 passage of the Achieving a Better Life Act (Public Law 113–295), “Contributions to the account, which can be made by any person (the account beneficiary, family and friends), must be made using post-taxed dollars and will not be tax deductible for purposes of federal taxes; however, some states may allow for state income tax deductions for contributions made to an ABLE account.”²² Although created through federal legislation, ABLE accounts are state specific and states are not required to offer such programs. ABLE accounts afford “many individuals with disabilities . . . the ability to save money to meet their own personalized needs while remaining qualified for benefits programs that are critical to maintaining their health and well-being.”²³

The ADA is another potential support; however, it provides no direct benefits but rather protects against discrimination in places of public accommodation, such as housing and employment based on one’s disability (ADA, <https://www.ada.gov/pubs/adastatute08.htm>). The ADA may also require that “reasonable accommodations” are made to support the individual identified as having a disability. These reasonable accommodations can include such things as an adapted physical environment, an assistive communication device, a service animal, and so forth.

SHARED DECISION MAKING: A POTENTIAL SOLUTION TO IMPROVING TRANSITION TO ADULTHOOD

Currently, only 2 states, Delaware and Texas, legally recognize supported decision making. The underlying principle expressed in the Delaware statute is that “[a]ll adults should be able to live in the manner they wish and to accept or refuse support, assistance, or protection as long as they do not harm others and are capable of making decisions about those matters.”²⁴ In Texas, the stated purpose of the supported decision-making statute is to “recognize a less restrictive substitute for guardianship for adults with disabilities who need assistance with decisions regarding daily living but who are not considered incapacitated persons for purposes of establishing a guardianship. . . .”²⁵

Many organizations, including the American Bar Association²⁶ and The Arc,²⁷ support this approach. In part, this approach to decision making has been favored because “guardianship creates tension between respect for patient autonomy and concern for patient competency. . . .”²⁸

Supported decision making, in conjunction with measures other than guardianship, is one way to respect the autonomy of the person with ASD. Respect for autonomy also gives the person a voice not only in his or her own care but more generally with respect to what is or is not helpful to others with ASD. Given that ASD is a spectrum and not generalizable, legal recognition of supported decision making is 1 way to promote social justice for persons with ASD.

In surveying these various issues, adolescents who are transitioning into young adulthood must be treated as individuals with their own set of values and preferences. The adage “if you’ve seen one person with autism, you’ve seen one person with autism” certainly applies. Some individuals with ASD may require full guardianship. Others may require a conservator. Others may only need supported decision making with a trusted third party (which may be a parent or other appropriate person). Moreover, in outlining the various needs, the authors wish to highlight that this population of

young people with ASD is not monolithic. However, they often do share similar challenges and concerns.

SUMMARY

One of the most difficult aspects of transitioning to adulthood for those with ASD and their caretakers is the complex web of services and supports that were once coordinated and provided by external sources, such as schools and health care professionals. As these former sources of support become increasingly diffuse and uncoordinated with no clear path to ensuring that the financial, housing, emotional, social, and medical needs of the individual are met, the hope is that any potential legal issues can be appropriately addressed. The variety of mechanisms described here recognizes that once the transition is complete, the person for whom decisions are being made is an adult with all the rights that come with such status. Ultimately, any plan must ensure a balance between the autonomy of adults with ASD while still protecting their interests if necessary.

DISCLOSURE

The authors have nothing to disclose.

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