

LEGAL MATTERS TO CONSIDER

What is Long-Term Planning?

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. However, it may help to remind yourself that with planning, you may find some peace of mind.

There are changes when a person with autism reaches the age of majority, which is 18 years old in most states (it is important that you check what the age of majority is for your state on the state page of this kit). Parents no longer have the legal rights that they were entitled to throughout their child's youth. This can include accessing confidential health and school records.

It can be difficult to take the first steps in planning for your child's future. As parents, you are often busy with the daily challenges of raising a child with autism. By taking action early on, you can help protect your child's future wellbeing and rest a bit easier.

Before your child with autism 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 are state-administered programs, and each state sets its own guidelines. You will want to check with your state agencies for guidance.

You can find the contact information for your state agencies on your state page of this kit or in the Autism Speaks Resource Guide at AutismSpeaks.org/community/resources.

Health Insurance

If your child has been covered under your private health insurance policy, it is important to know what happens when your child reaches the age of majority.

Medicaid health benefits are available for individuals who qualify for Supplemental Security Income (SSI). Medicaid provides government-funded health insurance for children and adults with disabilities who have limited financial resources.

Parents need to review private insurance policies carefully, in order to make effective decisions. Some policies allow the adult child to continue coverage if he or she is a full time student. Most policies will now allow continued coverage for dependents up to age 26. Some will allow indefinite continued coverage for adult children if they are disabled, and if the parent continues to provide 50% or more of that adult child's support and maintenance. This needs to be considered carefully if the child will be receiving Supplemental Security Income (SSI), because some aspects of SSI payments are based on whether or not the young adult is claimed as a dependent by his or her parents. Others will allow the parents to continue to support the individual.



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 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 you 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. For each area, assess whether your son or daughter 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 himself 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 Dept. of Disability Services, Dept. 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

- Have 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 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 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

Special Needs Trusts

■ *The below information comes from the Autism Speaks Legal Guide provided by Goodwin Procter LLP*
www.autismspeaks.org/docs/family_services_docs/GP_Legal_Guidelines.pdf

A Special Needs Trust is a trust to hold assets for a special needs beneficiary. Such Trusts can be used for a special needs beneficiary receiving public benefits, such as Supplemental Security Income or Medicaid, in order to supplement the beneficiary's income without impacting eligibility to receive benefits. 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 special needs beneficiary. The person who sets up the trust has the right to determine where any money left in the trust will go after the death of the special needs beneficiary.

(2) A Self-Settled Special Needs Trust is designed to hold property belonging to the special needs beneficiary. As such, if the special needs beneficiary is a recipient of a state Medicaid program, the state program must be repaid out of



the remaining funds upon the special needs beneficiary's death prior to distribution to those designated to inherit what remains.

A Special Needs Trust can ensure that money will be available for a child throughout his or her lifetime and that such money will not impact their access to means-tested benefits. A trustee, often the custodial parent, is designated to manage the Trust for the benefit of the special needs beneficiary. The trustee would be responsible for ensuring that payments from the Trust do not exceed the amounts that would render the beneficiary ineligible to receive benefit.

Upon divorce, a parent may want to revise his or her will and change beneficiary designations on insurance and retirement benefits so that property and proceeds are diverted to the Special Needs Trust rather than directed to their ex-spouse or to the child directly. Because child support payments are viewed as belonging to the child, there is a danger that such payments could disqualify the child from means-tested benefits. In order to avoid this issue, a parent may want to assign some or all child support payments to a Special Needs Trust. In many states, child support obligations do not terminate at the death of the non-custodial parent and future support can be obtained from the deceased parent's estate. It may be worth convincing the non-custodial parent to obtain life insurance and arrange for the proceeds to be deposited in a trust that continues to make the child support payments on his estate's behalf.

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, 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 be stand-alone from any other living trust your family may have.
- Trust is irrevocable in your child's name once funded. But the trust owns the assets, not the child.

For additional considerations in planning for your special needs child, see the online appendix for Top Ten Tips When Planning for Special Needs.

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)*. To qualify for these programs, a person must meet the Social Security Administration's definition of disabled.

The *SSA 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 if the applicant's disability is on a list of conditions that are considered "severe" and that the disability would prevent a person from working for a year or more.

Benefits and Qualifications

■ Not all children that receive special education services may be considered disabled under the SSA definition. Even if a family is receiving SSI for a child under the age of 18, they will need to go through a re-determination process to maintain SSI benefits as an adult.

To determine if an applicant meets the criteria the parents must submit the child's detailed medical records, along with a list of all current medications as well as all doctors, hospitals, clinics and specialists that the child has visited.

In addition, the child will be asked to go through an examination paid for by the Social Security. This process can take several months.

Supplemental Security Income (SSI)

■ Supplemental Security Income (SSI) is available to people whose disabilities prevent them from gainful employment. In order to be eligible, an individual must not have greater than \$2,000 in countable resources and must have a limited monthly income. At age 18, the income and resources of family members are not counted even if the individual continues to live at home. The amount of benefits is determined by a number of factors including where the person lives and what other income he or she may have.

Disabled Adult Child Benefits/Social Security Disability Insurance (SSDI)

■ 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. This benefit is available regardless of the individual's income and resources.

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. Parents seeking to become the re-payee for their disabled child's benefits must file an application in person with SSA. A parent can be established as a rep-payee without gaining guardianship over the child. If the child does not have income or resources aside from Social Security benefits, parents may prefer to avoid the guardianship appointment and pursue the simpler rep-payee process instead.

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



Appealing Decisions

If the SSA rejects an adult child's application for SSI or SSDI benefits, or if it simply reduces benefits, parents 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*: An applicant denied benefits may ask for his case to be reviewed by the person who originally decided it.
- *Appeals Hearing*: If the applicant is denied benefits again in reconsideration, he can request a hearing before an Administrative Law Judge. The judge will listen to testimony and review any additional documents that may help the applicant's case. At this hearing, applicants have the right to bring a representative.
- *Appeals Council Review*: An applicant has the right to appeal the decision of the Administrative Law Judge to the Appeals Council. The Appeals Council will review the applicant's file but will not hear new testimony.
- *Federal Court*: If the Appeals Council rejects an application, the applicant may then file an appeal in the U.S. Court system.

Resource: *Transition Matters: From School to Independence*, developed by the Resources for Children with Special Needs, Inc.

Medicaid Benefits

Individuals who qualify for SSI are eligible to receive Medicaid. Medicaid 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, including institutional care in nursing facilities and, in some cases, in non-specialized placements for people with disabilities.

Medicaid Eligibility

- Categorical—persons who fit in a specific category whom federal law permits coverage (age 65 or above, be blind, have disabilities).
- Financial—income and assets do not exceed state threshold.

Home and Community-Based Waiver Services

The HCBS waiver program is 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. Medicaid is a state-administered program and each state sets its own guidelines.



Other Legal Considerations

- Obtain a state I.D. card or driver's license from the Bureau of Motor Vehicles
- Register for Selective Service (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 www.sss.gov.)
- Register to vote
- Explore options for transportation; including driver's training

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, his or her current status, and what you hope for him or her in the future. It would be wise to write this letter today and add to it as the years go by, updating it when information about your son or daughter changes. To the maximum extent possible, it is also a good idea to involve your child in the writing of this Letter, so that the Letter truly "presents" and represents your child. 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.

Even though the Letter of Intent is not a legal document, the courts and others can rely upon the Letter for guidance in understanding your son or daughter, as well as your wishes. In this way, you can continue to "speak out" on behalf of your son or daughter, providing insight and knowledge about his or her own best possible care.

Adapted from: <http://specialchildren.about.com/od/longtermplanning/a/letterofintent.htm>

For more information about a Letter of Intent as well as an example please see the online appendix of this kit.



The following is a blog post by Marianne Sullivan, Autism Speaks Assistant Director of National Outreach and Resources. Marianne is also the mother of two young men, one of whom has autism.

This past year has been filled with a special kind of pride along with lots of anxiety as my son Hunter turned 18. I am so proud of all the hard work he has done in order to excel, despite his disability. There has also been anxiety anticipating the many challenges ahead for him as he prepares to live an adult life in the community as independently as possible.

Our recent trip to the local Social Security Office to apply for Supplemental Security income (SSI) was an event that marked this birthday and captured both the pride and anxiety I was feeling at the time. In preparation, I read articles and web postings about the application process. Once there in front of the eligibility clerk, I had some powerful reactions: Do they care about my son? Do they want him to succeed as much as I do? Will the income he receives be enough for him to live a comfortable adult life? Will he be able to deal with the system should a check not arrive or some other problems occur at some future time when I am no longer around to assist?

The eligibility clerk was a genuinely nice man, although he didn't become a surrogate parent as I had fantasized he might. Without too much difficulty, I was able to check myself on this and was reassured that he was doing his job in a manner that would help Hunter be more independent as an adult. The clerk asked a lot of questions and he typed with impressive speed.

And at one point, he asked me to ask my son to turn down his iPod. My internal thought was that this seemed to be an easy request. But then memories of past parent-child struggles flashed by from the past 18 years. I reminded myself that Hunter had successfully learned a lot of life's lessons from those struggles. As I then asked him to comply with the clerk's request, Hunter appeared bored with the process but quickly agreed to turn down his music, perhaps realizing to some degree that this was an important event for his future.

An hour and half later, the application was complete. Hunter and I had our own sense of relief as we stood up to leave.

For others about to go through this rite of passage, it goes without saying that it pays off to have your paperwork organized in an accessible file, including medical providers contact information, and copies of relevant medical records, the original birth certificate and official social security card. By the way, you can complete a large part of your application on their website at www.socialsecurity.gov. It is very important to not just show up but rather, you should call (800) 772-1213 to set up an appointment with your local Social Security office. Once eligible for SSI, depending on which state you live in, you may also be eligible for additional services from your state. For example, in California you will receive a supplemental income that is added onto your federal benefit. In California, the full benefit is \$846 a month.

The transition to adulthood stirs many emotions and creates anxieties. The visit to the Social Security Office was a big transition event for us. But, like any rite of passage, there is a lot worth celebrating as you look back at accomplishments while facing the new challenges that will arise on each step of the way.



Legal Issues Resources

Legal Planning for Special Needs in Massachusetts: A Family Guide to SSI, Guardianship and Estate Planning

by Barbara D. Jackins, attorney

Goodwin Procter LLP Legal Guide for Autism Speaks

www.autismspeaks.org/docs/family_services_docs/GP_Legal_Guidelines.pdf
www.goodwinprocter.com

Academy of Special Needs Answers

www.specialneedsanswers.com

Transition Matters: From School to Independence

developed by Resources for Children with Special Needs, Inc.

www.resourcesnyc.org

Adolescents on the Autism Spectrum: A Parent's Guide to the Cognitive, Social, Physical and Transition Needs of Teenagers with Autism Spectrum Disorders

by Chantal Sicile-Kira, foreword by Temple Grandin

National Association of Councils on Developmental Disabilities

www.nacdd.org

The Clearinghouse for Home & Community Based Services

www.hcbs.org

U.S. Social Security Administration

www.ssa.gov

Social Security Income

www.ssa.gov/disability

Eligibility Information: www.ssa.gov/ssi/text-eligibility-ussi.htm

What You Need to Know When You Get Supplemental Social Security Income (SSI)

www.ssa.gov/pubs/11011.html

Writing a Letter of Intent

by Amy Baskin and Heather Fawcett

<http://specialchildren.about.com/od/longtermplanning/a/letterofintent.htm>

The Medicaid Reference Desk: Information About Medicaid for People with Cognitive Disabilities

www.thedesk.info



Understanding Medicaid Home & Community Based Services: A Primer

U.S. Department of Health and Human Services:

<http://aspe.hhs.gov/daltcp/reports/primer.htm>



