



NEW PLAYERS, NEW ROLES

Schools have made great strides in serving students with disabilities. Parents have grown used to school personnel filling the following roles:

- ✓ case managers (usually a teacher, special education team member, or counselor),
- ✓ service coordinators,
- ✓ experts on the laws regarding children with disabilities, and
- ✓ information providers regarding: required documents, meetings parents should attend, and other services parents should locate.



When students leave schools, a similar “overarching agency” doesn’t exist to replace the public school. Parents and their young adults must provide these services themselves, a big change that sometimes takes parents by surprise. Not only do families lose the coordination provided by the school system, but they face the fact that when young people with disabilities become adults, the law no longer requires parental involvement or consent for services provided to their youth. Parents can be involved only if the young adult wants their involvement unless they have guardianship for their son or daughter. Young adults with disabilities can exclude their parents from participating in meetings and decisions about all aspects of their lives.

Let’s look at the new or changing roles family members play in transition.

THE ROLE OF THE YOUNG PERSON

Involving young people in making decisions about their own lives is extremely important. If a young person has had a say in making plans for the future, he or she is more likely to feel a strong commitment to making those plans work. “One of the great injustices that can occur during educational planning is charting a young adult’s future needs without consulting the person who is most affected.” NICHCY Transition Summary, March 1993.

As students move toward adulthood and greater independence the most important role they assume is that of a voice for their own interests. Often decisions are made for rather than with young people with disabilities. This may be because of paternalistic attitudes or a lack of belief in the capability of the individual. Often the focus of special education tends to be on bringing students up to a certain level and de-emphasizes the importance of the level the student has attained. Consequently, the need to build self-esteem and to give students experience in making choices and experiencing their own independence has been overlooked.

There are several other reasons for the limited participation of young people in planning for their futures. Sometimes the nature of young people’s disabilities makes it difficult for them to be involved in making decisions about their futures. Young people may have trouble talking about or thinking through their ideas and feelings to the point where they can communicate them. Because their disabilities may make them dependent on others, they may not have had much experience in making their own decisions.

If your child has special needs, so do you! We can help!

230 West 200 South, Suite 1101

Salt Lake City, UT 84101-1337

801-272-1051 or 800-468-1160

www.utahparentcenter.org

As your son or daughter approaches transition, discussions will help prepare them to participate. Discuss the following issues with your son or daughter:

“You probably have questions about your disability and how it will affect your future.

Let’s talk about your questions and your fears about the future. Together we can think of a way to get them answered.”

“As you become an adult, other people may have to do things for you that you would like to learn to do for yourself. It is important to keep trying to do more and more for yourself, and tell people you want to try to do it by yourself.”

“You can start by finding creative ways of doing things that are harder for you because of your disability. What are some things that are hard for you to do without help that we can find ways for you to do by yourself?”

“We can talk to other people with the same disability for information. Other people who have already become independent can help a lot with creative solutions to common problems.”

Making plans is the first step. Like all young adults, young people with disabilities will be presented with obstacles that they will have to overcome before they can put their plans into place. Overcoming obstacles will require them to become their own advocates.

One young person expressed the thoughts of many who have disabilities when she said: “If we let others speak for us all of the time, no one will ever see us as capable. Worse yet, we will not see ourselves as capable. We will stay dependent forever. We don’t want this! We want to become as independent as we can. In order to do this, people with disabilities will have to begin to take control of their own lives. We know ourselves best.”

Parents and professionals have been making many decisions for and about people with disabilities for many years. In most cases, these have been good decisions. However, there comes a time when people with disabilities are ready to and want to take control of their own lives. People with disabilities want to learn by their own successes as well as their mistakes. What things have you and your young adult student tried to help foster self-advocacy? These are four principles families can follow to help encourage self-advocacy in young adults:

1. Give your young adult opportunities to make decisions and experience consequences.
2. Teach him or her about the disability and how it impacts his or her life.
3. Together, role-play situations in which your young adult wants to be a self-advocate.
4. Allow and encourage independence.

“We must be allowed to try, to make decisions for ourselves, to say what we want. Sure we are afraid sometimes, but we feel better about ourselves when we are successful.”

- John, a young adult with a disability

As people with disabilities learn to become self-advocates, they will take many risks. Self-advocates and their parents need to be prepared to take these risks and expect and accept mistakes. Our young adults can learn as much from their mistakes as we can learn from ours.

People with disabilities are learning how to speak up and speak out for themselves and for each other. They are recognizing the value of advocating for themselves, and taking responsibility for ensuring that their rights are respected. They know they don’t need to be limited by other people’s attitudes and prejudices about disabilities. They are seeking recognition for their capabilities and accomplishments. This self-advocacy movement is powerful and exciting!

THE ROLES OF PARENTS – UNDERSTANDING YOUR CHANGING ROLE

As parents, you offer a great deal of information about your daughter which has great significance when devising a plan for transition. You need to provide details about her traits, interests, aptitudes, behaviors, and abilities that you have observed in the context of family life and activities. Your observations, along with an expression of your values, will provide the transition team with a greater understanding of what services may be necessary and appropriate for your daughter.

You are in a unique position to model attitudes, work habits, interpersonal skills, and appropriate self-confidence for your daughter. You will serve as an advocate, informed about transition planning, who can seek out available services and agencies. Your role as a financial planner will lead you to obtain necessary information about:

- guardianship,
- estate planning,
- Medicaid,
- Social Security (SSI and SSDI), and
- other possible sources of income as well as the costs of appropriate programs and services.

You will fill the role of record-keeper or assist your student with keeping accurate complete records. You'll recognize the value of saving information in writing about your experiences with educators, medical care providers, and service agencies. Such documentation will be very useful in developing and monitoring your daughter's transition plan and will be essential as you oversee how the plan is working. You will be motivated to make certain that the good intentions of the transition plan are being met and request follow-up meetings if adjustments are needed. Finally, you may act as cheerleaders who encourage your daughter to be a self-advocate in making the plan and pursuing her own transition goals to realize her dreams.

Develop a record-keeping system to help you keep track of which agencies, organizations, and providers have been contacted and the information you have received. You can organize your records by having separate file folders, large envelopes, or sections in a three-ring notebook for each agency.

Keep all letters they write to you and a copy of any letter you send to them. Review your records periodically to refresh your memory about any issues that are pending or need follow-up.

The roles of parents of a young person with a disability are essentially the same as for the parents of any other young person. Both are preparing their young adult to be independent and self-supporting individuals. However, because of the obstacles a young person with a disability is likely to encounter, their transition may have to be more carefully planned. Eight major roles have been identified that parents play in the lives of their children with disabilities. These continue, although often "in the background" as their young adult moves through the transition to adult life.

PARENTS AS PROVIDERS OF CAREER EDUCATION

Parents are advocates for and providers of career education when they:

- talk about their own jobs;
- describe what is involved in various careers in the community,
- use newspapers, magazines, television, and movies to begin discussions about jobs,
- and/or
- encourage students to explore hobbies using skills related to careers in which they are interested.

PARENTS AS PROVIDERS OF UNIQUE INFORMATION

Parents are providers of unique information about their:

- young adults' likes and dislikes,
- what motivates them,
- what they are good at,
- what is likely to frustrate them, and
- what they do successfully.

PARENTS AS ROLE MODELS

Parents are role models when they demonstrate some ways to develop appropriate work behavior including:

- assigning specific duties around the home to be completed in a certain way,
- emphasizing good grooming and physical fitness, and
- encouraging good social and communication skills.

PARENTS AS CASE MANAGERS

When young adults with disabilities move to adult services, there isn't an agency responsible for managing the coordination of services, although several offer some level of support in this area. Plans for transition services are not "self-executing". Parents and young adults need to track transition plans and adult service agency plans carefully to make sure that the good intentions of the plans are fully met.

PARENTS AS ADVOCATES

The best advocate is informed and knowledgeable, so parents need to be sure to do their homework – both at school and with job training! They will be advocates to some degree even when their role shifts to become more supportive of their son or daughter as they become a self-advocate. Parents and their child must become informed about:

- transition planning,
- services in the community, and
- agencies that provide programs and assistance.

PARENTS AS RISK TAKERS

Parents know that "letting go" is the best thing for their youth, but allowing a young person with a disability to take the risks that go with independence is hard. Parents' involvement with their young adult in planning for transition is a chance for parents to gain confidence in their youth. Taking the risk of letting go may include allowing young adults to:

- attend sporting events, school activities, and social events alone,
- use public transportation,
- spend their own money, or
- call friends on the phone (and make their own plans!!)

PARENTS AS FINANCIAL PLANNERS

Decisions about work and financial aid involve a balancing act between financial security and independence. Parents need to:

- Be informed!
- Consult with professionals about estate planning, if necessary.
- Consider whether or not you need to seek guardianship or obtain a power of attorney for your child.
- Know how earnings and income affect other benefits.

Often parents and young people with disabilities are faced with a dilemma caused by the fact that the eligibility requirements for financial assistance programs create reasons for people not to go to work. This

might involve choosing between accepting a minimum wage job with no medical benefits, leading to the loss of eligibility for Supplemental Security Income (SSI) and Medicaid, or staying at home without stimulation, opportunities for growth, and the satisfaction of work. Laws have been enacted in recent years to help address these issues and concerns. Benefits counselors are available through a number of state agencies to answer your questions and explore employment options. Decisions of this type involve a balance of financial security and independence.

PARENTS AS RECORD KEEPERS

Parents and students often find working with adult service providers confusing and time-consuming. It is extremely important to develop a record-keeping system to track the many organizations that have been contacted and what information has been gathered. Encourage your student to take as much responsibility as they are capable of. Here are some suggestions for developing such a system:

A record of all school transcripts, evaluations, tests, and therapy reports should be obtained when the student leaves the school. These records may be needed when coordinating adult services and in the future. (Parents have a right to have copies of all materials in the student's file under the Family Educational Rights and Privacy Act [FERPA]).

Keep records of any on-the-job training reports or other work experiences.

Keep accurate notes of all telephone conversations you have with agency personnel.

Keep a file folder for each organization you work with. Keep records, correspondence, brochures, and handouts in each folder.

Keep copies of letters you write to an agency or prospective employer as well as all the letters they write you.

It is critical to create as many opportunities as possible for young adults to practice independence. Which of these tasks can your young adult do part or all? Which are challenges? As our children become young adults, we must make a conscious effort to encourage and support them as they assume new roles. Transition is also a time when we may need to redefine our own roles in relation to our sons or daughters and the professionals who serve them.

*This content is taken from the Utah Parent Center handbook:
From NO Where to KNOW Where: A Parent Handbook for the Transition to Adult Life.*