

Chapter 8: Beyond Academics—Future Planning Issues

There is a positive new trend towards matching individuals with autism spectrum disorder (ASD) to work opportunities and job placement, building on the person's unique strengths and interests. A well written Individualized Education Plan (IEP) will include actions that lead to a good transition from high school to the adult world, including work. The IEP by itself is not enough, however, to assure that transition to adult life will be successful.

There are other aspects of planning for a child's future that families must address, including quality-of-life support for the individual when parents are not available, legal issues such as guardianship, financial planning to protect government benefits, and development of an advisory team and person centered action plan for the child, so that the child has plenty of support and ongoing therapies and interventions to live a healthy and meaningful life as an adult with autism.

Despite the growing number of persons with developmental disabilities in this country, few families have done any futures planning to address these issues. Like all of us, the child with a disability will be an adult longer than he or she will be a child, so futures' planning is critical. 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.

Planning Issues:

- 1) Quality of life**
- 2) Legal**
- 3) Financial**
- 4) Government benefits**
- 5) Age of majority; guardianship, partial guardianship, etc.**

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 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 methods of communicating that only the immediate family knows and understands are included.

Lifestyle Planning—Written Instructions

Essential lifestyle planning is part of a process in which a family records what they want for the future of their loved one in a document sometimes called the “letter of intent.” Although not a legal document, it is as important as a will and a special needs trust. The written instructions or letter of intent will include information on a variety of important issues, and can be used by others when parents are not available or unable to make sound decisions.

To guide decision-making for a document of intent, first start by developing a person centered plan for your child or loved one who has ASD. After developing a person centered plan, develop a letter of intent or written directive that discusses information regarding the needs and desires of the child with ASD. 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.

Putting together a plan for the future should be guided through a process of learning how someone wants to live and for developing that future plan to help make it happen. It’s also:

- ◆ A snapshot of how someone wants to live today, serving as a blueprint for how to support someone tomorrow.
- ◆ A way of organizing and communicating what is important to an individual in “user friendly”, plain language that anyone can understand.
- ◆ A flexible process that can be used in combination with other person centered planning techniques.
- ◆ A way of making sure that the person is heard, regardless of the severity of his or her disability.

Lifestyle plans are developed through a process of asking and listening. The best essential lifestyle plans reflect the balances between competing desires, needs, choice, and safety.

Personal futures planning should be guided by attention to the following values:

- ◆ Placement of emphasis on interdependency among people.
- ◆ Remembering that as a group, strengths and talents are multiplied and weaknesses become less significant.
- ◆ Continuing to use the on going process for the person and circle of friends.
- ◆ Using a decision making process of goal setting and acquisition of supports.

Personal Futures Planning

Every person with a developmental disorder should have a plan for the future. Development of the written plan starts now at this point in time. How to develop the plan and proceed begins with the following list of ideas that address the large picture and considerations:

- ◆ Think about the process of setting short and long-term goals.
 - Identify and develop immediate next steps to reach the goals.
 - Keep an eye on the future and change in systems, health status, family status, etc.
 - What is the “now” for the individual?

- Who is enrolled in the team?
- What are the roles of the team members?
- What does the person with ASD need to grow stronger?
- Identify steps for next month.
- Identify steps for three months, six months and one year.
- Assess the goals and plans at regular time intervals.

Some specific questions to look at and address in the written directive should cover:

- ◆ What are the person’s preferences and needs related to bathing and dressing?
- ◆ Does the person have special dietary needs and requirements?
- ◆ Does the individual have any chronic medical conditions? Who monitors the medication?
- ◆ What is the person’s daily schedule like?
- ◆ What leisure and recreational activities (music, computer, hobbies, sports) does the individual enjoy?
- ◆ What kinds of work activities does the person enjoy?
- ◆ Who are trusted friends and mentors?
- ◆ What supports can help the person to 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 the needs and how to resolve concerns. Both the cost of professional services as well as privacy concerns can be an issue.

Establishing an Advisory Team

As families begin to develop a person centered plan and written directives, it is important to identify a group of people who will act as an advisory team. This should include, when possible, the person with ASD, family members, an attorney, a financial advisor, caseworkers, medical practitioners, teachers, therapists, friends, and anyone else involved in providing services to the individual. Having input from each of these individuals can help ensure that all parts of the plan are coordinated and complete.

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 or written directive 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.

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.

Guardianship

As each child approaches age 18, parents need to research guardianship issues and decide which options are appropriate for the young adult. Guardianship is a legal determination that involves the child’s ability to make decisions regarding their own affairs, including financial, medical, and educational decisions. If the parents do nothing, when a child turns 18, the parents lose the legal right to make decisions and sign legal documents for the 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 Washington, refer to the Arc of Washington State documents on future planning and guardianship at: <http://arcwa.org/publications.htm>.

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 the decision has been made to prepare a plan, find someone to help 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 and/or 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 ASD by providing money and health care benefits under Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI), 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. However, laws change, so it is crucial to hire professionals with up-to-date legal expertise. Special needs require special lawyers, or at the minimum an attorney familiar with all the concerns.

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 under consideration for hire have specific expertise in planning for people with disabilities.

Information about trusts and special needs trusts is available from the Arc of Washington State at <http://arcwa.org/publications.htm>.