

Future Planning

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My son was two years from finishing high school when the IEP team finally took up his transition plan. “Shouldn’t we send him for manual assembly activity assessment?” the work-study coordinator suggested for the third time. My son had a 35 on the ACT in math. He was on his high school’s “In the Know” team. He has the fine-motor coordination of a 6-year-old. Somehow, an assembly job doesn’t seem to be the best fit, I thought. Then I reminded myself that parents are an integral part of the IEP team and spoke up!

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Although this chapter covers topics related to your child's life beyond high school, it urges parents to work on them even while their child is still in school. This chapter includes many suggestions for planning for the transition of your child from a school program to adult services, 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

We hope you won't wait until your child is a teenager to formulate plans for the future.

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 them 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. But in the adult service system there are no entitlements. Individuals must "qualify" or be determined eligible for services. Transition services within education should support parents and their child 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 Chapter 5) 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 (IDEIA §300.305(e)(3).

As mentioned in Chapter 6 under the section on the Ohio Department of Developmental Disabilities (DDD), at age 16 a child who has been determined eligible for DDD 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 DDD services, call the DDD intake worker to schedule an appointment for evaluation for eligibility. (See Chapter 6.)

Remember, you have the right to be present during this assessment. If your child is deemed eligible, she will be assigned a Service and Support Administrator who will serve as a case manager to assist you in identifying the range of services needed and in helping you establish 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 doesn't need them.

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 to plan for the transition from high school to adult life.

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 start planning early to ease the transition for the person with an ASD and 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.

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 towards a life after school. (Autism Society of America, n.d.)

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 Opportunities for Ohioans with Disabilities (OOD) and the county board of DD. (See Chapter 6 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 experience 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.

Ohio's Employment First Initiative

In 2012, Ohio's Governor took action to establish the Employment First initiative. Follow-up legislation required Ohio agencies to collaborate and align their services to make employment in the community the preferred option for youth and adults with developmental disabilities regardless of severity of the disability. It is based on the belief that every person has abilities, skills and talents to enrich the community and those around them when provided the proper support. Every agency, school, organization and individual within Ohio's developmental disabilities system plays a role by focusing on what everyone can do and in providing the best supports and services to enable people to choose and succeed in community employment. The effort has engaged parents, professionals and people with disabilities in planning and implementing new rules and policies for employment services at the state, regional and local levels. To find out more about the Employment First work check out this website: www.ohioemploymentfirst.org

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 Chapter 5.) 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, n.d.):

- What can your child do?
- What does your child like to do?
- What does your child need to explore?
- What does your child need to learn to reach his or 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?
- How will your child make ends meet?
- 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, we have added the following questions to guide discussion and decision-making in this area.

- Are supports needed to encourage friendship?
- 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 affiliation 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. After identifying areas of interests and setting goals, school personnel, parents and the student should take active steps to meet those goals.

For example, the BVR representative 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 accompanied by an aide 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 more 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 they may be.

The National Information Center for Children and Youth with Disabilities (NIHCY) has published a Transition Summary series to help families and students with disabilities focus on taking definite steps toward a successful transition. Although NICHCY no longer exists the NICHCY Transition Summary, No. 7, September 1991, is available in its entirety from the Center for Parent Information and Resources (CPIR) <http://www.parentcenterhub.org/?s=nichcy+transition+summary>. Below we have adapted a portion of the NIHCY Transition Summary.

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).
- 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 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.
- 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 experiences, 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 and address these gaps.

After High School: Achieve Your Goals

- If eligible for OOD services, make sure your child works with a BVR 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 county board of DD 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 DD 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 can 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.
- 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.

Resources

Ohio Department of Education, (2002). Operating standards for Ohio's schools serving children with disabilities. Columbus: Ohio Department of Education.

Ohio Center for Autism and Low Incidence, (2008). Transition to adulthood guidelines for individuals with autism spectrum disorders (ASD). Columbus: Ohio Center for Autism and Low Incidence.

For more information on transition planning and other transition resources, as well as webcasts of transition to adulthood topics, visit the OCALI transition webpage at <http://www.ocali.org/topic/transitions/>

Ohio Employment First: <http://www.ohioemploymentfirst.org/>

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 developmental disabilities in this country, fewer than 20 percent 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 futures planning is critical.

CareGuide@Home (2003) reported that at least one individual in 20 percent of U.S. households is a caregiver, either part-time or full-time. Planning for the futures of people with disabilities is something parents and caregivers must address – and the sooner the better. Whether the person with special needs is 4 or 40 years old, it is imperative that families create a plan.

The following planning topics need to be addressed:

- Quality-of-life issues
- Legal
- Financial
- Government benefits

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 (Stevens, n.d.).

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 purposes
- 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 videotaping 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.

For current information on guardianship in Ohio, refer to the Disabilities Rights Ohio documents on future planning and guardianship at: <http://www.disabilityrightsohio.org/faq-guardianship>

These documents also may be requested by calling toll free (800) 282-9181.

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 can 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.

This information was updated and adapted for Ohio from information posted on the Autism Society of America's website, www.autism-society.org.

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.

Information about trusts and special needs trusts is available from the Disability Rights Ohio at the following web address: <http://www.disabilityrightsohio.org>

You may also call Disability Rights Ohio toll free in Ohio at (800) 282-9181.

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

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- Guardianships: <http://www.disabilityrightsohio.org/topic-guardianship>
- Center for Parent Information and Resources (CPIR): <http://www.parentcenterhub.org/?s=transition+>
- Ohio Department of Jobs and Family Service website: jfs.ohio.gov
- Ohio Department of Developmental Disabilities website: <http://dodd.ohio.gov>
- Disability Rights of Ohio website: <http://www.disabilityrightsohio.org/>
- Opportunities for Ohioans with Disabilities (OOD) website: <http://ood.ohio.gov/>
- Social Security Administration website: www.ssa.gov/
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