

CHAPTER 7

Future Planning: Growing into Adulthood

My sons have reached the age where we need to plan for their future, but this process is only happening on a limited basis. I have to push for all these services and I'm not sure what all is available for them. I am frustrated as this is critical for their future!

-Donna Littrell

This chapter is critical for planning for the future related to your child's life after high school. Parents should work with school personnel throughout the middle and high school years to develop a person-centered plan for the future. This chapter includes many suggestions for planning for the transition of your child from a school program to adult services, including employment and living in the community. It also introduces important legal and financial planning issues that every family should think about.

Life after High School

Thinking about the future should begin immediately, and it is important to formulate plans for the future throughout your child's school experience.

One of the most challenging times for individuals with ASD and their families is when an adolescent is about to transition from a school program to the uncertainty of adult services. Questions about postsecondary education, vocational training, employment, community living, and sources of financial support for the individual with ASD must be addressed.

The Individuals with Disabilities Education Act (IDEA) requires that transition planning for this shift to adulthood and adult service systems begin by age 16, although it may begin earlier than age 16 if the IEP team agrees.

The student, parents, and members of the IEP team should work together to help the student make choices about his path for the future. This will involve discussions about where he wants to live, what kind of work he wants to do, and what recreation and leisure time activities he would like to be involved in when not working. Transition planning through the IEP process identifies the student's goals and a plan for reaching these goals in each of these areas:

Mandated Services versus Eligibility-Driven Services

One of the biggest changes that parents face at the time of their child's transition from education to community services is the shift from the mandated services of education to the eligibility-driven services of the adult service system. All children are entitled to educational services. In the adult service system, however, there

are no entitlements. Individuals must “qualify” or be determined eligible for services. Transition services within education should support parents and their children in applying for the services for which they are eligible.

In addition to the transition planning within the IEP process, IDEA also requires that the school develop a document called the Summary of Performance (see the chapter about Education) to help with this planning. When a student is no longer eligible for educational services, the school district must provide the student with a summary of their academic achievement and functional performance. This summary of performance must include recommendations on how to assist the child in meeting the student’s postsecondary goals (IDEA §300.305(e)(3)).

As mentioned in the chapter about Social Service Programs under the section of the Division of Division of Developmental and Intellectual Disabilities (DDID) at age 16 a child who has been determined eligible for DIDD services will have to be re-evaluated using adult standards. Your child’s Service and Support Administrator should discuss this re-evaluation with you. If not, or if your child has not received DIDD evaluation for eligibility.

Remember, you have the right to be present during this assessment. If your child is deemed eligible, he/she will be assigned a Service and Support Administrator who will serve as a case manager. The case manager will assist you in identifying the range of services needed and in helping you establish his/her eligibility.

Ask your service and support administrator to explain all of the services your child may be eligible for. Make sure you ask to have your child placed on waiting lists as early as possible for any services your child may wish to access in the future. You can always decline these services when they are offered if he/she does not need them. These lists are very long so it is never too early to be placed on these waiting lists.

The Ohio Center for Autism and Low Incidence (OCALI) has published “Transition to Adulthood Guidelines for Individuals with ASD”

You can read and download the guide at:

http://www.ocali.org/transition/trans_guidelines.php

Transition Planning

All students receiving special education services in public schools have regular meetings with family and school staff to discuss the student’s IEP. Once a student is in high school, these meetings should begin the planning for transition from high school to adult life. This may be an area that you will need to advocate for your child. If transition planning is not discussed, please do not hesitate to discuss this important topic with your child’s IEP team.

IDEA defines transition services as a coordinated set of activities for a student that promotes movement from school to post-school activities, including:

- Education after high school
- Job training
- Range of employment opportunities
- Help with coordinating support services (“case management”)
- Preparation for living independently in the community
- Recreation and volunteer opportunities

According to IDEA, these activities must be based on the individual student’s needs, preferences and interests and include activities in the areas of:

- Instruction
- Community experiences
- The development of employment and other post-school adult living objectives
- Acquisition of daily living skills and functional vocational evaluation

It is important that families and schools begin planning early to ease the transition for the person with ASD to increase success and independence in adult life. According to IDEA, this should begin by age 16. Beginning earlier, however, can only benefit the child and is highly encouraged.

Individualized Transition Planning

Because transition planning is the foundation for a student’s adult life, IDEA has provided much guidance to school districts on the content and process for developing an individualized transition plan to support students with disabilities.

In transition planning the following four points should be considered:

- The plan, including goals and services, must be based on the individual needs, preferences, and skills of the person with an ASD.
- Planning should be oriented to life after high school, not limited to what will be accomplished before leaving school
- There should be a master plan that includes long-range goals and a coordinated set of activities for each goal.
- The services provided should promote positive movement toward a life after school (Autism Society of America)

Interagency Planning

Interagency collaboration is an important part of a student’s transition planning. Other agencies and organizations may provide training or direct services to individuals with disabilities that will help schools support a student’s transition to community life. Ask your school district to involve other agencies in developing your child’s plan for transition. This can include the local office of the Office of Vocational Rehabilitation (OVR) and your Community Mental Health Center (see the Social Services chapter for more information on these agencies).

Schools may also seek support from other local agencies and organizations such as independent and supported living centers if they are located in your area. Parents should strongly encourage interagency collaboration as part of transition planning.

Transition planning can involve finding opportunities for job experiences for your child. These can be arranged for the school year and during summer breaks. When a student is given the opportunity to experience different settings and develop work-appropriate skills, he will be able to choose the best path. A good transition plan will allow the student's parents, school officials, and agency personnel to work together to make these opportunities available.

Questions to Guide the Transition Process

Parents can begin thinking about transition planning as early as when the child enters middle school. It can be helpful to start the process with a list of questions to act as a springboard for discussion. These questions can be similar questions parents develop when preparing for an IEP meeting (see the chapter about Education). Some families hold family meetings with siblings and the adolescent with ASD so that they can all share in the planning.

Below is a list of questions developed by a mother whose son has autism (Autism Society of America):

- What can your child do?
- What does your child like to do?
- What are your child's interests?
- What does your child need to explore?
- What does your child need to learn to reach his/her goals?
- What about college (four-year University, two-year community college), vocational education, or adult education?
- How about getting a job (competitive or supportive employment)?
- Where can your child go to find employment and training services?
- What transportation will your child use?
- Where will your child live?
- What living skills has your child mastered?
- How will your child make ends meet?
- Who will be involved in your child's life?
- Where will your child get health insurance?

Many people think of adulthood in terms of getting a job and living independently, but having friends and a sense of belonging in a community are also important. Transition planning through the IEP process is designed to help students and parents plan for this aspect of community life as well. To address these areas, additional questions have been included to guide discussion and decision-making in this area.

- Are supports needed to encourage friendships?
- Do people in the community know your son or daughter?

- Are supports needed to structure time for recreation? Exercise?
- Does your child have any special interests that others may share as a hobby?
- Can you explore avenues for socializing such as religious affiliations or volunteer work?

Make sure the IEP team is reminded that the pattern of strengths and weaknesses in ASD is unique. Don't design a plan that relies heavily on the individual's weaknesses.

Taking Action

It is also important that the transition process involve taking action even though it may be a number of years before your child graduates. After identifying areas of interest and setting goals, school personnel, parents, and the student should take active steps to meet those goals.

For example, a Vocational Rehabilitation Counselor arranges a job experience for a student with ASD who has particularly sharp computer skills. The student is dismissed from school early a few days a week and is accompanied by a job coach to work at a data processing office. In preparation for this job, the student's school program is designed to teach the student appropriate office skills, office procedures (such as using a time clock), and social skills.

Another student, who prefers to be outdoors, would be better suited to work with a community clean-up project than in an office. Her school program is designed to teach landscaping and horticultural skills, as well as social and job skills. The team would identify a job experience site that would allow the student to work in a local nursery. The transition plan must be tailored to each individual's skills and preferences.

Experience with three or four different work activities during transition planning is helpful in assessing a student's interests and capabilities while she is still in high school. For some students, transition activities will be designed to prepare them for further education. The transition plan should address the student's goals for life after high school-whatever the goals may be.

The National Information Center for Children and Youth with Disabilities (NICHCY) has published a Transition Summary series to help families and students with disabilities focus on taking definite steps toward a successful transition. Below we have adapted a portion of NICHCY Transition Summary page: This is an excellent site to visit for more information besides transition. www.nichcy.org/resources/transition_students.asp

Middle School: Start Transition Planning

- Involve your child in career exploration activities
- Visit with a school counselor to talk about interests and capabilities

- Have your child participate in vocational assessment activities
- Along with your child, use information about interests and capabilities to make preliminary decisions about possible careers (academic versus vocational or a combination of the two).
- Along with your child, make use of books, career fairs, and people in the community to find out more about careers of interest.

Keep in mind that while self-determination needs to be considered, students with ASD may mature more slowly than others. Therefore, their timetables for independence may be longer. Beware of eliminating options too early based on academic and behavioral expectations they may not have been achieved at the same age as their peers.

High School: Define Career/Vocational Goals

- Make sure the IEP includes a transition plan and work with school staff and community agencies to define and refine the transition plan.
- Help identify and make sure your child takes high school courses that are required for entry into college, trade schools, or careers of interest. Also, make plans for taking college entrance assessments, such as the ACT starting in the junior year of high school (These tests can be taken with the required modifications as outlined on his/her IEP).
- Help identify and make sure your child takes vocational programs offered in high school, if a vocational career is of interest.
- Encourage your child to become involved in early work experience, such as job try-outs, summer jobs, volunteering, or part-time work.
- Reassess interests and capabilities based on real-world or school experiences. (Is the career field still of interest? If not, redefine goals).
- Make sure your child participates in ongoing vocational assessment and identify gaps of knowledge or skills that need to be addressed. Address these gaps.

After High School: Achieve Your Goals

- If eligible for Vocational Rehabilitation services, make sure your child works with a VR counselor to identify and pursue additional training or to secure employment (including supported employment) in her field of interest.
- If your child is not already receiving Supplemental Security Income, contact the local Social Security Administration office shortly before she turns 18. Family income is no longer considered in determining eligibility for benefits after the person's 18th birthday. If eligible for social security benefits such as Supplemental Security Income, find out how work incentives apply.
- Contact your Community Mental Health Center or DIDD to determine your child's eligibility for services, including Medicaid and waiver services. (See Chapter 6 for contact information.) Even if your son or daughter can be maintained on your medical insurance plan, Medicaid can be useful as

supplemental insurance. In addition, Medicaid eligibility is required for many adult DIDD services.

- Contact agencies that can help, like disability-specific organizations such as the state or local chapter of the Autism Society of America. Ask about all services the student may be eligible for.
- Continue to work through the plan by following through on decisions to attend postsecondary institutions or obtain employment.

Education and Training Prior to Employment

- Have the IEP team and other disability support organization help identify postsecondary institutions (colleges, vocational programs in the community, trade schools, etc.) that offer training in a career of interest for your child.
- Identify the accommodations that would be helpful to support your child. Make sure that documentation is current on your child's IEP. This will support your child's request for accommodations at an educational institution. Find out if the educational institution makes, or can make, these accommodations. Some colleges such as Western Kentucky University, through the Kelly Autism Program, offer additional assistance for individuals with ASD.
- Write or call for catalogues, financial aid information, and request an application.
- Help identify and make sure your child takes any special tests (e.g., PSAT, SAT, ACT) necessary for entry. Deadlines to apply for this testing are generally earlier when accommodations are requested.
- Visit the institution, contact the office of disability services at the institution, and confirm that the accommodations needed for college coursework are available.

Other Future Planning Issues

There are other aspects of planning for your child's future that are not covered in the transition planning process through the IEP. These address issues like quality-of-life support for your child if you are not available and legal issues such as guardianship, and financial planning to protect government benefits.

Despite the growing number of persons with ASD in this country, fewer than 20% of families have done any futures planning to address these issues. Like all of us, your child with a disability will be an adult longer than she will be a child, so future planning is critical.

The following planning topics need to be addressed:

1. Quality-of-life issues
2. Legal
3. Financial
4. Government benefits
5. Guardianship

To guide decision-making when you are not available, discuss information regarding the needs and desires of the child with ASD and compose a directive document. This document should address lifestyle, financial, legal, and government-benefit issues. Whether people with ASD function entirely on their own or need assistance, such a directive can provide instruction for their daily care, as well as provide guidance for unexpected contingencies. Some of the questions this directive should cover include:

- How would your child like to be bathed and dressed?
- Does your child have special dietary needs and requirements?
- Does your child have any chronic medical conditions? Who monitors your child's medication?
- What leisure activities (music, computer, hobbies) does your child enjoy?
- What things can help your child live with dignity, quality, self-esteem and security?

While most people realize they need to plan, for a variety of reasons many fail to do so. Some believe the task is overwhelming and don't know where to find qualified professionals who understand their needs and how to resolve their concerns. The cost of professional services can also be an issue, as can privacy concerns.

Establishing an Advisory Team

As families begin to develop their plan, they should begin by identifying a group of people who will act as an advisory team. This should include, when possible; family members, the person with an ASD, an attorney, a financial advisor, caseworkers, medical practitioners, teachers, therapists, and anyone involved in providing services to the individual. Having input from each of them can help ensure that all parts of the plan are coordinated and complete.

Letter of Intent

Lifestyle planning is a process in which a family records what they want for the future of their loved one in a document called the "letter of intent." Although not a legal document, it is as important as a will and a special needs trust. This letter of intent will include information on a variety of important issues.

Quality of Life

Quality-of-life issues are those everyday things that need to be in place for each of us to be comfortable in our daily lives. Addressing quality-of-life issues for our loved one with ASD requires decisions and information regarding:

- Where the person will live
- Religious affiliation
- Continuing education programs desired
- Employment preferences
- Social activities preferred
- Medical care required

- Behavior management practices
- Advocacy and/or guardianship needs
- Trustees identified for financial planning purpose
- Final arrangements desired
- Detailed instructions for assisting the person with the typical activities of daily living such as bathing, dressing, feeding, and toileting
- Description of any special ways of communicating that only the immediate family knows and understands are included

TIP: Use videotape to record the individual performing activities of daily living, including communicating. Consider taping the individual having a meltdown and demonstrate the best ways of responding if that tends to be a relatively common occurrence.

Should parental support no longer be available, imagine how much easier and less traumatic it will be for the person with ASD and his or her care providers if they have detailed instructions immediately available, rather than having to figure things out on their own. What could take weeks or months to adjust to, could be shortened to a few days.

The ultimate goal of the letter of intent is to make the transition from parental care to independent or supported living or moving in with other family members as easy as possible, bearing in mind the comfort and security of the individual.

Guardianship

As each child approaches age 18, parents need to research guardianship issues and decide which options are appropriate for their young adult. Guardianship is a legal determination that involves your child's ability to make decisions regarding her own affairs, including financial, medical, and educational decisions. If you do nothing when your child turns 18, you legally lose the right to make decisions and sign legal documents for your child. Determining guardianship can sometimes be a difficult decision. Parents should discuss the issue with professionals and with other parents to learn about all the implications.

Estate Planning

"Who will care when you are no longer there?" is an overwhelming question that parents of children with disabilities must address, but solutions and help are available.

Estate planning allows the family to state its wishes regarding the distribution of the family's assets and to appoint executors to settle the estate. In conjunction with estate planning, a trust should be established to provide supplemental funds for the individual with ASD, but in a way that maintains the individual's eligibility for government benefits. An estate planning team should include:

- Attorney
- Accountant

- Life underwriter/financial services provider
- Trust officer

A comprehensive estate plan should:

- Provide lifetime supervision and care if necessary
- Maintain government benefits
- Provide supplementary funds to help ensure a comfortable lifestyle
- Provide for management of funds
- Provide dignified final arrangements
- Avoid family conflict

Once you have decided to prepare a plan, find someone to help you or hire a professional planner. Referral sources are available through governmental agencies, organizations, or local support groups. Use a life-plan binder. Place all documents in a single binder and notify caregivers/family where they can find it. At least once a year, review and update the plan and modify legal documents as necessary.

Establishing a Trust

Government entitlements play a key role in the lives of many persons with autism spectrum disorders by providing money and health care benefits under SSI (Supplemental Security Income), SSDI (Social Security Disability Insurance), Medicaid, and/or Medicare. A basic understanding of federal and state entitlement programs is essential in order to be sure that an individual gets all that he or she is qualified to receive. That said, laws change, so it is crucial to hire professionals with up-to-date legal expertise.

In establishing a trust, financial planning is used to determine the supplemental needs of the person over and above the government benefits they may receive. First, a monthly budget is established based on today's needs while projecting for the future. Then, by using a reasonable rate of return on the principal, the family identifies how much money is needed to fund the trust. The life expectancy of the person must be considered and then the need projected into the future using an inflation factor.

Once this is done, the family must identify the resources to be used to fund the trust. They may include stocks, mutual funds, IRAs, 401(k)s, real estate, and home or life insurance. Professional management for investing the assets may be done by the trustee, or the trustee may hire advisors.

Legal language has changed over time as state policies and legal decisions have evolved. When carefully drawn according to strict legal guidelines, trusts have been able to provide spending money to enhance the individual's daily life. Trusts can be a valuable tool for families, regardless of the size of their estate.

Make sure that the attorney and other planning professionals you hire have specific expertise in planning for people with disabilities.