



# Community Advocacy

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## Transition to Life After High School

When an individual with autism completes the high school years and exits the school system, services and how they are accessed change dramatically. Although there is key federal legislation in place to support adults with disabilities, the programs and avenues of access become more complex and dispersed among agencies that facilitate and provide adult services. Before a student receiving special education services departs from high school, a thoughtful transition plan must be implemented by the school and documented according to measurable goals. The point of the transition plan is to provide a scaffold for this critical passage into adult life, with the goal of successful transition outcomes. Currently, individuals with autism face significant barriers during this transition to life after high school. Recent research indicates that “[y]ouths with ASDs are especially vulnerable during this period because of their challenges with communication and social interaction, greater reliance on others for aid, and high rates of comorbid health and mental health problems.”<sup>2</sup> Therefore, it is critical to develop advocacy strategies to meet the needs of adults with autism, as well as to support them as they become more self-determined in services planning. As a first step in the advocacy learning process, it can be useful to learn about key federal legislation that has been passed to support individuals with disabilities. Indeed, our success in advocacy as family members, professionals in the disability fields, and people with autism depends upon informing ourselves of basic rights and programs that are protected and funded by this legislation.



2. Shattuck, Paul, et.al. Post-high school service use among young adults with an autism spectrum disorder, *Pediatrics and Adolescent Medicine*, February 2011, Vol 165, No. 2, <http://archpedi.jamanetwork.com/article.aspx?articleid=384252>





## Relevant Federal Legislation

### Americans with Disabilities Act

The Americans with Disabilities Act (ADA) is the most comprehensive piece of legislation that protects the civil rights of individuals with disabilities. It was enacted and signed into law on July 26, 1990. In many respects, the ADA is an extension of the Civil Rights Act of 1964, which made discrimination based on race, religion, sex, and national origin illegal. Knowing the rights of an adult with autism whom you support, and assisting that individual in understanding these rights as well, can provide a powerful frame of reference that you may turn to in many situations that require advocacy skills.

The ADA is broken down into five sections or “titles.” These include the following categories of legal protection: 1) Employment, 2) Public Services, 3) Public Accommodations, 4) Telecommunications, and 5) Miscellaneous Provisions. A self-test activity follows. By working through this quiz, you will learn more about each title of the ADA. Keep in mind that the ADA is a complex document, and the information provided in the self-test is by no means exhaustive.

For more in depth information on the ADA, visit the official website at [www.ada.gov](http://www.ada.gov).<sup>3</sup>

### Olmstead v. L.C.

In 1999, an important Supreme Court case led to a decision that would impact the lives of people with disabilities with regard to community integration and community-based services. The decision involved Public Services, Title II of the Americans with Disabilities Act, and stated that no individual with a disability may be denied access to community-based programs and services if treatment providers have deemed that such integrated settings are appropriate. The decision came in response to the prolonged institutionalization of two women, both dually diagnosed with intellectual disabilities and mental illness, based upon the rationalization that their inclusion in community-based programs, though recommended by experts, was too expensive. This was deemed discriminatory by the Supreme Court, leading to important steps in building greater infrastructure in community-based settings.

For more in depth information on Olmstead v. L.C., click [here](#).

### Developmental Disabilities Assistance and Bill of Rights Act

The Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act) instituted four programs that together create a network of important research organizations, program and training centers, advocacy access, and state DD councils as follows:

1. State Councils on Developmental Disabilities (DD Councils)
2. Protection and Advocacy (P&A) Systems
3. University Centers for Excellence in Developmental Disabilities (UCEDDs)
4. Projects of National Significance (PNS)

For more in depth information on the DD Act, click [here](#).

3. Paradiz, Valerie, *The Integrated Self-Advocacy ISA® Curriculum, Teacher’s Edition*, AAPC, Shawnee Mission, Kansas, 2009, pp. 102-104.





## The Rehabilitation Act

The Rehabilitation Act of 1973 (or Rehab Act) includes important funding authorizations that support vocational rehabilitation, supported employment, independent living and client assistance. It also includes provisions involving the rights of people with disabilities, encompassing seven titles:

1. Vocational Rehabilitation Services
2. Research and Training, including the creation of the Interagency Committee on Disability Research
3. Professional Development and Special Projects and Demonstrations
4. National Council on Disability
5. Rights and Advocacy, including establishment of the Architectural and Transportation Barriers Compliance Board (Access Board)
6. Employment Opportunities for Individuals with Disabilities
7. Independent Living Services and Centers for Independent Living

For more in-depth information on the Rehab Act, click [here](#).

## Social Security Act

Finally, the Social Security Act, first passed in 1935, has been amended across more than seven decades to include significant programs for people with disabilities and their families. These programs include the Disability Insurance Trust Fund, Medicare, Medicaid, Early and Periodic Screening, Diagnosis and Treatment (EPSDT) Services for all Medicaid-Eligible Children, Intermediate Care Facilities (ICF) for Individuals with Developmental Disabilities, and Supplemental Security Income (SSI).

For more information about the Social Security Act, click [here](#).

## Navigating Adult Services

Adults with autism are often eligible for services to support them in various aspects of their lives. Services vary from state to state, but most involve a team component comprised of the individual, family members, friends, and coordinators from an agency or organization providing the service (if the individual has qualified for services through agencies). Although the information provided on services below is not exhaustive by any means, it provides some basic information to help you and the person you support begin to navigate programs and options.

## Applying for Supplemental Security Income (SSI)

SSI is a Federal Social Security cash benefit that is available to disabled individuals who demonstrate financial need. If a child is under 18, a family's income is used to determine eligibility. After the age of 18, financial need is based on the individual's ability to earn income. Receiving SSI does not prohibit a person from working. SSI operates on a sliding scale. The amount of cash received monthly is adjusted according to the individual's current income.





Applying for SSI can take several months and involves providing detailed medical or other documentation, as well as undergoing evaluation(s) by qualified SSI medical professionals. Therefore, it is good to plan ahead and initiate the process as part of a young adult's transition plan. If the individual is school aged and already has SSI, he/she must reapply as an adult, at age 18. It is never too late to apply for SSI. The process can be initiated by a family member, support person, or by the individual directly at any time. For more information on SSI, visit [www.ssa.gov](http://www.ssa.gov) or call or visit your local Social Security Administration office.

## Accessing the Voting Process

An important step you can take to foster citizenship is supporting an individual with autism to access the voting process. It is critical to provide the necessary accommodations needed for the individual to understand the voting process and its purpose, learn about candidates in local, state and national level elections, register to vote, and vote either at polling places or remotely via US Mail. For information on how to provide this support, or to access it directly if you are a person with autism, visit the Arc of the United States' *We've Got the Power Campaign* [here](#). Another good resource for voting rights for people with disabilities is: National Disabilities Rights Network <http://www.ndrn.org/index.php>.

## Obtaining Gainful Employment

While important federal legislation, such as the Rehabilitation Act, has been passed and amended over the years to support gainful employment and counter discrimination of individuals with disabilities in the workplace, “[l]ack of understanding on the part of employers and a lack of effective and accessible vocational rehabilitation/ counseling services” continue to be “barriers to regular employment for many adults with autism.”<sup>4</sup> This is due in large part to the autism community's historical emphasis on funding programs and research that focus primarily on children with ASD. Add to this the significant increase in the diagnostic rate of autism in the past 10-15 years, and our community faces a crisis in infrastructure in adult services across the board. Nowhere is this felt more dramatically for people with autism and their families than in the employment and daily living/housing sectors. Among disability groups, people with autism experience a significantly higher rate of unemployment and underemployment. Many advocates—both individuals with autism and the family members who support them—have experienced systemic failure in employment services, due largely to a lack of information and training for workers staffing programs such as Vocational Rehabilitation. Countless individuals have been denied DVR services or, when provided, have felt services were ineffective due to the profound misunderstanding of the attributes, abilities and challenges associated with autism. In this way, as a result of our advocacy as a community, employment is swiftly becoming a priority. One excellent source for the latest research, training models, advocacy initiatives, federal and state demonstration projects, and employment capacity-building efforts can be found in the VCU-RRTC Newsletter and on its associated [website](#). Click [here](#) to learn about the results of Autism Speaks' 2012 Employment Think Tank.



4. Van Pelt, Jennifer. Social Work Today, Vol 8, No 5, p. 12, <http://www.socialworktoday.com/archive/090208p12.shtml>





## Receiving Services from the Division of Vocational Rehabilitation (DVR)

Vocational Rehabilitation provides support to assist individuals with disabilities in preparing for finding and maintaining a job to match skills and abilities. Eligibility is based upon a person's disability and whether the disability currently presents obstacles to employment that can be remediated through vocational rehabilitation services. In order to qualify, DVR reviews medical and educational history, as well as employment experience, to ascertain how the disability affects an individual's ability to be employed. For many with autism spectrum disorders, achieving eligibility for DVR services has posed a problem, due to insufficient knowledge and training of Vocational Rehabilitation workers with regard to autism. Additionally, eligibility guidelines in some states are limited in that they are based upon IQ scores or physical disability as a core determinant in receiving services. Because some people with autism might have higher IQ scores than the cutoff point for eligibility, or because they do not possess mobility or other physical challenges, they are often readily eliminated as candidates for DVR services. This is in spite of the fact that as a population, adults with autism have one of the highest unemployment rates among all disability groups. This is a significant arena where community and personal advocacy play an important role. To learn more about applying for Vocational Rehabilitation Services, visit your local DVR office or your state DVR web site.



## Accessing Social, Therapeutic and Medical Resources, Supports and Services through the Developmental Disability (DD) Waiver

The DD Waiver provides funding for home and community-based services for adults with developmental disabilities, including autism. Eligibility is determined through a screening process conducted by the local county social service agency. When an individual qualifies, services are identified in detail in the Individual Service Plan (ISP) or an equivalent document. Generally, a caseworker is also assigned to support the individual's various needs and goals. Services can be provided wherever the adult with autism lives (his/her own

private home, in the home of the individual's parents or other family members, or in other group and residential home settings). In addition to services covered by medical assistance, the following additional supports might become a part of an individual's service plan: adult day care, assistive technology, support provider training and education, case management, consumer-directed community supports, consumer training and education, day training and habilitation services, housing access coordination, supported employment services, supported living services, transitional services, transportation services, and more.





## Attending and Participating in an Adult Services Meeting (for Individuals with ASD)

Each service provider has unique meeting requirements they must fulfill for their “consumers”, or individuals receiving their services. For example, some case workers are required to meet with an individual regularly, such as every 90 days, or they must complete a more substantial annual review meeting to address goals and program requirements. Meetings such as these usually include:

- Person-centered planning elements, such as supporting the individual’s dreams and aspirations
- Goals for community integration
- Supports to enhance independent living
- Employment programming
- Transportation needs
- Medical requirements

Sometimes individuals with autism miss out on the important experience of self-directing their supports at their adult service meetings. Reasons for this may vary. For example, the meeting environment itself might be too challenging. In other instances, individuals may not have the skills needed to lead a meeting, they may not understand their rights, or they may not have been supported enough in the creative development of their goals and programming in advance of the meeting. Reviewing the accommodations necessary to attend a meeting is a first step toward integrating an adult with autism in becoming a fuller participant in his or her program planning. Additionally, offering supports to prepare in advance for an upcoming meeting can be very effective, so that the individual knows what to expect and what he or she wishes to contribute.

## Employment Disclosure and Advocacy with Employers and Co-workers

When an individual with autism is employed, acquiring some basic advocacy skills and understanding the Americans with Disabilities Act (ADA) can be useful in maintaining the job and ensuring that reasonable accommodations in the workplace can be provided. Because people with autism experience some differences that aren’t widely understood—specifically sensory, social and communication differences—both employers and co-workers might understand an individual better if they are properly informed. However, this in turn touches upon the important issue of disclosure in the workplace and the degree to which an individual with autism wishes to disclose his or her diagnosis.

One very important aspect of self-advocacy is disclosure. Disclosure involves telling someone that you have an autism spectrum disorder. There are some instances when it is important and perhaps even necessary to self-disclose, such as in encounters with law enforcement. In the workplace, however, the ADA provides certain protections to people with disabilities. For example, during a job interview, it is the individual’s choice whether he or she wishes to disclose the disability. Upon becoming hired, again it is the individual’s right whether to disclose or not. The positive side of disclosure in the workplace is that the person may then request reasonable accommodations. Such accommodations might include adjustments to the environment to address sensory, social or communication differences. Accommodations supported by an employer can make performing work assignments easier for individuals with autism, leading to longevity of employment.





In some instances with co-workers, it might not be wise or appropriate to disclose a disability; however, a *partial disclosure* might be in order if it assists in helping others understand the need to adjust the lighting in a shared office, for example. Rather than fully disclosing and revealing the diagnosis, the individual might instead reveal that fluorescent lighting leads to severe migraines. In this way, co-workers understand the need for the accommodation and are more likely to be supportive. Finally, the ADA states that it is against the law to discriminate in the hiring of someone due to disability. Once on the job, an individual may not be fired because of a disability.

## Futures Planning

When it comes to advocacy across the life span for individuals on the spectrum, it is important to consider establishing a Special Needs or Supplemental Needs Trust. Assets held in such trusts do not play a role in determining eligibility for benefits and can be used to supplement services that Medicaid and Medicaid Waiver do not cover. It's often a good idea to work with an attorney with a background in estate planning and developmental disabilities to create such a trust.

Additional information can be found online at [sntcenter.org](http://sntcenter.org).

## Legal Guardianship

In the eyes of the law, even a person with a significant developmental, cognitive, or mental health disability is legally permitted to make decisions on his or her own behalf at the age of majority (18 in most states). The only way parents can continue making decisions for their child is to become their legal guardian.

*"Families need to keep in mind that guardianship is not the same as serving as a substitute parent. A guardian is an individual that is truly person-centered and focused on the needs of the individual with disabilities. They will not be required to provide parental types of support"*.



**Guardianship** is a court-ordered arrangement in which one person is given the legal authority to make decisions on behalf of another person whom a court has deemed to be "incapacitated." The guardian's decision-making authority extends to all areas specified by the court.

**Limited Guardian:** A limited guardian makes decisions in only some specific areas, such as medical care. Limited guardianship may be appropriate if the person with a disability can make some decisions on his or her own.

**General Guardian:** A general guardian has broad control and decision-making authority over the individual. General guardianship may be appropriate if the person has a significant intellectual disability or mental illness and, as a result, is unable to meaningfully participate in important decisions that affect him or her.

**Conservator:** A conservator manages the finances (income and assets) of a person with a disability. A conservator has no authority to make personal decisions (medical, educational, etc.) for the person whose funds he or she is managing.





## Deciding Whether Guardianship is Necessary

For parents, the decision to seek guardianship can be difficult. You need to protect your son or daughter with autism, but there may be some areas where he or she can make sound decisions. Fortunately, legal guardianship is not an “all or nothing” proposition. It is possible to carve out some areas where your son or daughter can retain important decision-making rights and control of his or her own life.

When considering how much authority you need—and how much independence your son or daughter should retain—you should begin with an assessment of the different areas in which your son or daughter may need your assistance. These areas may include: medical, educational, financial, vocational/adult services, living arrangements, legal, self-care, safety, and communication.

## Obtaining Guardianship

To obtain guardianship, an attorney is not legally required. But you may want to consider hiring an attorney with expertise in this area. Each family is unique in that there are many significant choices and decisions to be made in this process.

## Conservatorship

Conservatorship must be filed in Probate Court of Superior Court, in the courthouse where the proposed individual resides based on zip code. Most courthouses use Judicial Counsel forms and local court-required forms. Conservatorship is a lifelong process. The conservator must comply with the court for lifetime of the individual.

*Resource for above Guardianship information: Special Needs Alliance, [www.specialneedsanswers.com](http://www.specialneedsanswers.com)*

## Housing Advocacy

### Disability Rights in Housing from the United States Department of Housing and Urban Development (HUD)

Regardless of whether individuals with autism live in private or public housing, federal laws such as the [Fair Housing Act](#) provide, among others, the following rights to persons with disabilities:

- **Prohibits discrimination against persons with disabilities.** It is unlawful for a housing provider to refuse to rent or sell to a person simply because of a disability. A housing provider may not impose different application or qualification criteria, rental fees or sales prices, and rental or sales terms or conditions than those required of or provided to persons who are not disabled.
- **Requires housing providers to make reasonable accommodations for persons with disabilities.** A reasonable accommodation is a change in rules, policies, practices, or services so that a person with a disability will have an equal opportunity to use and enjoy a dwelling unit or common space. A housing provider should do everything s/he can to assist, but s/he is not required to make changes that would fundamentally alter the program or create an undue financial and administrative burden. Reasonable accommodations may be necessary at all stages of the housing process, including application, tenancy, or to prevent eviction.
- **Requires housing providers to allow persons with disabilities to make reasonable modifications.** A reasonable modification is a structural modification that is made to allow persons with disabilities the full enjoyment of the housing and related facilities.

For more information about federal housing and residential entitlements for individuals with disabilities, click [here](#).

To learn about the Fair Housing Laws and Presidential Executive Orders, click [here](#).

