

Legal Matters to Consider When Planning for the Future

You may have subconsciously avoided the topic of long-term planning for a long time. This is not unusual. You may suddenly feel that you are back to the beginning stages of accepting the diagnosis. It can help to remind yourself that with planning, you will begin to feel much better about what lies ahead!

There are changes when a person with autism reaches the age of majority, which is 18 years old in most states. Parents no longer have the legal rights to which they were entitled throughout their child's youth. This can include accessing confidential health information and school records.

It can be difficult to take the first steps in planning for your child's future. By taking action early on, you can help protect your child's future well-being and rest a bit easier.

Before your child reaches the age of majority, we suggest that you consult with professionals: attorneys, financial planners and others who can help you make critical decisions about your child's future.

Many of these topics involve state-administered programs, and each state sets its own guidelines. You will want to check with your state agencies for guidance.

When planning for the transition to adulthood, there are several important legal matters to think about, including health insurance laws, special needs trusts and more. This section provides an overview of these topics. More information can be found on the Autism Speaks website.



Health Insurance

Obviously a key component to think about for your child as he or she becomes an adult is health insurance. One of the most significant changes in healthcare law that came from the Affordable Care Act of 2010 is that insurers must now cover dependents on a parent or guardian's plan up to age 26, no longer age 18. Insurers cannot deny or restrict coverage based on certain factors about the child's status. To learn whether your plan or policy offers dependent coverage, check the plan materials or ask your insurer or employer.

Another significant change under the Affordable Care Act is that insurers can no longer deny coverage for pre-existing conditions, even if you have been refused coverage in the past. A diagnosis of autism has been treated as a pre-existing condition in many states and under the new law, this will not affect your child's access to health insurance.

The Affordable Care Act also allows states to choose whether to expand their Medicaid programs to low-income adults, many of whom have never been eligible for coverage before. The new law allows states to expand Medicaid coverage to most adults with incomes up to 138 percent of the poverty level. You can learn more about these options and enroll in

Medicaid at [healthcare.gov](https://www.healthcare.gov). In addition, the Children's Health Insurance Program (CHIP) provides low-cost health coverage to families that earn too much money to qualify for Medicaid. Each state offers CHIP coverage. To learn if your child is eligible for CHIP, you can visit insurekidsnow.gov.

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. The only way parents can continue making decisions for their child is to become his or her legal guardian. There are a few options to consider:

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

There are two types of guardians. A **limited guardian** can make decisions in only some specific areas, such as medical care. This may be appropriate if the person with autism can make some decisions on his or her own. A **general guardian** has broad control and decision-making authority over the individual. This 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.

With **conservatorship**, 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.

With a **Power of Attorney** (POA), your child will need to appoint you as the authority to make decisions on his or her behalf under agreed upon terms in the legal document. Unlike guardianship, with a

Power of Attorney, courts are not involved and the arrangement is often simpler and easier to change. The individual maintains more control over decisions than with a guardianship arrangement and as a result, this option is more common among more independent individuals.

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 child 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 assistance.

The below list covers some of those areas – for each area, assess whether he or she can do the following:

Medical

- Seek medical care when he or she is sick or injured
- Weigh the risks and benefits of any particular medical procedure that is being proposed
- Understand the need for routine medical care
- Understand that even if a medical procedure is painful or unpleasant, it may still be necessary
- Assess whether a particular medication is desirable, even though it may have unpleasant side effects
- Provide accurate information about his or her medical condition
- Follow medical advice

Education

- Grasp the essentials of his or her learning problems and understand the services needed to learn effectively
- Advocate for him or herself to obtain necessary education services

Finances

- Understand money basics, including the purpose of money, how to count money and how to make change
- Safeguard his or her money so that it is not lost or stolen
- Budget money so that some funds are available to pay expenses at the end of the month

Vocational/Adult Services

- Apply for services from the Department of Disability Services, Department of Mental Health or other agency that serves people with disabilities
- Access necessary services and supports such as job training, employment support or a day habilitation program
- Negotiate with the agency overseeing his or her care to obtain the best possible services

Living Arrangements

- Provide for his or her own physical care and well-being such as purchasing proper food, clothing and shelter
- Live harmoniously in a group setting, respecting others' needs for quiet, privacy and cleanliness

Legal and Decision-making

- Understand the implications of signing documents
- Make sound decisions in important areas such as living arrangements, school and work



Self-care and Safety

- Understand personal safety skills, such as staying out of dangerous areas, not talking to strangers and keeping doors locked
- Know how to summon help in an emergency such as a fire or accident
- Have basic safety skills such as being careful around fires, stoves, candles, etc.

Communication

- Communicate effectively (verbally or by other means)
- Understand that he or she has choices and be able to express them

Even if your son or daughter needs help with any of the above items, you should also consider whether or he or she could be assisted by any means short of guardianship. For example, sometimes a person who needs help to make medical decisions can appoint a health care agent to act on his or her behalf. A person who receives government benefits such as Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI) can have a representative payee manage them.

Obtaining Guardianship

To obtain guardianship, an attorney is not legally required, but you may want to consider hiring one with expertise in this area. Each family is unique in that there are many significant choices and decisions to be made in the process and an attorney can help you with those. You can search for an attorney in your area by visiting the Autism Speaks Resource Guide at autismspeaks.org/resource-guide.

Conservatorship

Conservatorships must be filed in the 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 the lifetime of the individual.



Special Needs Trusts

The information below comes from Autism Speaks' Legal Guide provided by the law firm Goodwin Procter LLP:

A Special Needs Trust is a trust to hold assets for a special needs beneficiary. Such trusts can be used for an individual receiving public benefits, such as SSI or Medicaid, in order to supplement his or her income without impacting eligibility to receive benefits.

A Special Needs Trust can ensure that money will be available for your child throughout his or her lifetime and that such money will not impact his or her access to means-tested benefits. The trustee, often the parent, is designated to manage the trust for the benefit of the child.

There are generally two kinds of Special Needs Trusts:

(1) A Third Party Special Needs Trust is designed to hold property provided by someone other than the special needs beneficiary. A parent, custodial or non-custodial, or anyone else can put money in a trust for the benefit of the individual.

(2) A Self-Settled Special Needs Trust is designed to hold property belonging to the individual.

Does your child need a Special Needs Trust? Here are some things to consider when answering this question:

- Diagnosis is not required.
- Consider whether or not your adult child can manage his or her contracts and finances, and resist fraud and undue influence.
- Consider hiring a lawyer. There are many important choices and decisions to be made in the process.
- The Special Needs Trust needs to stand alone from any other living trust your family may have.
- The trust is irrevocable in your child's name once funded. But the trust owns the assets, not the child.

Support Programs

The Social Security Administration (SSA) has two kinds of benefits for people with disabilities over the age of 18: Supplemental Security Income (SSI) and Social Security Disability Insurance/Disabled Adult Child Benefits (SSDI). In order for your child to qualify for these programs, he or she must meet the Social Security Administration's definition of disabled.

The SSA's definition of disability is: the inability to engage in any substantial gainful activity by reason of medically determinable physical or mental impairment which can be expected to result in death or has lasted or can be expected to last for a continuous period of not less than 12 months. (There is an actual number that is used to measure substantial gainful activity and it varies by year.)

SSA will review whether your child's disability is on a list of conditions that are considered "severe" and if the disability would prevent him or her from working for a year or more.

Not all children who receive special education services may be considered disabled under the SSA definition. Even if your family is receiving SSI for your child when he or she is under the age of 18, you will need to go through a redetermination process to maintain his or her SSI benefits as an adult.

To determine if your child meets the criteria, you must submit his or her detailed medical records, along with a list of all current medications, as well as all doctors, hospitals, clinics and specialists that he or she has visited. In addition, he or she will be asked to go through an examination paid for by the SSA. This process can take several months.

Social Security Income (SSI)

SSI is available to people whose disabilities prevent them from gainful employment. In order to be eligible, your child must not have greater than \$2,000 in countable resources and must have a limited monthly income.



At age 18, your family's income and resources are not counted, even if your child continues to live at home. The amount of benefits is determined by a number of factors, including where your child lives and what other income he or she may have.

Social Security Disability Insurance (SSDI)

SSDI provides income supplements to people who are restricted in their ability to be employed because of a disability. Unlike SSI, this benefit is available regardless of the individual's income and resources.

Anyone whose disability developed prior to age 22, and whose parent or guardian is either deceased or getting Social Security retirement or disability benefits, may qualify for a form of insurance called Disabled Adult Child Benefits.

Representative Payee

The SSA appoints an administrator called a representative-payee (rep-payee) for all beneficiaries who are incapable of managing their own SSI or SSDI benefits. If you are seeking to become the rep-payee for your child's benefits, you must file an application in person with the SSA. You can be established as a rep-payee without gaining guardianship over your child. If he or she does not have income or resources aside from the Social Security benefits, you may prefer to avoid guardianship appointment and pursue the simpler rep-payee process instead.

It is important that careful records be kept of your child's monthly income and that it be reported on time to the SSA. A copy of everything you send to the SSA should be kept.

Appealing Decisions

If the SSA rejects your child's application for SSI or SSDI benefits, or it simply reduces benefits, you can take several steps to reverse the decision. There are four levels of the appeals process, described below. Beneficiaries have 60 days to file an appeal at each level of the appeal process:

Reconsideration: You may ask for your child's case to be reviewed by the person who originally decided it.

Appeals Hearing: If you are denied benefits again in reconsideration, you can request a hearing before an Administrative Law Judge who will listen to testimony and review any additional documents that may help your child's case. At this hearing, you have the right to bring a representative.

Appeals Council Review: You have the right to appeal the decision of the Administrative Law Judge to the Appeals Council which will review your file but not hear new testimony.

Federal Court: If the Appeals Council rejects your application, you may then file an appeal in the U.S. court system.

Medicaid Benefits

Individuals who qualify for SSI are eligible to receive Medicaid, which pays for a wide array of services for people with disabilities and provides government-funded health insurance for children and adults with disabilities who have limited financial resources. Medicaid also provides government funding for long-term services and supports.

Medicaid Eligibility:

Categorical: Persons who fit in a specific category for whom federal law permits coverage (age 65 or above, blind, disabled, etc.)

Financial: Persons whose income and assets do not exceed the state threshold

Home and Community-Based Waiver Services

In the past, Medicaid funding was limited to those who live in certain types of facilities. But now, through the use of Medicaid Home and Community-Based Waivers, people with autism and other disabilities can use these funds more flexibly. Waiver services are an option available to states to provide integrated community-based long term care services and supports to qualified Medicaid recipients. The programs "waive" some of the rules of Medicaid to serve children and adults otherwise requiring an institutional level of care who can instead be served at home or in the community.

These programs may provide a combination of both traditional medical services (dental services, skilled nursing services) and non-medical services (respite, case management, environmental modifications, etc.). Family members and friends may be providers of waiver services if they meet the specified provider qualifications.

Each state set its own guidelines.

All states operate HCBS programs for people with developmental disabilities (some states also have specific HCBS waivers for people with autism). Services in HCBS waivers vary across waivers and states but may include respite, employment supports, residential services (e.g. group homes, supported living, etc.), family support and many other community supports. The state Medicaid agency or the state Developmental Disabilities agency is usually responsible for the operation, eligibility and enrollment into these programs – individuals interested in waiver services should contact these agencies to find out about enrolling and/or placing their name on the waiting list.

Other Legal Considerations

- Obtain a state identification card or driver's license from the Bureau of Motor Vehicles.
- Register for Selective Services. (Note that all males, regardless of disability, must register for Selective Service at age 18. They may register at the post office or online at sss.gov.)
- Register to vote.
- Explore options for transportation, including driver's training.

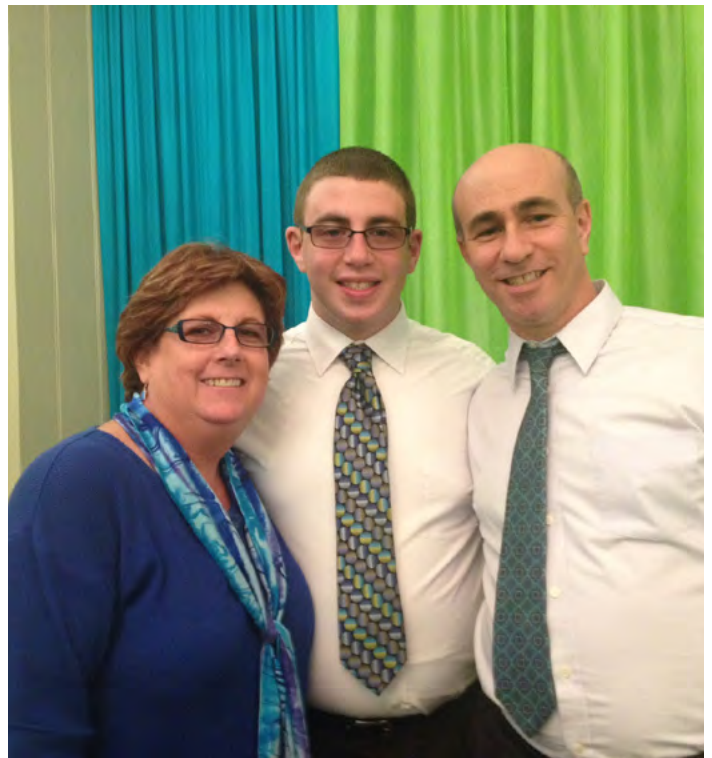
Achieving a Better Life Experience (ABLE) Act of 2014

The Achieving a Better Life Experience (ABLE) Act, passed by Congress and signed by President Obama in December 2014, allows people with disabilities and their families to set up a special savings account for disability-related expenses, similar to the current 529 education savings plans that help families save for college.

Earnings on an ABLE account are not taxed and account funds are generally not considered for the SSI program, Medicaid and other federal means-tested benefits, which generally cap (usually at \$2,000) the amount an individual with a disability may save. An eligible individual is someone who becomes disabled before age 26 and (1) receives SSDI or SSI; or (2) files a disability certification under IRS rules.

Expenses made for the benefit of a disabled individual include education, housing, transportation, employment training and support; assistive technology and personal support services; health, prevention, and wellness; financial management and administrative services; legal fees; expenses for oversight and monitoring; funeral and burial expenses; and any other expenses approved under regulations. It is important to keep in mind that individual states may regulate ABLE accounts differently.

You can learn more about the ABLE Act and check on its status in your state at autismspeaks.org/advocacy/federal/able.



The Letter of Intent

A Letter of Intent is a document written by you (the parent or guardian) or other family member that describes your son or daughter's history, current status and your hopes for his or her future.

You might want to start the letter now and add to it as years go by, updating it when information about your child changes. It is also a good idea to involve your child when writing the letter, so that the letter truly "presents" and represents your child, to the best of his or her ability. The letter is then ready at any moment to be used by all the individuals who will be involved in caring for your son or daughter, should you become ill or disabled yourself, or when you should pass away.

The letter is not a legal document, but it can provide the courts and others with insight and knowledge about the best possible care for your child.

Conclusion

As you can see, there are many factors to consider when thinking about long-term planning for your child's future. This information may seem overwhelming, but if you start early, you will feel better prepared for the time when he or she transitions into the world of adulthood. Determining finances, benefits and decision-making, or even starting the conversation about these important issues when your child is still young, can help ensure the correct services and supports are in place in advance. Keep in mind you have successfully navigated your child through the special education system and other childhood-related issues, now it is time for step two.

And with effort and work, you can be sure your child will be equally supported and provided for as an adult!

