

Entering Adult Life with Autism or other Developmental Disabilities: What Families of Teens and Young Adults Need to Know

At age 18 all children legally become adults with new rights and responsibilities. They can vote, sign legal contracts, decide on medical treatments, and make many decisions without you. Reaching adulthood also brings new and exciting opportunities.



This guide focuses on those “non-school” strategies for parents and guardians to consider that provide benefits and protection for a child with autism or another developmental disability. Many first become available to your child at age 18. Some may be easier to do before the child exits the school system. Take time to consider the options that are best for your family situation. Look to others for support. Family, friends, support groups, school staff, disability and government agencies, and many organizations can help you navigate the system.

Begin by talking with your child about the kind of life he or she wants. Then work together to plan a quality life for your child based on personal interests and strengths. Talk about employment, further schooling or training, housing, transportation, leisure and social activities, and safety in the community. Assess independence in daily life. Look into volunteering as one way to gain skills and discover likes and dislikes. Work with your child to set goals to become more independent. Then make plans and take steps together to achieve those goals. One workbook to get you started is called *It's My Choice* (http://www.mncdd.org/extra/publications/choice/Its_My_Choice.pdf).

One of the most important things you can do for your child is to model and to teach good decision making. Give children the tools to understand their disability and to advocate for themselves.

Things to Consider Now

Official Identification: By age 18, your child needs official identification. Choices are a Driver's License, Illinois State ID, or an Illinois Person with a Disability ID. For more information, visit your local Driver Services Facility or http://cyberdriveillinois.com/departments/drivers/drivers_license.

Health Care and Insurance: It's important for your child to learn about health care needs, to communicate and manage needs, and to advocate for good health care. The American Academy of Pediatrics has several resources (<http://illinoisAAP.org/projects/medical-home/transition>). Find out when your child needs to switch from pediatric care to a doctor in the adult system.

There are many options for paying for health care for your adult child. They include continuing as a dependent on a parent's or guardian's health insurance plan, obtaining insurance through a child's college or employer, or a private plan. Your child may also qualify for government insurance. Many young adults can continue as dependents on their parent's employer health insurance plan until age 26. After age 26, you will need to take steps to qualify your child as a Disabled Adult Child (DAC). Find help from your employer's Human Resources Department, or at <http://www.familyvoicesillinois.org> (1-866-931-1110).

Forms of Protection: Doctors and hospitals may not let you take the lead in your adult child's health care or communicate with you unless you have a Power of Attorney or Guardianship. You and your adult child can fill out and file a simple medical Power of Attorney form at most doctors' offices. There are also Powers of Attorney for finances. If your child does not understand these agreements, consider applying for Guardianship. There are Complete Guardianships as well as guardianships limited to medical decisions (Guardianship of the Person) or financial decisions (Guardianship of the Estate). In each case you or someone else is appointed guardian through a court proceeding. Families need to consider the benefits of protection versus the loss of decision-making opportunity for the adult child with a guardianship. See <http://gac.state.il.us/guardfaq.html> for more information about guardianships and alternatives.

Voter and Selective Service Registration: All citizens at age 18 are entitled to vote. Your son or daughter may register to vote online or at many places in the county in which they live.

Almost all males between the ages of 18 and 26 must register for the Selective Service. Having a disability does not exempt someone from registering. Registration does not determine whether a person is eligible to be drafted or to serve. Registration is required to be eligible to receive federal student aid and some job training benefits. For more information, contact the Selective Service at 1-888-655-1825. Or register online at <http://www.sss.gov>.

Community Organizations and Agencies: Learn what resources and supports your local agencies and organizations, like *The Autism Program of Illinois*, have to offer. Check out support groups, too, for a great way to network and find out what is available. Join organizations that advocate for more and better services.

Questions to ask yourself when considering protections and benefits described in this guide:

- Does my child have the ability to earn an income for self-support?
- Does my child have the capacity to make decisions and to understand the consequences of those decisions?
- Is my child vulnerable or easily persuaded by others?
- How independent is my child in the community and at home?
- Does the disability entitle my child to continue health insurance and other employee benefits as my dependent?

Government Assistance

Things change when your child turns 18! Many children with disabilities qualify for **SSI** (Supplemental Security Income) and **Medicaid** for the first time when they become adults. At age 18, the Social Security Administration looks only at the adult child's income and resources and not that of the parents or guardians, even if the child is living at home. To qualify, Social Security must determine that the child has a disability and has less than \$2000 in specific income and resources in his or her name.

Social Security offers two programs for the disabled that pay a monthly cash benefit: SSI and SSDI (Social Security Disability Insurance). These two federal programs are very different, but are often confused.

SSI: Persons with disabilities age 18 and over who do not earn enough income for self-support may qualify for SSI. Besides having little income, the adult needs medical records to prove the disability began before age 22. Call 1-800-772-1213 or your local Social Security office for an interview appointment. You can fill out the Disability Report online before the appointment. Visit <http://www.ssa.gov/ssi> for more information. Ask questions during the interview to make sure you understand the application and decision process. Once eligible for SSI, your child will also be eligible for work incentive programs. These work incentive programs can help by providing training and financial incentives, even while your child is still in school.

SSDI requires a paid work record and little or no earnings. Your adult child with a disability needs only six eligible credits (quarters) before age 24 to qualify. After that age, the number is higher. In some cases children qualify based on the past work record of a parent or guardian who paid into Social Security and is now retired or disabled and receiving benefits, or is deceased. SSDI also offers work incentive programs. You can contact Social Security at 1-800-772-1213 or get more information at <http://www.ssa.gov/dibplan>.

Medicaid: Medicaid is a federal program operated by the state that funds health care for people with disabilities or with little income. Medicaid has a low or no co-pay on most medications, doctor visits, eye glasses, and surgery. It also can be used to supplement private health insurance. Since your child needs to be determined disabled by Social Security to qualify, it is best to apply for SSI first, then Medicaid. You need to make a separate application in Illinois. You can find your local Department of Human Services (DHS) Family Community Resource Center by calling 1-800-843-6154 or by visiting <http://www.dhs.state.il.us>.

Children under the age of 18 qualify for SSI or SSDI and Medicaid under different rules than adult children. If your child is receiving these benefits, he or she will have to be interviewed again around age 18 by the Social Security Administration to redetermine eligibility for these programs. Contact Social Security as your child nears age 18 to schedule an interview.

Illinois Developmental Disabilities Services: Adults services are based on eligibility and funding. There is a very long waiting list in Illinois called PUNS (Prioritization of Urgency of Need for Services). Your child must be on this list to get most state-funded services. Examples are in-home and community supports, training and employment programs, respite care, and living arrangements. Contact your local Independent Service Coordination (ISC)/Pre-Admission Screening (PAS) Agency to enroll your child on this waiting list **now**. The length of time on the list and the urgency of needs are factors in being selected for services. Learn more about the PUNS and find your local ISC Agency by visiting <http://www.dhs.state.il.us> or by calling 1-888-337-5267.

Some community and government agencies may offer programs which do not require PUNS enrollment. One example is the DHS Division of Rehabilitation Services. Visit local agencies in advance of needing services. Find out what they have to offer, discuss needs, share ideas and future plans, and get on waiting lists.

Planning for the Future Today

Financial and estate planning are important for all parents, but especially for parents of children with special needs. Your decisions in these areas can impact your child's ability to receive government assistance and services in the future. Since most services in Illinois are funded by Medicaid, your child needs to stay eligible for Medicaid, and that means having little money. For example, if a child inherits money, SSI and Medicaid may be lost until the child has less than \$2000 again. It is very important that you obtain assistance from professionals who have experience working with special needs children and their families. If you hope to provide some monetary support to your child after your death, you will want to look into setting up a Special Needs Trust (SNT). A SNT can help to provide a higher quality of life for your child than government benefits alone. It gives you a way to save for future supplemental needs and wants, yet allows the child to remain eligible for government benefits. More information is available at <http://www.specialneedsalliance.org>.

You also need to think about the people who will support your child if you cannot, either because of your death or your own disability. These will be the guardians and trustees you name in your documents. They might also be family, relatives, friends, or paid consultants. You can help them by writing a Letter of Intent. This "letter" is not a legal document, but it provides practical information and lists your intentions for your child. No one knows your child like you do, so it is helpful for others to read about your child's daily routine and your hopes and dreams for the future. It can include information about your child's medical needs, interests, likes and dislikes, level of independence in activities, and accommodation needs. It also lists names and contact information of important people, for example, your child's doctor, an advocate, or clergy. A sample Letter of Intent can be found at <http://specialchildren.about.com/od/longtermplanning/a/letterofintent.htm>. Remember that it is important to review and update goals and plans regularly as needs and laws change.

Resources for More Information

The Autism Program of Illinois (TAP) is the nation's largest statewide autism resource and services network. The TAP Service Network includes universities and nonprofit organizations across Illinois. Additional resources on this topic and many other subjects can be found on the TAP web site: www.theautismprogram.org.

- ***Building Bridges to the Future: Assisting Families and Professionals in Transitioning Students With Developmental Disabilities to the World of Adult Services***, by Intersect for Ability. (http://www.seguin.org/adult_services/building_bridges).
- ***Family Manual: Transition to Employment and Adult Services for Youth with Developmental Disabilities in Illinois***, by The Arc of Illinois. (<http://familyvoicesillinois.org>).
- ***Transition Tool Kit***, by Autism Speaks. (<http://www.autismspeaks.org>).
- ***The Special Needs Planning Guide: How to Prepare for Every Stage of Your Child's Life***, by John W. Nadworny and Cynthia R. Haddad. Baltimore, MD, Brookes Publishing Co., 2007.

The Autism Program of Illinois (TAP) does not provide medical, financial or legal advice or services. Rather, TAP provides general information about autism as a service to the community. The information provided in this publication is not a recommendation, referral or endorsement of any resource, therapeutic method, or service provider and does not replace the advice of medical, financial, legal or educational professionals. Families should make their own decisions regarding the information presented here based on the specific needs and strengths of each family.

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