



Utah Parent Center

Parent Training and Information Center

FROM 'NO' WHERE... ...TO 'KNOW' WHERE

A PARENT HANDBOOK FOR THE TRANSITION TO ADULT LIFE



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Contact the Utah Parent Center for more information on:

- Free Utah Parent Center workshops
- Additional information on topics covered in this book

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From 'NO' Where to 'KNOW' Where Transition to Adult Life – Parent Handbook

This handbook for parents of youth with disabilities will:

- equip parents to be active participants in developing transition goals and activities to be included in the last IEP before students turn 16, or younger if appropriate,
- guide parents in preparing for successful adulthood of their son or daughter, and
- assist parent in pursuing and achieving transition goals.

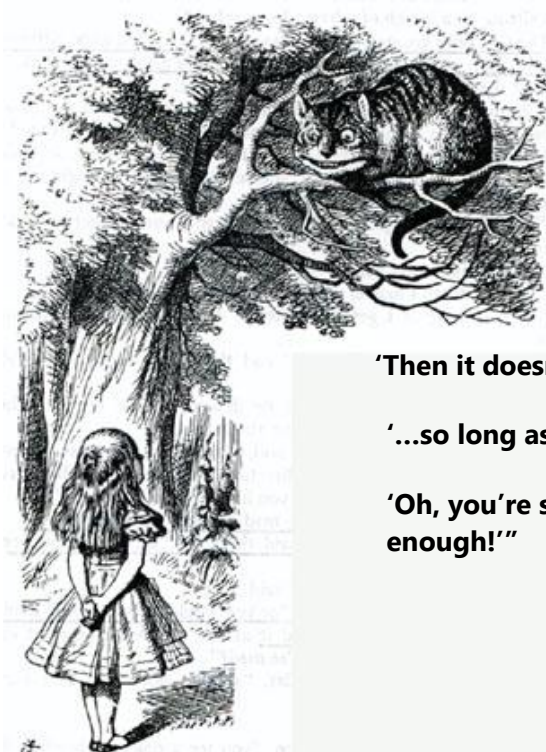
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Introduction



The following topics are included in this section:

- ✓ How Special Education and Adult Services Differ
- ✓ Six Key Areas to Ensure a Smooth Transition
- ✓ Helping Your Youth Discover a Vision



"Alice went on, 'Would you tell me, please, which way I ought to walk from here?'"

"That depends a good deal on where you want to get to," said the Cat.

"I don't much care where..." said Alice.

"Then it doesn't matter which way you walk," said the Cat.

"...so long as I get somewhere," Alice added as an explanation.

"Oh, you're sure to do that," said the Cat, "if you only walk long enough!"

Lewis Carroll, Alice in Wonderland

Alice didn't care where she went as long as it was 'somewhere'...As parents of young people with disabilities; we do care where they are going and how they get there. It does matter which way they go. Alice asked for direction from the Cheshire Cat. Often our children look to us for directions. As parents, we too need people who can give us direction at this challenging time in the lives of our kids. Transitioning to adult life is an exciting, sometimes frightening time, but we've been participating, supporting, and advocating for a long time! We're tired but must keep going!

What is in store for youth with disabilities after they leave school? What will happen to your daughter* when she no longer receives the educational services or accommodations which have been mandated by federal law? These questions are important to all parents of youth with special needs, and even though disabilities may vary greatly in their severity or impact, the need to plan for the future is very important.

FROM SPECIAL EDUCATION TO ADULT SERVICES

It is vitally important for families to realize that transition represents the process of moving from services in school that eligible students are entitled to under their Individualized Education Program (IEP) to services in adult programs that are available based on varying eligibility criteria.

In Utah students with disabilities are entitled to educational services until a regular high school diploma is earned or up to the age of 22. After leaving school programs, they must meet eligibility criteria to qualify for post-school services. Some programs often have long waiting lists.

Families who begin planning early will have more time to identify concerns, overcome challenges or barriers that arise or create opportunities which will help their student achieve goals. Planning for the future early will alleviate disappointment and anxiety as the student approaches adulthood.

The transition plan should be unique for each student. It should address specific needs, strengths, preferences, and interests. It will be affected by the availability of programs and services. It should reflect the student's values and those of her family, peers, and the community in which she lives.

Use this handbook as a guide to design a process that will lead your student to a bright future. It is designed to acquaint you with the issues and range of options to be considered so you can explore possibilities and make educated choices. Some sections may be more applicable and helpful than others based on your needs and the needs of your son or daughter. You will likely need additional information in some of the areas that are addressed as you move from "NO" where to "KNOW" where.

DIFFERENCES IN SERVICES

The special education system differs from adult services in the following ways:

Special Education

- Special Education is an entitlement program that provides services to all qualified students.
- Parents are the advocates, spokespersons, and decision-makers for their children until their children turn 18 years old. After age 18, guardianship can be considered.

Adult Services

- Adult service agencies are eligibility programs. A set of specific requirements determines whether an individual qualifies for services.
- All young people legally become adults at age 18. Young adults with disabilities are no exception. At 18 years of age, young adults with disabilities are legally responsible for making their own decisions, unless some form of guardianship is obtained.

Another major difference is that special education is responsible for coordinating services for young people while they are in school. When students leave the schools, in spite of many services and options that may be available, there no longer exists a 'central agency' or person assigned responsibility to plan, coordinate, and oversee the provision of information and services.

For this reason, it is helpful for parents to have some information to get started. Keys are used to start vehicles that we use to move from one place to another. Information can be the 'key' that helps us get on our way to successful transition for our young person.

SIX KEY AREAS TO ENSURE A SMOOTH TRANSITION

In this handbook, we will consider **six key areas**. An understanding of the information in these areas will help ensure effective planning and a smooth transition.

- The first key area is to have an **understanding of the laws**. Understanding the laws providing rights to adults with disabilities helps parents and young adults advocate more effectively for those rights.
- The second key area is to have an understanding of the planning process and the role of “informed choice”. Understanding how the adult system works can help young adults with disabilities access the system with informed and realistic expectations. Understanding the planning process and the role of “informed choice” in developing programs will help parents encourage young adults to include their own interests and preferences. The term “informed choice” is used in vocational rehabilitation. Other terms with similar meanings are “self-determination” and “self-advocacy”.
- The third key area relates to information gathering, documentation, and assessments needed to apply for adult services. Helping young adults with disabilities and their parents gather information, documentation, and assessments needed to apply for adult services will streamline the process.
- The fourth key area is knowing about the wide range of adult services and programs. Knowing about options and possibilities allows the young adult and their parents to investigate more fully and helps make for a successful transition and planning services.
- The fifth key area is to understand how the adult system works. Understanding how the adult system works can help young adults with disabilities access the system with informed and realistic expectations.
- The sixth key area is learning about the legal requirements and appeal processes available in various agencies. This will help parents advocate effectively for and with their young adult.

HELPING YOUR YOUTH DISCOVER A VISION

Before you start down the road to transition planning it is important to understand where your son wants to be in the future. Sometimes the nature of his disabilities makes it difficult or impossible for him to think through or talk about his ideas and feelings. He may lack experience in making his own decisions. The following suggestions may help in preparing him to participate more fully in developing a transition plan.

- Begin by asking simple questions: Where do you want to spend time as an adult? Doing what? With whom?
- Compare his skills and abilities with those who succeed.
- If he expresses interest in an occupation clearly beyond his abilities, find out the reasons he is interested in a particular job. He may be attracted to a job because of the uniform that is worn or because of the place where the job is done. Discuss other jobs related to his interests which might be a better fit for his strengths.
- Help him learn about his disability and how it may affect his future.
- Talk about things he would like to do independently and ways he can learn those skills.
- Consider what support services or technology may be needed to make his vision a reality. Figure out who can help make it happen.
- Get information from other people with the same disability; they may have creative solutions to common problems.

Even a student with the most significant disabilities has unique needs, interests, and preferences. By recognizing and addressing them appropriately, his quality of life can be enhanced, and you can support the plan with less reluctance and more enthusiasm. Some families have obtained valuable input and ideas by developing a person-centered plan. (Contact the Utah Parent Center to get more information about person-centered planning.)

If the severity of your son's disabilities makes it impossible for him to answer even simple questions, this does not mean that a transition plan is unnecessary. Instead, it may be helpful to discuss your hopes and dreams for his future with other members of your family. Answer the same questions with a subtle twist. For example, how do we want him to spend his time as an adult? With whom? What supports will he need? What needs to happen for these dreams to become a reality? Seek out information about people who have pursued inventive ways of addressing the future needs of their loved ones.

Laws



This section will introduce the laws that impact the transition of individuals with disabilities from school to adult life. The laws that will be introduced in this section include:

- ✓ Individuals with Disabilities Education Improvement Act or IDEA 2004,
- ✓ Family Education Rights and Privacy Education Act (FERPA),
- ✓ Rehabilitation Act of 1973,
- ✓ Section 504 of the Rehabilitation Act – An Anti-Discrimination Law,
- ✓ Americans with Disabilities Act (ADA),
- ✓ Carl D. Perkins Vocational and Applied Technology Education Act,
- ✓ Fair Labor Standards Act (FLSA),
- ✓ School-To-Work Opportunities Act, and
- ✓ Ticket to Work and Work Incentives Improvement Act of 1999.

INDIVIDUALS WITH DISABILITIES EDUCATION IMPROVEMENT ACT OR IDEA 2004

In 1990, amendments reauthorized Public Law 94-142 – originally enacted in 1975 – under a new public law number, Public Law 101-476. This reauthorization also changed the name of the original act to the Individuals with Disabilities Education Act, now commonly referred to as IDEA. In 2004, IDEA was again amended and became the Individuals with Disabilities Education Improvement Act – Public Law 108-446.

This act ensures that all children with disabilities have available to them a free appropriate, public education that includes special education (individually designed instruction) through the Individualized Education Program (IEP), in the least restrictive environment and related services to meet their unique needs.

The six principles of IDEA '97 are key to understanding the intent and spirit of the law. These include:

1. **Free Appropriate Public Education (FAPE):** FAPE means special education and related services are available to eligible children with disabilities age 3 to 22 and are to be provided at no cost to the parents. The provision of FAPE differs for each child, but the principle is the same. FAPE applies to all children with disabilities, including those who have been suspended or expelled from school.
2. **Appropriate Evaluation:** Appropriate evaluation is used to gather accurate information to determine eligibility and continued eligibility, as well as identifies the student's strengths and educational needs. An Individualized Education Program (IEP) is then designed to respond to the student's needs.

3. Individualized Education Program (IEP): The IEP is a legally binding, written document that outlines the special education program services and related services based on the child's educational needs.
4. Least Restrictive Environment (LRE): LRE is the environment where the student can receive an appropriate education designed to meet his or her special education needs, while still being educated with nondisabled peers to the maximum extent appropriate.
5. Parent and Student Participation in Decision-Making: IDEA requires that parents must be given the opportunity to play a central role in the planning and decision-making of their child's education. Parents must have the opportunity to participate in meetings regarding identification, evaluation, educational placement, and the provision of FAPE to the student. Student rights and participation are expanded and encouraged, particularly when addressing transition planning.
6. Procedural Due Process: Procedural due process refers to the safeguards designed to protect the rights of the parents and their child with a disability, as well as give families and schools a mechanism for resolving disputes.

Part B of IDEA outlines the special education process for eligible children from age 3 through graduation or age 22, whichever comes first. This includes special education preschool which serves children with disabilities who are ages 3 to 5. The Utah State Office of Education is the lead agency responsible for overseeing special education. The specific child identified educational needs and services are written in an Individualized Education Program or IEP. Transition planning within the IEP is covered later in this handbook.

The IEP is a critically important provision of the IDEA. Parents need to understand the process through which IEPs are developed to fully understand transition planning within the IEP process. Parents have important roles and responsibilities on behalf of and with their child. For more information about IEPs, contact the Utah Parent Center at 801-272-1051 or toll-free in Utah at 1-800-468-1160.

FAMILY EDUCATION RIGHTS AND PRIVACY ACT (FERPA)

This act guarantees parents the right to inspect and review their child's file, says that only people who need to see the file can, and allows the parents to challenge information in the file you feel is inaccurate or misleading. If you disagree with things in the file, you can ask the school to take them out. If they refuse you may attach a letter to the page in question telling why you disagree or request a due process hearing.

REHABILITATION ACT OF 1973

In 1992 the Rehabilitation Act of 1973 was amended significantly and on March 13, 1997 Final Rule amendments to regulations governing the State Vocational Rehabilitation (VR) Services Program became effective. The Act shows changes in the way Americans see people with disabilities. Historically, having a disability has been seen as a medical problem to be "fixed". Attitudes are changing; people are starting to understand that individuals with disabilities are capable of participating in all of life's growth experiences, responsibilities, and growth.

The act assumes that people can benefit from Vocational Rehabilitation (VR) services regardless of the severity of their disability, if given appropriate services and supports. The burden of proof that a person with a disability cannot work is placed on the VR agency.

This Rehabilitation Act uses the *same definition of transition as the IDEA* in an effort to encourage collaboration between education and rehabilitation. There are three major areas of emphasis dealing directly with transition in the Act. It:

1. uses the same definition of transition as IDEA.
2. reduces the gaps of services and barriers for consumers moving from public school systems to VR.
3. requires that VR and education work together to fund and train young adults with disabilities to prepare them for meaningful employment.

There are key areas specific to transition discussed in the law, namely:

1. **Eligibility** - the Act specifically states that existing documentation from education agencies should be used whenever possible as evidence that there is a mental or physical disability.
2. **Assessment** - the rehab agency is to use documentation from other agencies, including education agencies in the development of the Individualized Plan for Employment (IPE).
3. **Career Development** - the Act supports the development of a career as opposed to the emphasis on the attainment of a single job. This emphasis will allow more support of consumers in post-secondary programs, including colleges and universities.
4. **Individualized Plan for Employment (IPE)** - to support coordination and collaboration, the IPE can be developed before a student leaves school to assure no break in service. This also allows the rapid, efficient, and appropriate determination of eligibility before exiting school.
5. **Funding** - the Act requires the Department of Rehabilitation and Department of Education to develop agreements that include clarification of funding, i.e. who pays for what?
6. **Section 504: Anti-Discrimination** - the Act contains provisions to safeguard the rights of people with disabilities. It gives them protection against discrimination in all programs receiving federal money as well as protection from discrimination by federal agencies or contractors.

SECTION 504 OF THE REHABILITATION ACT: AN ANTI-DISCRIMINATION LAW

The law states that, "No qualified individual with disabilities based upon their disability status, shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance."

A person has a disability within the definition of Section 504 if he or she:

- has a mental or physical impairment which substantially limits one or more of such person's major life activities;
- has a record of such impairments; or
- is regarded as having such an impairment.

Section 504 emphasizes the following areas related to transition-age students:

- employment,
- program accessibility, and
- requirements for post-secondary education.

Section 504 protects individuals with disabilities from discrimination when participating in any program that receives federal funding. More information about Section 504 and Vocational Rehabilitation is available from the Utah Parent Center or the Utah State Office of Rehabilitation. The School Guidelines for Educators and for Parents can be found on the USOE website. They have many ideas for how to use accommodations and implement the law. A parent guide to section 504 can be found online by visiting the Utah State Office of Education's or the Utah Parent Center's websites.

AMERICANS WITH DISABILITIES ACT (ADA)

The Americans with Disabilities Act (ADA), Public Law 101-336, is a federal law signed by President Bush in 1990. Its purpose is to provide clear and enforceable standards addressing discrimination against individuals with disabilities and to help them join the mainstream of American life. The ADA prohibits discrimination against people with disabilities in:

- employment,
- transportation,
- public accommodations, and
- communications and activities of state and local government, including colleges and universities

The ADA requires educational institutions to make programs and facilities accessible to students with a variety of disabilities. In addition, schools cannot have discriminatory policies and practices. The ADA also requires employers, employment agencies, and labor organizations to provide non-discriminatory application procedures, qualification standards, and selection criteria, and reasonable accommodations for limitations of a qualified applicant or employee unless to do so would cause the business undue hardship. Examples of accommodations are:

- modifying training materials (large print, Braille, audio cassette, etc.),
- modifying work schedules, such as allowing a person to reduce work hours, or lengthen the work day to include rest periods, and
- providing auxiliary aids and services such as: interpreters, assistive listening systems, readers, materials in Braille, and speech synthesizers.

The ADA requires that students be educated about their legal rights and that employers be aware of the requirements of the law.



OTHER LEGISLATIVE SUPPORTS FOR TRANSITION

Other pieces of legislation that help individuals in the transition from school to adult life are:

- **The Carl D. Perkins Vocational and Technical Education Act of 1998:** This act (Public Law 101-392) is a federal law designed to develop the academics of vocational and technical skills of secondary and post-secondary students who elect to enroll in vocational and technical education (formerly applied technology) programs. This law provides services and assistance to students from special populations.
- **Fair Labor Standards Act (FLSA):** This act allows the Department of Labor to monitor child labor laws, minimum wages, overtime pay, and sub-minimum wage certification. The FLSA defines situations pertaining to school vocational programs in which students with disabilities may be considered “trainees” rather than “employees” while participating in community-based vocational instruction.
- **School-to-Work Opportunities Act:** This law promotes school and business partnerships to facilitate transition and develop a highly skilled workforce and includes students with disabilities, but provides noncategorical protection. It also calls for the involvement of disability-related organizations and service providers. It contains a vision of opportunities available to all students. A combination of federal and state implementation grants were funded to coordinate with the business community to provide an integration of school-based and work-based learning.
- **Ticket to Work and Work Incentives Improvement Act of 1999:** This act was enacted on December 17, 1999. It increases beneficiary choice in obtaining rehabilitation and vocational services, removes barriers that require people with disabilities to choose between health care coverage and work, and assures that more Americans with disabilities have the opportunity to participate in the workforce and lessen their dependence on public benefits.

What is Transition?

Included in this section is an overview of what transition is and why it is so important.

- ✓ What is transition and why is it important?
- ✓ Transition Quiz – Questions and Answers
- ✓ What is transition planning?

WHAT IS TRANSITION AND WHY IS IT IMPORTANT?

Transition is change. It is passage from one stage to another. We each face many changes or transitions in life, but right now we are specifically talking about the transition from school to whatever is next for your son or daughter with disabilities. Yes - this transition is change...and change is scary and it is hard - for all of us!!



This change from child to young adult is a tough one! Our students are changing and the systems that support them are changing. We may not like it, but it is so and this is a transition that must be anticipated and planned for. If this transition - this change - is to be “seamless” - which means with no interruption in services – we need to remember the lesson learned by Alice in Wonderland and help our sons and daughters decide where they want to go and what they want to do. Then we’ll know how to get them there. We need to consider what will happen...

WHEN THE BUS DOESN'T COME...THAT'S TRAUMATIC!!

Some parents don't think about what will happen after school until a few months before graduation, and then they realize that “the bus won't be coming!” That's traumatic! –OR- they do plan and find that what is available through adult service agencies and in the community may not provide the ongoing assistance needed by our young people. We may find that our young people don't have choices for a myriad of reasons including not being eligible for services and a lack of funding to provide needed services and options. Options for work, living, or recreation may not exist. Our family member may even choose not to access or participate in programs and services.

Given these factors we might ask, “Why plan a set of coordinated activities to improve post-school outcomes?” To help us decide, let's consider information that answers these questions:

1. What is the quality of the lives of young adults with disabilities after they leave the school system?
2. Is the outcome of a productive and satisfying life a reality for students with disabilities leaving public schools?

The answers may surprise some of us with discouraging information.

Studies examining the post-school results of students with disabilities (such as post-secondary education, employment, living arrangements, mobility, and leisure) have found that a large portion of these students do not go on for further training. Additionally, they often do not receive needed post-

school supports and services and as adults are not as successful when compared to the general population.

According to various studies and reports, the disturbing truth is that 2/3 of adults with disabilities in our society are NOT working. Reasons for this high unemployment rate include such factors as:

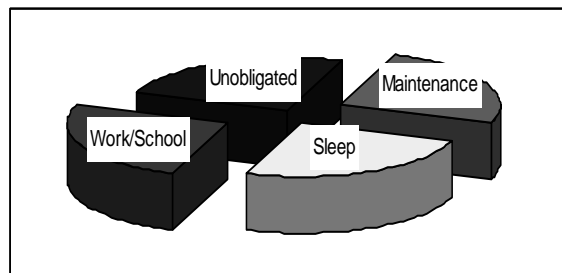
- the nature of the individual's disability
- the lack of appropriate education and preparation to work
- employer perceptions and attitudes
- lack of social skills
- transportation concerns - e.g. "How does the person get to work?" or "Is accessible transportation available?"
- economic and benefit disincentives - e.g. "They may risk losing SSI and Medicaid benefits if they go to work."
- family beliefs and concerns - "She's too disabled to work!" "He can't do that!" "She doesn't need to work!"
- lack of appropriate jobs
- lack of devices or aids to help in job performance - e.g. assistive technology, job coaches, etc...

Even with this generally bleak outlook, there is also an increasing awareness that self-sufficiency, employment, and independent or semi-independent living can be achieved by individuals with disabilities. In fact, research shows that working makes a big difference in the lives of people with disabilities; it improves their self-esteem and satisfaction with life.

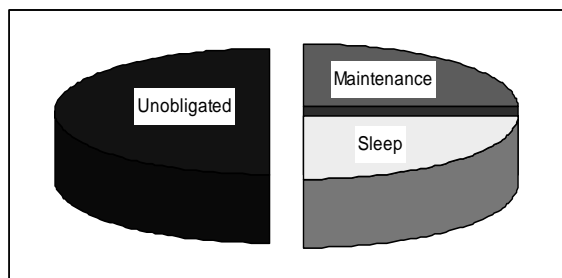
The conflict between the desire and the ability of people with disabilities to work and the factors that inhibit their going to work, creates tension, especially for the families of young adults getting ready to leave school. The transition from school to adult life can be distressing for both young adults with disabilities and their parents. Without careful planning, 12 to 18 or more years of hard work completing school yields only a diploma and a graduate at home with not much to do. School activities no longer occupy 7 or 8 hours each day. The bus doesn't pull up each morning. Social interaction with other students is no longer a natural part of each day.

To illustrate the difference in how our young people will likely spend their time, let's look at two charts referred to as the "Pie of Life".

This is what the slices in the "pie of life" usually look like when students are in school. Each quarter, or "piece of the pie", represents a quarter of the day, or 6 hours. Consider how much of the time your son or daughter spends doing the following: sleep, school or work, maintenance (chores, hygiene, meals, etc.), and unobligated time.



When students are no longer in school, the slices in the pie of life look more like this pie. Our look at the statistics about the high unemployment rate in adults with disabilities tells us that after struggling to complete 12 to 18 or more years (if they started in preschool) of school, many students graduate and have nothing to do. They have a lot of unobligated time. Without careful planning,



your son or daughter with a disability may be at home with this chunk of unobligated time - time wasted and gains made in school quickly lost.

When we look at the laws affecting transition services, addressed earlier in this manual, it is clear that legislators intend for families, students, schools, and adult services agencies to work together to help with the transition to post-school activities. Most government agencies, such as schools and vocational rehabilitation also have specific mandates to work together to streamline the transition process.

The one institution providing services to young adults with disabilities that falls outside of the arena of legislation is the family of a person with disabilities. Families are the most vital caregivers for their family member and are often the advocates and spokespersons. However, the individuals themselves are usually the best spokespersons for themselves, especially when they reach transition age. They - the individuals AND families - need to be involved in all efforts to collaborate and plan for the future.

When students without disabilities graduate, many parents have expectations about the young adult's path to independence. These expectations can't be taken for granted for the student with a disability. Specific plans need to be made to ensure a successful transition from school to meaningful employment and activities after school. Why? Because what a young person does after school will be different and the future for him/her won't necessarily be better unless we do something about it! And we can!

With all of the concerns and problems that we have, people with disabilities are generally better off when they transition from school to work than they've ever been!!

Transition Quiz – True/False

- ___ 1. Transition planning has always been part of the IEPs of older students.
- ___ 2. According to IDEA, a transition IEP promotes movement from school to work.
- ___ 3. A transition plan is based on the needs of the student, not his/her interests and preferences.
- ___ 4. Transition planning must begin with the student is 15 years old.
- ___ 5. After students with disabilities leave school, they are no longer entitled to additional services.
- ___ 6. The issuance of a standard diploma terminates a student's eligibility for public education services.
- ___ 7. As long as the plan addresses the student's future employment and training needed for the job, it satisfies the intent of the legislation.
- ___ 8. The transition plan will specify how different agencies will work together to provide needed services, including when a specific objective needs to be completed and by whom.
- ___ 9. If the transition plan is working and goals are being accomplished, the annual review is optional.
- ___ 10. When a student reaches age 18, she becomes her "own parent".

Transition Quiz Answers

1. TRUE. The transition plan is part of the IEPs of older students.
2. FALSE. According to IDEA, a transition IEP promotes movement from school to work.
3. FALSE. A transition plan is based on the needs of the student, not his/her strengths, interests, and preferences.
4. TRUE. Transition planning must begin when the student is 15 years old.
5. TRUE. After students with disabilities leave school, they are no longer entitled to additional services.
6. TRUE. The issuance of a high school diploma terminates a student's eligibility for public education services.
7. FALSE. As long as the plan addresses the student's future employment and training needed for the job, it satisfies the intent of the legislation.
8. FALSE. The transition plan must specify how different agencies will work together to provide needed services, including when a specific objective needs to be completed and by whom.
9. FALSE. If the transition plan in the IEP is working and goals are being accomplished, the annual review is optional.
10. TRUE. When a student reaches age 18, she becomes her "own parent".

WHAT IS TRANSITION PLANNING?

When the Individuals with Disabilities Education Improvement Act (IDEA 2004) was reauthorized in 2004, it continued to recognize the need and includes the federal mandate for transition services. It clearly intended that those services be an integral part of the Individualized Education Program (IEP). Transition planning is designed to assist students with disabilities as they move from school into the adult world.

Because the Individualized Education Program (IEP) is so important in identifying a student's needs and making plans to meet them, the Utah Parent Center has developed a workshop and an information booklet and video, "Parents as Partners in the IEP Process."

This excellent resource can help guide parents through the provisions of the Individuals with Disabilities Education Act (IDEA 2004) and provide information to help them in the process of developing their student's IEP, including transition plans.

When the law was reauthorized in 2004, it specified that "for a student with a disability beginning not later than the first IEP to be in effect when the student turns 16 (such as in an IEP meeting conducted when the student is 15 years old), or younger if determined appropriate by the IEP team, the notice of meeting must indicate: that a purpose of the meeting will be the consideration of the post-secondary goals and transition services for the student; and that the LEA will invite the student; and any other agency that will be invited, with the consent of the parents or student age 18 or older, to send a representative. All of the IEP rules apply, but transition IEPs have additional requirements.

Transition services are to include linkages to services and programs in the community. The law also requires that the transition IEP must be reviewed annually to assure that the long-range goals are

accompanied by specific objectives and activities which successfully focus on strengths, and abilities rather than just educational processes and meet graduation requirements.

Transition planning prior to age 16 may be especially important for students who expect to graduate with peers of their same age or who are at risk of dropping out. Early identification of concerns and proactive appropriate planning are essential to keep students on a successful track to complete their school experiences.

Parents of a student receiving accommodations under Section 504 of the Rehabilitation Act can address transition issues when developing his Student Educational Occupation Plan (SEOP) and 504 Plan. The Booklet, "A Parent and Educator's Guide to Section 504 of the Rehabilitation Act" can be obtained from the Utah Parent Center or the Utah State Office of Education at no cost to parents or downloaded online by visiting: www.utahparentcenter.org or <http://www.schools.utah.gov/equity/Section%20504/504.main.htm>.

The components of a transition IEP according to IDEA must be based on the student's needs and take into account his interests and preferences. Also, it must be designed to promote movement from school to work. It identifies a coordinated set of services which include his goals for post-school activities, objectives, timelines, and assigned responsibilities. It incorporates input from his teachers, special education administrators, and other representatives of agencies and/or organizations likely to provide or pay for services.

The goal of transition services is to maximize the self-sufficiency, employment, independent living, and positive community involvement of individuals with disabilities. These services will provide your son with opportunities to develop his skills and use his abilities so he can have more choices and satisfaction in life. Also, his active participation in society will enhance the quality of life for others - especially his family and friends.

ESSENTIAL TO THE TRANSITION IEP:

- Includes a statement of transition service needs to be in place by age 16, or younger, if appropriate,
- Beginning at 16, or younger, if appropriate, states what services are needed and identifies interagency responsibilities,
- Is based on student's needs,
- Considers student's interests and preferences,
- Focuses on strengths and abilities rather than educational processes,
- Promotes movement from school to post-school activities,
- Is reviewed at least annually, and
- Consideration of social needs.

Developing the Transition Plan

Included in this section is an overview of what transition is and why it is so important.

- ✓ Purpose of the Transition IEP Planning Meeting
- ✓ Preparing for Transition Planning
- ✓ Steps to Transition
- ✓ Who is Involved in Transition Planning?
- ✓ Helping Students to Participate in the Transition Planning Meeting.
- ✓ Transition Meeting
- ✓ Transition Timeline
- ✓ Post Transition Meeting



Now let's look at developing the transition plan as part of a student's IEP. We'll look at when a transition timeline should be developed, who is to be involved in planning, what the purposes of the meeting are, seven "steps" to help us through the transition process, and the key requirements for the transition IEP.

PURPOSE OF THE TRANSITION IEP PLANNING MEETING

The purposes of the meeting should be to:

- determine the needs of the student,
- target the services available to meet identified needs,
- develop a formal transition plan,
- monitor the progress of the student, and
- provide information and training for parents about the transition process.

PREPARING FOR TRANSITION PLANNING

It is unlikely that anyone is more concerned about your daughter's future than you are. As you learn about her disability and become better aware of the impact it would have on her life and yours, you may have avoided thinking about her adult years. Transition planning will help you, may even force you, to think about the future and the inevitable changes that lay ahead.

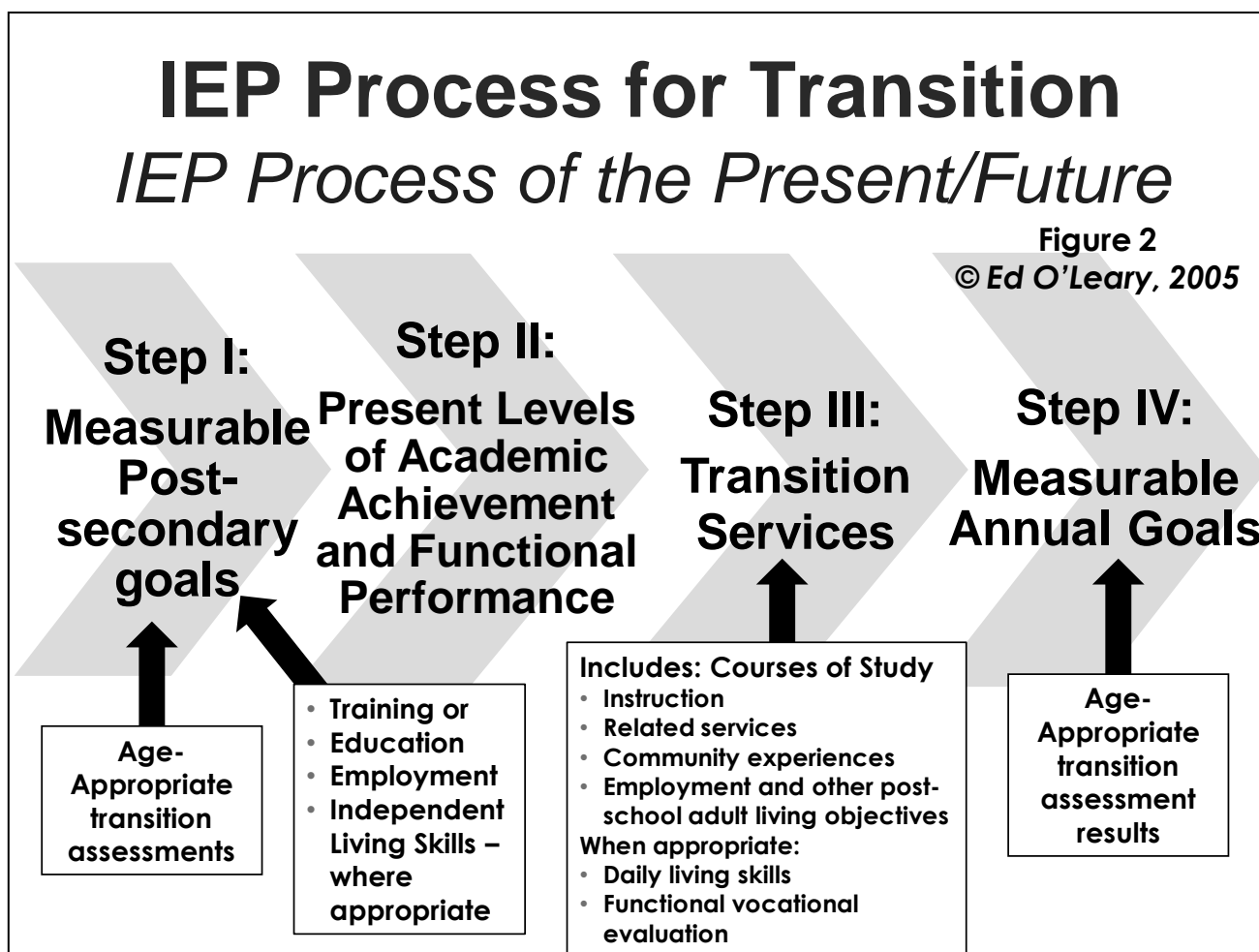
The law defines several of the key phrases found in transition planning. "Transition services" is defined as a coordinated set of activities for a student that is designed within an outcome-oriented process, which promotes movement from school to post-school activities." It also says that "the coordinated set of activities shall be based upon the individual student's needs, taking into account the student's

preferences and interests and shall include instruction, community experiences, employment development, related services, and other post-school adult living objectives, and when appropriate, acquisition of daily living skills and functional vocational evaluation. Post-school activities include: post-secondary education, vocational training, integrated employment (including supported employment), continuing adult education, adult services, and independent living.

SEVEN STEPS TO TRANSITION

The better prepared you and your son or daughter are before the IEP meeting, the more efficient and effective the process will be. Steps 1-7 below will prepare you for a successful IEP meeting and for successful transition outcomes. Have in mind a long-range vision for the student.

“The IEP team needs to take a longitudinal view of where the student would like to end up, and then build an IEP that will help them get there. This process, perspective, and futures planning will make the IEP a more useful, meaningful, and dynamic tool to help insure the student’s post-school success and transition into the adult world.” - Ed O’Leary



Begin with the End in Mind!!!

**Having a long-range vision for what the outcomes should be can help us to do better planning.
If we're not sure what the vision is, the following steps can help!**

1. Identify the environments and planning areas important to the young adult from this list: education/training, community involvement, health, life skills, social: relationships/friends, living arrangements, self-determination, recreation/leisure, employment – including “soft skills”, communication, and other.
2. Identify the skills needed for your son or daughter to succeed in each targeted planning area. Identify the student's current skills for each area. Compare the current skills with the skill demands of each area.
3. Prioritize needs, interests, and preferences to be considered in the IEP. Have the student list his or her preferences, interests, and needs. Have the parent/family list priorities based on family values, plans, concerns, and student needs. Teachers and other professionals should also list priorities based on school requirements, assessments, observations, and experiences with the student. Identify potential resources, programs, services, and support options. Consider sharing the lists with other team members prior to the meeting.
4. Prepare for the IEP meeting. You will need to identify any team meeting participants you would like to invite. They should then be invited. Parents must be invited to the IEP transition meeting at a mutually agreeable time and place. Parents and students must be informed of the purpose, time, and location of the meeting and be told who will attend. If the student does not attend the meeting, steps must be taken to consider the student's preferences and interests. If the student is going to conduct the IEP meeting, the student should prepare the agenda and practice. If parents do not attend the meeting, steps must be taken to ensure participation. Parents can help their students prepare to actively participate in meetings. (Refer to page 24 on team members. Also see page 28 for more information on helping students participate.)
5. Develop the transition plan during the IEP meeting. You will need to: keep the long-range vision of the student's life clearly in front; select priority outcomes; write a list of needed transition services; write a statement of measurable annual goals, including academic and functional goals; write short-term objectives to measure progress toward the goals for students who take alternate assessments, identify supports (who will help with what); identify linkages(how different agencies need to work together to provide “seamless service”); write down the date by which each objective needs to be completed (timeline) and by whom (responsibilities); and confirm with team members that they understand their responsibilities.
6. Implement (start working on) and monitor the IEP. You will need to: provide the services and implement the program; collect information on the student's progress toward measurable annual goals and short-term objectives; communicate with all IEP team members; identify other strategies for meeting annual goals (and short-term objectives) or modify them if they are not being met; and meet again as an IEP team if services are not being provided.
7. Watch and record outcomes. You and the transition team should continually watch and record outcomes. Did the student make progress? Reach his goal? The team should: review the IEP at least once per year and revise the plan if necessary. Remember to celebrate successes!

Throughout this entire process, remember that when you have concerns about services or placements being offered or provided to your son or daughter, it is best to express those concerns in terms of the young adult's needs and work together with the team to negotiate the best way to meet those needs. Always seek to resolve concerns at the lowest level possible. If negotiation breaks down, you have a right to several remedies including mediation or a due process hearing. For more information on remedies, please see the handbook "Parents as Partners in the IEP Process" or contact the Utah Parent Center.

WHO IS INVOLVED IN TRANSITION PLANNING? KEY PLAYERS...

You may be asking yourself: "Who is involved in transition planning?" Transition plans are most effective when they are developed by team members who are working together. IDEA requires that the following people be part of the IEP development:



- the student,
- parents – and if desired, the family,
- special education teacher (at least one),
- regular education teacher (at least one) who has knowledge of the student,
- related service providers (if appropriate, speech or occupational therapists, etc.),
- Local Education Agency (LEA) representative, and
- other adult service providers, such as:
 - Vocational Rehabilitation counselor, and
 - Support Coordinator (case managers for the Division of Services for People with Disabilities – DSPD)

As quoted in Utah's Special Education Rules: "For an IEP team meeting that includes as a purpose of the development of a transition plan:

- The LEA must invite the student with a disability to attend the student's IEP meeting if a purpose of the meeting will be the consideration of the post-secondary goals for the student and the transition services needed to assist the student in reaching those goals.
- If the student does not attend the IEP meeting, the LEA must take other steps to ensure that the student's preferences and interests are considered.
- To the extent appropriate, with the consent of the parents or a student who is age 18 or older, the LEA must invite a representative of any participating agency that is likely to be responsible for providing or paying for transition services."

The following information was also taken from the Utah Special Education Rules: "Beginning not later than one year before the student reaches the age of majority (age 18), the IEP must include a statement that the student and the student's parents have been informed of the student's rights under Part B of the IDEA that will transfer to the student on reaching the age of majority (except for a student with a disability who has been determined incompetent by a court). These rights include:

- An adult student has the right to approve his or her own educational placement and Individualized Education Program (IEP) without help from parents, family, or special advocates.
- An adult student has the right to allow parents, family, or special advocates to help if he/she desires.

"The LEA must provide any notice required by Part B of the IDEA and Utah's Special Education rules to both the student and the parents. All rights accorded to parents under Part B of the IDEA transfer to the student. These rights will also transfer to students who are incarcerated in an adult or juvenile, State or local correctional institution."

The student is an important team member whose input is essential in developing an effective transition plan. Your son's preferences, goals, and aspirations are the driving force of the plan. When he has a say in planning his future, he is more likely to be committed to making the plan work. If he is following his dreams, he will be motivated from within to see them become reality.

Because the school is expected to initiate her preparation for transition to work and adult life, the guidance and support of school personnel is essential. It is also necessary to identify who else will participate in the IEP meeting along with them, your daughter, and you. They may include regular education teachers, guidance counselors, vocational educators, social workers, psychologists, etc. If she is capable, your daughter should extend the invitations to participants, in cooperation with school personnel. As a courtesy, additional participants should be announced to all parties prior to the meeting.



Keep in mind how important it is to have a team whose primary desire is to equip your student for a future that is meaningful, satisfying, and as independent as possible. This task requires all members of the team to participate honestly and with total commitment to a positive outcome; there is no room for private agendas or negative feelings.

PEOPLE TO INVITE TO THE TRANSITION IEP MEETING

Fill in the blanks with the names of the appropriate individuals.

Family Members:

_____	_____
_____	_____

Teachers:

_____	_____
-------	-------

Other School Personnel:

_____	_____
-------	-------

Vocational Rehabilitation Counselor:

_____	_____
-------	-------

Community Agency Representatives (DSPD, Mental Health, Independent Living):

_____	_____
_____	_____

Current or Prospective Employer:

_____	_____
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It may also be appropriate to have a Vocational Rehabilitation Counselor attend. The services provided by Utah’s Division of Rehabilitation Services exist to assist eligible individuals with disabilities to prepare for and engage in gainful employment. Among their services are: assessment, career guidance, counseling and placement, acquisition of assistive technology and medical or other services if necessary, interpreter and reader services, occupational licenses, tools, etc., and, a variety of training programs. More information about Vocational Rehabilitation services can be obtained from the Utah Parent Center.

When appropriate, representatives of community programs like residential specialists, mental health workers, and support coordinators with the Division of Services for People with Disabilities are included. Any adult agency which has services that link school experiences with realistic employment and independent living opportunities should be encouraged to send a representative. Prospective or current employers may be invited as well.

When you have prioritized her needs from your perspective and invited those who need to attend the IEP meeting to address them, you are ready to map the course for her to move from the school system to adulthood.

HELPING STUDENTS PARTICIPATE IN THE IEP PROCESS

Students who have not participated in their IEP meetings often view the IEP process with fear or mistrust. They may perceive goals as being arbitrarily imposed. Students who participate in the IEP process are more committed to working on the IEP goals.

Steps in preparing a student to participate appropriately in the IEP process:

1. Explain what the process is and obtain a commitment from the student to participate.
2. Describe an IEP meeting and demonstrate how to participate by role playing with the student.
3. Help the student to do a self inventory. Teach the student to plan for the conference just like you do. The student could fill out a simple form that includes important information.

As part of the inventory, have the student list:

- Learning strengths – list as many as possible.
- Learning weaknesses, if there are a lot, help him prioritize and list the most important ones.
- Goals and interests
 - School
 - Non-school
 - Long range (after graduation)
- Learning instructional preferences
 - How do I learn best? (e.g. listening, reading, doing)
 - What kind of group is best for me? (e.g. large, small)
 - What kinds of tests are best for me? (e.g. written, untimed)
 - What kinds of study materials are best for me? (e.g. written, taped)
 - What kinds of aids help me? (e.g. tape recorder, computer, calculator, friend taking notes for me, buddy)
- For a secondary student, as a part of the inventory, you could use a chart (see following example) listing goals she is willing to work on in each class or deficit area.

Class Area	Skills Needed for this Class	Skills I Need to Improve
English	Writing Sentences	Using commas correctly
	Being prepared	Being prepared
Study Skills	Skimming	Outlining
Social Skills	Accepting criticism appropriately	Accepting criticism appropriately

4. Teach the student how to share information from the inventory appropriately. Teaching the SHARE process is one method of helping students who need this skill.

The SHARE Process

S = Sit up straight

H = Have a positive attitude

A = Active listening

R = Relax

E = Eye contact

5. Have the student *practice* sharing the material. (If this is done in a classroom situation, the students could do this as a group first and give each other feedback.)
6. Obtain a commitment from the teacher and others attending the IEP to help the student participate actively. Some suggestions for encouraging student participation are:
 - Establish the purpose and goals of the meeting
 - Ask the student relevant questions, such as asking them to talk about:
 - Strengths and weaknesses
 - Skills he wants to improve
 - Goals for school
 - Career or vocational interests
 - Ways he learns best
 - Types of tests that are best
 - Etc...
 - Listen and attentively take notes.
 - Give the student plenty of time to think and respond. This is crucial.
 - Use the information she provides.
 - Encourage questions and discussion.
 - Summarize the student's goals and plans.
 - Keep eye contact with the student. (Teachers usually tend to look at and talk to the parent, which is discouraging to the student.)
7. Follow up after the IEP. Help the student evaluate his participation.
 - List at least three things he did right.
 - List one or two areas for improvement.

These techniques can be used either in a classroom situation or with an individual student. Research shows that when a student participates in her IEP, she likes it and feels important. The student will bring up most of the real concerns and you can add the rest. The student is usually quite accurate. In addition, the teacher obtains insight into what the student thinks about her studies.

An added benefit of a student participating in the IEP is the building of self-esteem and commitment because the student feels like a partner in the process.

The "Helping Students Participate in the IEP Process" portion is based on notes from a lecture by Candace S. Bos and is used with her permission. For more complete information on this topic, refer to "The Education Planning Strategy" by Anthony K. Van Reusen, Candace S. Bos, Jean B. Schumaker, and Donald D. Deshler.

WHAT MUST BE ON A TRANSITION IEP?

In addition to the contents that are required for all IEPs, IDEA requires additional content for a transition IEP, including:

- Appropriate measurable post-secondary goals, including academic and functional goals, based upon age-appropriate transition assessments related to training or education, employment, and, where appropriate, independent living skills;
- The transition services, including courses of study, need to assist the student in reaching their post-secondary goals; and
- All of the other items that are required for an IEP (as outlined in the Utah Special Education Rules).

Transition services and planning began as one of many ideas for increasing the quality of life for young adults with disabilities. Today, transition from school to adult life is more than a nice idea; it is a requirement of the law. The Individuals with Disabilities Education Act (IDEA) requires that transition services be included in every student's transition-age IEP.

Transition, as outlined in the IDEA, requires a shift in thinking and planning from an 'expert-based' model to a model with the individual with a disability at its center. The foundation of the plan needs to be a coordinated effort among the student, parents, schools, and adult service providers to achieve a desirable future for the individual. The focus should always be the young adult's vision of the future.

The law defines several of the key phrases: "Transition services" means a coordinated set of activities for a student with a disability that is designed to be within an outcome-oriented process, that is focused on improving the academic and functional achievement of the student with a disability to facilitate the student's movement from school to post-school activities, including post-secondary education, vocational education, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation.

The coordinated set of activities shall be based on the individual student's needs, taking into account the student's strengths, preferences, and interests; and shall include:

- Instruction;
- Related services;
- Community experiences;
- The development of employment and other post-secondary adult living objectives; and
- If appropriate, acquisition of daily living skills and provision of a functional vocational evaluation.

Transition services are designed to be a results-oriented process that is focused on improving the academic and functional achievement of the student with a disability to facilitate the student's movement from school to post-school activities, including:

- post-secondary education,
- vocational education,
- integrated employment (including supported employment),
- continuing and adult education,

- adult services,
- independent living, or
- community participation.

For all students, when writing the IEP before the student turns 16 (or younger, when appropriate), the IEP team must:

- Actively involve the student in his or her IEP development.
- Base the IEP on the student's needs, preferences, and interests.
- Refine the student's desired post-secondary goals.
- Review the student's transition services such as the courses of study or multi-year description of coursework, adjusting them as needed to achieve the student's desired post-secondary goals.

To facilitate the development of the statement of the interagency responsibilities, "the public agency shall also invite a representative of any other agency that is likely to be responsible for providing or paying for transition services. If an agency invited to send a representative to a meeting does not do so, the public agency shall take other steps to obtain participation of the other agency in the planning of any transition services".

WRITING MEASURABLE POSTSECONDARY GOALS

Measurable postsecondary goals are outcomes that occur after the person has left high school. They tell what a student *WILL* do (be enrolled in, attending, working at, etc.).

Some tips for writing measurable postsecondary goals:

- Use results-oriented terms such as "enrolled in", "work", "live independently"
- Use measurable descriptions such as "full time" and "part time"
- Begin the goal with "After high school . . ."
- Goals can be broader to begin with and then refined and updated with each annual IEP as the student progresses.
- Sometimes goals in education and employment can be combined.
- Sometimes several goals are needed in one area.

Measurable postsecondary goals are required in three areas:

- Training or education—specific vocational or career field, independent living skills training, vocational training program, apprenticeship, on the job training, Job Corps, four year college or university, technical college, two year college, shorter vocational or technical program, etc.
- Employment—paid (competitive, supported, sheltered); unpaid (volunteer, in a training capacity); military, etc.
- Independent Living, where appropriate—adult living, daily living, independent living, financial, transportation, etc.

Sample Measurable Postsecondary Goals

14 year old student with a mild disability

- Training/Education—After high school, Eric will get on the job training in an area related to dirt bike racing.
- Employment—After high school, Eric will work full time with dirt bikes.
- Independent Living—After high school, Eric will live in an apartment with friends.
- Combined Training/Education and Employment—After high school, Eric will get on the job training while working full time in an area related to dirt bike racing.

17 year old student with a mild disability

- Training/Education—After high school, Sherry will enroll full time at Weber State University in the nursing program.
- Employment—After high school, Sherry will work full time as a nurse.

20 year old student with a significant disability

- Independent Living—After completion of school, I/ Lance will live with my mother and continue to take part in community activities like bowling, going to church and visiting friends and family.
- Training/Education—After completion of school, I/Lance will attend the XYZ Center and receive training on work behaviors and skills.
- Employment—After completion of school, I/Lance will be employed in a sheltered environment at the XYZ Center

18 year old student with a moderate or significant disability

- Independent Living—After completion of school, I/William will live with my brother and take part in community social and recreational activities.
- Training/Education—After completion of school, I /William will attend ADAPT and receive vocational skills training.
- Employment—After completion of school, I /William will work at ADAPT in the supported employment program.

18 year old student with a mild or moderate disability

- Training/Education—After high school, I/David will get on-the-job training to become a farmer.
- Employment—After high school, I/David will work full time as a farmer.

20 year old student with a moderate disability

- Independent Living—I/Courtney will live in a group home with other friends or roommates. I will need assistance with buying food, caring for myself, and doing work around the house.
- Education/Training—I will receive on-the-job training at Pick N Save.
- Employment—I will work part time in a grocery store like Pick N Save.
- Community Participation (not required)—I will be involved in my church and spend time with other people in Brookfield. I will go shopping in different stores. I like working outside by raking leaves and picking up sticks.
- Recreation and Leisure (not required)—I will join Special Olympics, go to baseball, football, and basketball games. I will play soccer, basketball, football, and baseball/softball with my friends. I like to watch movies and read store ads.

This information on writing measurable post-secondary goals is used with permission from Ed O'Leary. Summarized from information given at the Utah Transition Conference, April 3, 2008. © Utah Parent Center

MEETING TO DEVELOP THE TRANSITION PLAN

The best way to start the meeting is with introductions. It would be fitting for your son to make the introductions or ask the individuals to introduce themselves. When it is your turn, it would be helpful to remind everyone how important it is to succeed in developing a long-range plan so your son will have a meaningful life after leaving school.

The first step in developing a plan is to select and agree on priority outcomes. This will lead to a statement of long-range goals for at least the next three to five years. In the case of students at risk of dropping out of school, it may be beneficial to develop a transition plan before age 14, when warranted. Realistic goals will be selected after reviewing the present level of educational performance along with your son's strengths and interests.

Based on the desired outcomes, the team can identify any barriers that exist and select strategies to overcome them. This is also the time to identify opportunities available for him. Written annual goals will specify ways to overcome the barriers and maximize his use of existing opportunities. Needed services and available resources, along with specific activities and experiences to help him reach the goals will be noted.

In addition to long-range goals and annual goals, the written transition IEP will include short-term objectives for those students who will be participating in alternate assessments.

While preparing to leave the meeting, express anticipation of successful outcomes and appreciation to all the participants. They will be valuable allies in the weeks, months, and years ahead. By developing good working relationships with team members, your student's plan has a higher likelihood of succeeding.

His written plan must also specify how different agencies will work together to provide needed services. The final step is confirming with team members to assure that they understand their responsibilities and agree to them. The "Transition Timeline", found on page 29 can help you keep track of what is needed to smooth the transition process.

WHEN SHOULD A TRANSITION TIMELINE BE DEVELOPED?

A transition timeline for your student should be set up beginning not later than the first IEP to be in effect when the student is 16 (such as a meeting conducted when the student is 15 years old), or younger if determined appropriate by the IEP team, and should be updated annually. Notice of the transition IEP meeting must:

- Indicate that a purpose of the meeting will be the consideration of the post-secondary goals and transition services for the student; and
- Indicate that the LEA will invite the student; and
- Identify any other agency that will be invited, with the consent of the parents or student age 18 or older, to send a representative.

TRANSITION PLANNING TIMELINE

Student Age	Action Needed*	By Whom	By When
10 – 16	<ul style="list-style-type: none"> • Include social skills, communication, functional math and reading, self-help, and self-advocacy skills on IEPs. • Develop and use a plan to increase independence at home. • Participate in U-PASS assessment. 		
16	<ul style="list-style-type: none"> • Initiate transition planning as part of the IEP process by age 15 (last IEP before age 16). • Identify vocational interests and abilities. • Include activities such as: career exploration, job sampling, and an introduction to vocational training. • Begin to identify community services that provide job training placements. • Prepare a job placement file with references and a description of acquired skills. • Initiate application to adult service agencies with lengthy waiting lists (e.g. DSPD). • Participate in U-PASS assessment. 		
16 – 18	<ul style="list-style-type: none"> • Contact appropriate adult service programs. <ul style="list-style-type: none"> – Postsecondary education/training – Social Security Administration – Residential or independent living services – Vocational Rehabilitation – Recreation/leisure • Participate in UBSCT assessment.** 		
17 – 18+	<ul style="list-style-type: none"> • Begin to consider and research guardianship. • Take ACT or SAT tests and complete college applications for postsecondary training. • Participate in UBSCT assessment.** 		
18+	<ul style="list-style-type: none"> • Continue annual review and update of transitional IEP. • Establish needed health benefits. • Develop long-term financial support plan (e.g. SSI) 		
*IEP Transition Plan is to be reviewed and updated at least annually.			
**Beginning sophomore year.			
+Depending on the existing disability, some students will have until at least their 22 nd birthday to accomplish their transition goals. <i>(Ask your school district transition specialist for more information about Utah's state requirements.</i>			

AFTER THE MEETING

As soon as a plan has been prepared, it is time to implement it. Part of working the plan is collecting information on the progress being made. It is important to communicate with all IEP team members as you monitor your daughter's progress. Keep a written log of telephone calls and face-to-face conversations which include the date, the name of the program, and the person contacted as well as a summary of the discussion. Also keep copies of letters, notes, progress reports, homework assignments, IEPs, work performance reviews, and any other relevant records (e.g. testing results, medical reports, etc.).

It is very important to keep good records because it is impossible for you or any of the professionals working with your child to remember everything. There are so many details involved with planning your child's future that it is important to keep the information that you are collecting organized and easily accessible. There are many reasons you as a parent should keep track of important information about your child. Some professionals may know part of what is going on with your child, but you are the only one that knows everything! When you have a good record keeping system, all of the information is easily accessible and together. It is very helpful to have a system in place that includes information pertaining to your child's school services up to the current date.

NOTE: You may want to make duplicate files – one for you and for the student.

To help you remember the numerous details important for your student, refer to the timelines. It identifies things which need to be done and when to do them. It is meant to supplement the IEP and assure that progress is being made.

Keep in mind the IEP must be reviewed at least annually. If no review meeting is held, do not hesitate to contact the school. Cooperate with them in scheduling a meeting of the team as soon as possible to review your daughter's transition plan and IEP. You may always request to reconvene as needed.

If goals or objectives are not being met, determine whether or not modifications are needed. Request another meeting of the team if agreed upon services are not being provided or if strategies are not working. Any concerns about services or placements must be expressed in terms of your daughter's needs. In the case of disagreement, it is best to negotiate with the team. If negotiations break down, you have a right to mediation and a due process hearing.

FAILURE TO MEET TRANSITION GOALS

If a participating agency, other than the LEA, fails to provide the transition services described in the IEP, the LEA must reconvene the IEP team to identify alternative strategies to meet the transition goals for the student set out in the IEP.

Nothing relieves any participating agency, including a State vocational rehabilitation agency, of the responsibility to provide or pay for any transition service that the agency would otherwise provide to students with disabilities who meet the eligibility criteria of that LEA.

If any public agency other than an educational agency is otherwise obligated or assigned responsibility to provide or pay for any services that are also considered special education or related services, the public agency must fulfill that obligation or responsibility, either directly or through contract or other arrangement or as provided in an interagency agreement. Such services could include but are not limited to:

- services relating to assistive technology devices,
- assistive technology services,
- related services, supplementary aids and services, and
- transition services that are necessary for ensuring a FAPE to students with disabilities within the State.

If a public agency other than an educational agency fails to provide or pay for the special education and related services, the LEA must provide or pay for these services to the student in a timely manner. The LEA is authorized to claim reimbursement for the services from the non-educational public agency that failed to provide or pay for these services and that agency must reimburse the LEA in accordance with the terms of the interagency agreement.

Your Right to Due Process –

What To Do If the Process Breaks Down?



NOTE: At this point it is critical to use good communication skills. The old saying “You can catch more flies with honey...” rings true in these situations. Be prepared to negotiate! Also it is good to have support. Some people you might consider asking for support are: a friend or relative, or an advocate. You may also get advice from a disability organization or support group and/or legal representation.

INFORMAL RESOLUTION:

Make sure to follow the chain of command. First, try to work things out with the teacher. Then request that she go with you to the next level – usually the principal. A lot of problems get solved at this level. If not, follow the chain of command: the School District or Charter School, Special Education Director/Supervisor; Superintendent of School District or principal of the charter school; Utah State Office of Education, Special Education Department. Your Local School Board Member (elected official) or Utah State Board of Education School Board Member for your district (elected official) may also be resources.

OBTAINING SUPPORT FOR INFORMAL RESOLUTION

IEP COACHES:

IEP Coaches are uniquely and specially trained by the Utah Parent Center. They have current knowledge regarding the IEP process, Utah’s Special Education Rules, and effective advocacy techniques. The IEP Coaches are parent volunteers who support parents and help them advocate for their children in the special education process. IEP coaches help parents to prepare for meetings and may also accompany them to meetings in a supportive role. Contact the Utah Parent Center for more information about IEP coaches.

PROBLEM SOLVING FACILITATORS:

In Utah there is a program which provides trained impartial Problem Solving Facilitators who are available to give support in the IEP process. The purpose of these Facilitators is to help parties work through problems before they escalate and become more difficult, expensive and time consuming. Problem Solving Facilitation may be requested by a parent or the district at any time. Both parties must agree to the process. The Utah State Office of Education assigns a trained facilitator. The purpose of the facilitator is to act as a neutral person to keep the communication open and to help resolve concerns. This is an informal process that is available at no cost to the parent. More information is available from the Utah Parent Center or from the Utah State Office of Special Education (USOE).

FORMAL RESOLUTION

Several more formal options are also available to help resolve disputes.

STATE COMPLAINT:

A state complaint is an allegation that federal or state law is not being followed. If negotiation doesn't resolve a conflict, you can file a complaint in writing to the local school district special education director or charter school administrator. A copy must also be sent to the State Director of Special Education. If the parents are unable to file in writing, they can contact the local school district or charter school or the Utah State Office of Education (USOE) for assistance. Allegations of substance (substantial claims) may be made by public agencies, private individuals or organizations. For more detailed information on how to file a complaint, please see "Parents as Partners in the IEP Process", the Utah Parent Center's parent handbook on IEPs, or the Utah Special Education Rules. A complaint form is available on the Utah State Office of Education website.

MEDIATION:

Each local school district (LEA) has procedures that are established to allow the opportunity to use mediation to resolve disputes involving a written request for a due process hearing or any matter under this part of the law. Mediation is voluntary. Mediation may not deny or delay the parents' right to a due process hearing or deny any other rights. Mediation is available at any time and can be requested by either a parent or the school district. Both parties must agree to participate in the mediation process. Upon request, the Utah State Office of Education (USOE) assigns a trained mediator from their list. The settlement agreement is binding on both parties. A form to request mediation is available on the USOE website. For more detailed information on mediation, please see "Parents as Partners in the IEP Process", the Utah Parent Center's parent handbook on IEPs, or the Utah Special Education Rules.

DUE PROCESS HEARING:

A due process hearing is a more formal process where parties are generally represented by attorneys. An impartial hearing officer hears both sides of a dispute and issues a written decision which is binding. Parents may request a due process hearing at any time if they are unable to resolve differences. Because the requirements for filing are very specific and detailed, parents should be well informed about the specifics of the process before filing. If you decide to proceed with a due process hearing, it is recommended you have legal help. Because due process is a very formal (and costly for the LEA and often for the parent) legal proceeding, an attorney is usually used. Try all forms of early dispute resolution before considering a due process hearing but do not be afraid to advocate for your own and your child's rights. For more detailed information, please see the Utah Special Education Rules.

More information as well as various forms are available at the USOE website www.schools.utah.gov

HANDLING PROBLEMS UNDER SECTION 504:

Section 504 falls under the management responsibility of the general education program. Parents should work to resolve differences at the teacher or school level by scheduling a meeting to discuss differences with the school's Section 504 Coordinator. The next step is to set up a meeting with the school district's Section 504 Coordinator. If parents are unsuccessful, they may ask for mediation,

which is a free service for parents. A neutral person will work with the parent and the school to resolve differences. If no solution is found, parents may ask the Section 504 Coordinator how to file a grievance. The final step is contacting the Office for Civil Rights, Region VIII, in Denver, Colorado.

THINGS TO REMEMBER AS YOU PURSUE YOUR RIGHTS:

- Proceed carefully!
- Seek to resolve difficulties at the lowest level.
- Remember to use good communication skills and a positive approach. You may wish to attend a workshop on interest-based negotiation such as the one provided by the Utah Parent Center.
- Be prepared to negotiate.
- Have the support of a relative, friend, advocate, or obtain advice from a support group or legal representative.
- Keep the educational/transitional needs of your student as the focus at all times!

STUDENTS WITH DISABILITIES IN ADULT PRISONS

The requirements relating to transition planning and transition services, do not apply with respect to those students whose eligibility under Part B of the IDEA will end, because of their age, before they will be eligible to be released from prison based on consideration of their sentence and eligibility for early release.

The obligation to make FAPE available to all students with disabilities does not apply with respect to students ages 18 through 21 to the extent that State law does not require that special education and related services under Part B of the IDEA be provided to students with disabilities who, in the last educational placement prior to their incarceration in an adult correctional facility:

- Were not actually identified as being a student with a disability; and
- Did not have an IEP under Part B of the IDEA.

The exception does apply to students with disabilities, ages 18 through 21, who:

- Had been identified as a student with a disability and had received services in accordance with an IEP, but who left school prior to their incarceration; or
- Did not have an IEP in their last educational setting, but who had actually been identified as a student with a disability.

Graduation

WHAT ABOUT GRADUATION?

Graduation issues should be addressed in each student's IEP. The IEP is the place to document modifications to graduation requirements so that they meet the unique educational needs of students with disabilities. The IEP must completely document the modifications made to accommodate a student with disabilities so that they are clearly understood by all IEP team members.



Students with disabilities and their parents must be able to make informed decisions regarding graduation options. It works best if parents are to be notified enough ahead of time to allow them to follow the appeal process if they consider it necessary.

Please note that the issuance of a regular high school diploma terminates a student's eligibility for public education services. Some agencies will not serve eligible adults with significant disabilities in day programs until they turn 22, even if they have graduated. A parent may not require the school district to withhold issuance of a diploma until age 22 if the student with disabilities has met the graduation requirements as determined by the IEP team. It is necessary to make an informed decision in selecting a graduation option and to make certain it is recorded on the IEP. This should reduce misunderstanding and clarify the time-frame available to attain transition goals, including whether to graduate with peers or continue with additional schooling.

Parents must be notified of their student's graduation as a change in placement with enough time to appeal the action. If state and federal regulations have been followed, graduation should not come as a surprise to parents, since transition needs would have been addressed by the time the student turned 16. Services would begin by age 16, or younger, depending on which was most appropriate. Schools should have been holding IEP meetings which addressed graduation requirements in the transition plan.

UTAH'S GRADUATION OPTIONS

A high school diploma will be awarded to a student who has successfully completed all Utah State Office of Education and school district graduation requirements.

Certificate of Completion: According to school district or school criteria, a certificate of completion may be awarded to students who:

- Have completed their senior year
- Are exiting the school system
- Have not met all state or district requirements for a diploma

Eligibility Ends: Graduation with a regular high school diploma or a Utah Adult Secondary Diploma from the Adult High School Completion Program ends eligibility for FAPE, and graduation is a change of placement requiring prior written notice.

Graduation is NOT: an alternative degree that is not fully aligned with the state's academic standards, such as: a certificate of completion, an alternative diploma, or a GED. (These options will not end eligibility.)

IEP Amendment to Graduation Requirements: A student's IEP team may amend graduation requirements and must document in the IEP the nature and extent of any modifications, substitutions, and/or exemptions made to accommodate the needs of a student with disabilities. The IEP team must refer to the USOE Special Education Guidelines for additional information.

For more information visit: <http://www.schools.utah.gov/sars/DOCS/resources/graduation8-30-12.aspx>

TIP: It works best to start working on amendments to graduation requirements before the student enters 9th grade (when credits start to count for graduation).

Summary of Performance: For a student whose eligibility terminates due to graduation from secondary school with a regular diploma, or due to exceeding the age of eligibility for FAPE under Utah law, an LEA must provide the student with a summary of the student's academic achievement and functional performance, which shall include recommendations on how to assist the student in meeting the student's postsecondary goals.

- If graduation requirements as amended on the IEP are completed, the student will graduate and receive a Utah Alternative Assessment (UAA) diploma.
- If graduation requirements as amended on the IEP are not completed and the student's Transition Plan documents the need for transition services offered by the L.E.A. outside of the local high school, the student may be allowed to participate in the graduation ceremonies; however, a diploma would not be issued until the student has successfully completed his/her program.
- If the graduation requirements as amended on the IEP are not completed and the IEP team determines that the student can benefit from continued educational programming in the local school, the student may be allowed to participate in graduation ceremonies and receive a diploma at such time as amended graduation requirements are met.
- If graduation requirements as amended on the IEP are not completed before the student reaches age 22, the student may be issued a certificate (e.g. Certificate of Completion or Progress) indicating that a record of competencies can be made available to them or to others who may legitimately inquire.

If graduation requirements as amended in the IEP are not completed due to factors that are not a direct manifestation of the student's disability, the student is not eligible to participate in graduation ceremonies or receive a diploma until the amended requirements are met. The local principal is authorized to make this decision.

TRANSITION PLANNING AREAS

Once you have a vision for the future, the next step is to identify important planning areas. In order to make a successful transition from school to life in the community as an adult, consider these general planning areas:

- Employment
- Post-secondary training and education
- Independent Living
- Community Participation

These areas are addressed in more detail on following pages. As you review the sections, compare your son's current skills with those necessary to succeed in realizing his dreams. Use these sections as tools to maximize his involvement in the planning process. Help him identify skills that he needs to develop so they can be included in his IEP.

If he is unable to complete the next four sections on his own, you can interview him to get his input. In some cases you may need to answer the questions and complete the checklist for him. Be sensitive to his attentiveness, working more frequently for shorter periods if needed. Encourage him to participate as fully as he is able and make it an enjoyable experience.

By utilizing appropriate curriculum, vocational assessment, instruction, training, and encouraging interagency collaboration, the school can provide the framework for transition. Cooperation and commitment are necessary, along with adequate monitoring and follow-up procedures, for transition to be successful.

Employment



Identifying possible careers which suit your interests and abilities is very important to building your future. To help you do this, find out what School-to-Careers activities exist at your school and participate; no one can be excluded because of disabilities.

Answer the following questions and complete the checklists to help identify activities and training issues which will equip you for successful employment.

What kind of work would you like to do? _____

What kind of environment will you enjoy working in? _____

What kind of training will you need for that work? _____

Will you need on-the-job support? _____

If yes, what kind and for how long? _____

EMPLOYMENT TRAITS ASSESSMENT

Rate yourself, and then have someone who knows you really well (like a parent) *complete this checklist of qualities that employers look for in employees:*

	Needs Training	Needs Support	Does Now
PUNCTUALITY			
Is ready for school on time	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Shows up at expected time	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
DEPENDABILITY			
Calls if late or absent	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Rarely or never absent	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
RESPECTS SELF AND OTHERS			
Tells the truth	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Respects others' belongings	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Accepts constructive criticism	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
TAKES PRIDE IN WORK			
Does careful and accurate work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Attempts to correct mistakes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Takes initiative to do new duties	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
APPEARANCE			
Good personal hygiene	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Wears appropriate clothing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
COMMUNICATION			
Able to follow directions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Asks appropriate questions at the times	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
INTERPERSONAL SKILLS			
Works well with others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Has appropriate social behaviors	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Able to handle peer pressure	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
USE OF TRANSPORTATION			
Able to get to work area from drop-off point	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Able to get to pick-up point from work area	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Needs Training	Needs Support	Does Now
--	----------------	---------------	----------

FLEXIBILITY

Adjusts to changes in assignments	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Able to learn new, related tasks	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

JOB PRODUCTIVITY

Handles equipment and supplies carefully	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Knows and follows the rules of the job	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Stays on task	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Works at adequate speed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Has adequate endurance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

- Have a vocational assessment to find out what you can do best.
- Check with career guidance counselors to learn about the many career possibilities and School-to-Career activities.
- Get some work experience in school or the community such as volunteer work, a summer job, work study, or job shadowing.
- Learn about supported employment services that help you learn to do a job successfully, like a job coach or working in a group.
- Find out what career related courses are available in school to help you reach your goals (such as computer literacy, college preparatory or vocational/technical).
- Find out about adult services like Vocational Rehabilitation, Division of Services for People with Disabilities, Social Security Administration, etc. which have eligibility requirements.
- Learn what habilitative day training programs are available if you are unable to learn job skills.
- Other: _____

As you consider various work/day programs, here are some questions to help you determine their suitability:

- What services are provided and when?
- What skills areas are included in the training?
- What are the entry requirements and costs of the program?
- What is the earning potential for participants in this program?
- What opportunities for access to the community are provided?
- How long do people stay and where do they go when they leave?
- How long is the wait to get into the program?

SET EMPLOYMENT BASED GOALS

First, write three goals based on the information gained in this section on employment. Next, write three specific activities for each goal that will help to reach that particular goal.

Example:

Goal: Get a part-time job.

Activities: Write or update résumé.
Practice interview skills.
Contact and apply to three businesses.



Goal 1: _____

Activity 1a. _____

Activity 1b. _____

Activity 1c. _____

Goal 2: _____

Activity 2a. _____

Activity 2b. _____

Activity 2c. _____

Goal 3: _____

Activity 3a. _____

Activity 3b. _____

Activity 3c. _____

POSTSECONDARY TRAINING AND EDUCATION

Another important step to building your future is determining what additional training and education you will need, along with finding the best place to get it. This section will help you identify goals that will target areas of training and steps to realize those goals.



What type of further training or education are you interested in? _____

Where could you get it? _____

What supports will you need to complete your schooling or training? _____

Which of the following may help prepare you to achieve your employment goals? Circle the choices that apply.

- Community College (2 years)
- College or University (4 or more years)
- On-the-Job Training
- Applied Technology Education
- Military
- Apprenticeship Program
- Trade or Business School
- Other:

In which of the following areas do you need additional help? Circle the choices that apply.

- Study Skills
- Time Management
- Organizational Skills
- Understanding Entrance Requirements
- Preparing for SAT or ACT
- Locating Campus Disability Resource Center and/or Resources
- Submitting Necessary Applications
- Identifying Necessary Accommodations

SET POSTSECONDARY EDUCATION OR TRAINING BASED GOALS

First, write three goals based on your interests and the information gained in this section on postsecondary education and training. Next, write three specific activities for each goal that will help to reach that particular goal.

Example:

Goal: Get certified as a nursing assistant.

Activities: Get information from school career center.
Visit two or three schools which offer appropriate courses.
Discuss needed accommodations with school representatives.



Goal 1: _____

Activity 1a. _____

Activity 1b. _____

Activity 1c. _____

Goal 2: _____

Activity 2a. _____

Activity 2b. _____

Activity 2c. _____

Goal 3: _____

Activity 3a. _____

Activity 3b. _____

Activity 3c. _____

INDEPENDENT LIVING

Thinking about where you want to live as an adult and what skills you will need is another important area to consider in planning your future.



Where would you like to live? (With your family or on your own? With a friend or several friends?)

What skills will you need to learn for this to happen? (Cooking, cleaning, shopping, using transportation...)

How will you take care of your health needs?

How will you manage your finances?

What choices and decisions do you already make at school? At home?

INDEPENDENT LIVING SKILLS ASSESSMENT

No matter where you live as an adult, there are important skills needed for independence. On the following checklist, indicate which areas you need to consider. *Check all that apply to you:*

LIFE SKILLS

These are some of the skills you will need to learn so that you can live on your own:

- ☐ Cooking
- ☐ Cleaning
- ☐ Shopping
- ☐ Laundry
- ☐ Personal hygiene

HOUSING OPTIONS

These are possibilities from which you can choose:

- ☐ Remain in family home
- ☐ Group home
- ☐ Host home
- ☐ Supervised apartment
- ☐ Supported living arrangements
- ☐ Dormitory
- ☐ Apartment
- ☐ Skilled care facility

TRANSPORTATION

Finding and using suitable transportation will help you be more independent.

- ☐ Independent (bicycle, car, etc.)
- ☐ Public (bus, taxi, etc.)
- ☐ Specialized: _____

MEDICAL AND SUPPORT SERVICES

These services may be needed to live successfully on your own:

- ☐ Access to medical and dental services
- ☐ Insurance
- ☐ Managing personal medications
- ☐ Personal care services
- ☐ Assistive Technology: _____
- ☐ Counseling
- ☐ Knowing when and how to seek medical care

FINANCIAL MANAGEMENT

Taking care of your bills is an essential part of being an adult.

- ☐ Managing a bank account
- ☐ Supplemental Security Income (SSI)
- ☐ Social Security work incentive programs
- ☐ Public assistance services
- ☐ Guardianship, wills, and trusts
- ☐ Prepare a budget

Consider the following questions to assess your needs and identify activities that can be included in the transition plan that will help you achieve long-range goals for independent living:

What information do you need about possible places where you can live? _____

What skills do you need to learn at home to prepare you to live independently? _____

Where else could you learn these skills? _____

What tasks need to be done by a support person or a personal care attendant to assist you in independent living? _____

What are your transportation needs? _____

SET INDEPENDENT LIVING SKILLS BASED GOALS

If you need help to acquire independent living skills, make sure the IEP includes information about where they will be taught, by whom, and the timeframe for doing so. *Write some goals and activities that would be helpful for you based on the needs you have discovered in this section.*

Example:

Goal: Have my own checking account.
Activities: Take personal finance class in school.
Go to bank for more information.
Open an account with at least \$100.



Goal 1: _____

Activity 1a. _____

Activity 1b. _____

Activity 1c. _____

Goal 2: _____

Activity 2a. _____

Activity 2b. _____

Activity 2c. _____

Goal 3: _____

Activity 3a. _____

Activity 3b. _____

Activity 3c. _____

COMMUNITY PARTICIPATION

In addition to having a career and a place to live, you can discover ways to have fun and been involved in your community. Consider the following:

What are your hobbies and interests outside of school? _____

How much time do you expect to spend on them as an adult? _____

How much money can you spend each month for entertainment and /or recreation? _____

How will you travel to participate in leisure activities in the community? _____

What services do you need to get involved in the community? _____

Where will you meet new friends? _____

What sports, games, or hobbies would you like to learn? _____

Which of the following areas interest you? ***Check all that apply to you:***

- | | | |
|--|--|---|
| <input type="checkbox"/> Advocacy activities | <input type="checkbox"/> Gardening | <input type="checkbox"/> Reading |
| <input type="checkbox"/> Baseball | <input type="checkbox"/> Golf | <input type="checkbox"/> Science |
| <input type="checkbox"/> Basketball | <input type="checkbox"/> Hairstyling | <input type="checkbox"/> Scouting |
| <input type="checkbox"/> Bike riding | <input type="checkbox"/> History | <input type="checkbox"/> Scrabble |
| <input type="checkbox"/> Bowling | <input type="checkbox"/> Home repair | <input type="checkbox"/> Service groups |
| <input type="checkbox"/> Camping | <input type="checkbox"/> Horse riding | <input type="checkbox"/> Sewing |
| <input type="checkbox"/> Card playing | <input type="checkbox"/> Jewelry making | <input type="checkbox"/> Shuffleboard |
| <input type="checkbox"/> Carpentry | <input type="checkbox"/> Knitting | <input type="checkbox"/> Shopping |
| <input type="checkbox"/> Car repair | <input type="checkbox"/> Languages | <input type="checkbox"/> Singing |
| <input type="checkbox"/> Ceramics | <input type="checkbox"/> Lawn games | <input type="checkbox"/> Social clubs |
| <input type="checkbox"/> Chess | <input type="checkbox"/> Leather work | <input type="checkbox"/> Special Olympics |
| <input type="checkbox"/> Church activities | <input type="checkbox"/> Lectures | <input type="checkbox"/> Swimming |
| <input type="checkbox"/> Classical music | <input type="checkbox"/> Model building | <input type="checkbox"/> Table games |
| <input type="checkbox"/> Clothes | <input type="checkbox"/> Musical instruments | <input type="checkbox"/> Television |
| <input type="checkbox"/> Collecting | <input type="checkbox"/> Movies | <input type="checkbox"/> Tennis |
| <input type="checkbox"/> Concerts | <input type="checkbox"/> Needlework | <input type="checkbox"/> Traveling |
| <input type="checkbox"/> Conversation | <input type="checkbox"/> Painting | <input type="checkbox"/> Upholstery |
| <input type="checkbox"/> Cooking | <input type="checkbox"/> Photography | <input type="checkbox"/> Volleyball |
| <input type="checkbox"/> Crocheting | <input type="checkbox"/> Picnics | <input type="checkbox"/> Volunteering |
| <input type="checkbox"/> Dancing | <input type="checkbox"/> Ping Pong | <input type="checkbox"/> Woodworking |
| <input type="checkbox"/> Dating | <input type="checkbox"/> Plays | <input type="checkbox"/> Writing |
| <input type="checkbox"/> Decorating | <input type="checkbox"/> Politics | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> Dramatics | <input type="checkbox"/> Pool | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> Exercise | <input type="checkbox"/> Puzzles | |
| <input type="checkbox"/> Football | <input type="checkbox"/> Radio | |

SET COMMUNITY PARTICIPATION BASED GOALS

Write some goals and activities that will help you become an active participant in the community.

Example:

Goal: Learn to ice skate.

Activities: Call to find a class and the class schedule.
Find transportation to and from classes.
Save money to pay for lessons.



Goal 1: _____

Activity 1a. _____

Activity 1b. _____

Activity 1c. _____

Goal 2: _____

Activity 2a. _____

Activity 2b. _____

Activity 2c. _____

Goal 3: _____

Activity 3a. _____

Activity 3b. _____

Activity 3c. _____

SETTING PRIORITIES FOR TRANSITION PLANNING

Now that you have considered the four planning areas, the next step is to prioritize the needs identified according to your family's values, plans, and concerns. Consider including other family members, especially siblings, who can provide support and encouragement to your daughter when you are no longer available.

As you work together on your checklist, indicate the most important goals that you want to see accomplished first and so on. Your prioritized list, along with your daughter's priorities and those of teachers and others who work with her, will be very helpful as the team develops the transition IEP. It will also be helpful to identify programs, services, and resources which can address her specific needs.

This series of checklists can help prioritize goals for your daughter's future. Based on what you know about her, complete this assessment. For the first five areas, circle those that match the dreams which have been identified.

CAREER/EMPLOYMENT

- ☐ Full– or part-time regular job (competitive employment)
- ☐ Full– or part-time job with additional supervision and support
- ☐ Supported employment
- ☐ Military service
- ☐ Volunteer work
- ☐ Other: _____

EDUCATION

- ☐ College or University
- ☐ Community College
- ☐ Vocational Training
- ☐ On-the-job Training
- ☐ Personal development classes
- ☐ Other: _____

RESIDENTIAL/LIVING

- ☐ Independently in a house, condo, or apartment
- ☐ With a roommate
- ☐ Supervised living situation (group home, apartment)
- ☐ With family (please identify): _____
- ☐ Other: _____

RECREATION/LEISURE

- ☐ Independent recreational activities
- ☐ Organized activities (clubs, team sports)
- ☐ Activities with friends
- ☐ Classes (to develop hobbies, explore interests)
- ☐ Supported/supervised recreational activities
- ☐ Other: _____

TRANSPORTATION

- ☐ Have a driver's license and access to a car
- ☐ Walk or ride a bike
- ☐ Use public transportation (bus, taxi, train) independently
- ☐ Supported transportation (family, service groups, car pool, special services)

For the following areas, identify up to five areas of greatest concern:

SOCIAL/INTERPERSONAL

- ☐ Making friends
- ☐ Setting goals
- ☐ Relationships with the opposite sex
- ☐ Family relationships
- ☐ Handling anger
- ☐ Communicating needs/wants
- ☐ Handling legal responsibilities
- ☐ Other: _____

PERSONAL CONCERNS

- ☐ Hygiene
- ☐ Safety
- ☐ Mobility
- ☐ Personal care
- ☐ Money management/budgeting
- ☐ Time management
- ☐ Domestic skills
- ☐ Other: _____

HEALTH

- ☐ Sex education
- ☐ Information on substance abuse
- ☐ Ongoing care for serious medical condition
- ☐ AIDS awareness
- ☐ Other: _____

Adult Services

The transition from school to work is recognized as a difficult one for the student. Equally important is the stress and apprehension it causes parents. The focus of transition to employment and adult services and activities should be on the strengths of the individual. We need to be asking, "What does the person do best and enjoy?" not "What are the weaknesses that will make this person's transition difficult?" This positive approach will open our minds to more possibilities.



The basic problem that we are faced with in transition planning is that students in transition from school are leaving a somewhat organized provider system and entering a more complex and confusing world, not fully understood by most school professionals, much less by parents or consumers. The biggest challenge that we have is that it is impossible to prepare for transition to work and adult living if we do not know anything about agencies and services to which our students will be transitioning. Let's find out how we can solve this problem and meet this challenge.

Families that remember these two points when setting up their expectations will probably be more successful:

1. No one is entitled to services. Each agency or program has its own eligibility requirements and acceptance may be based on the individual's capacities and the potential for successful outcomes in that program.
2. Services are not coordinated or housed under one roof. Families may be required to access several programs and agencies to achieve goals and be creative, innovative, and open-minded in achieving goals.

The following list suggests some ways families and young adults can prepare to effectively access adult and community services:

- Encourage your son or daughter to take the lead. Be sure that services offered are based on their needs and desires...not yours.
- Clarify your expectations. You and your child both need to be clear on your expectations of service and share those expectations with the professionals with whom you work.
- Participate as an equal on the team! Rather than giving the professional too much power, you and your young adult with a disability should be an equal part of the team.
- Understand the services offered. Be sure you understand the services offered by each agency.
- Network with professionals and other parents. Begin networking with support coordinators and other professionals in the adult services. Renew your efforts at least every 6 months. Also, connect with parents who are ahead of you in the process.
- Ask for a statement of rights and appeal procedures. Ask all service providers for a statement of rights and appeal procedures.
- Become active on advisory boards. Becoming active on advisory boards and agency board of directors are good ways to make sure that your concerns are voiced and heard.
- Attend and participate in public comment meetings. Get information about public comment meetings. Attend those meetings and participate. Speak up!!

- Develop strategies and supports by yourself or with others who need the same services. When services don't exist, develop a system of strategies and supports by yourself or with other parents or advocates needing the same services.

"Are we lost?" Milo asked.

"...I know one thing for certain; it's much harder to tell whether you are lost than if you were lost, for, on many occasions where you're going is exactly where you are. On the other hand you often find that where you've been is not at all where you should have gone, and since it is much more difficult to find your way back from somewhere you've never left, I suggest you go there immediately and then decide."

- The Phantom Tollbooth, Norton Juster, 1989

Sometimes this is how it feels for families when we try to make sense of adult services. Yes, we are lost!! To help us 'find our way', let's identify a number of adult agencies and organizations that offer services and programs to young adults with disabilities. Here are some brief descriptions of some of the adult service providers that exist. There may be others. Please do some research on your own in your own community.

Vocational Rehabilitation (VR)

The mission of Vocational Rehabilitation (VR) is to assist individuals with disabilities to prepare for and obtain employment. VR services help people with disabilities prepare for work and find a job so they can live more independently.

Independent Living Centers (IL Centers):

The general mission of Utah's Independent Living Centers is to assist persons with disabilities achieve greater independence. They are located in six communities. Each serves a region of the state. Generally, services and programs are similar, but may vary. The six centers are located in the following communities: Logan, Ogden, Salt Lake City, Provo, Price, and St. George. Satellite offices are located in other communities. Contact the Center closest to you for information about their programs and services.

The Division of Services for People with Disabilities (DSPD):

The mission of the DSPD is to promote opportunities and provide supports for persons with disabilities so that they will have every opportunity to participate fully in Utah life. DSPD serves people with severe or chronic disabilities caused by intellectual or physical impairments, or a combination of impairments, which are likely to continue, resulting in substantial limitations in three or more major life activities.

The Division of Mental Health and local mental health services:

The Division of Mental Health is part of the Utah State Department of Human Services. Their mission is to make mental health services available to the citizens of Utah. There are local offices of the Division of Mental Health throughout the state of Utah. Services may vary in the various community mental health centers.

Social Security and Other Sources of Financial Support:

Supplemental Security Income (SSI) is one of the disability programs directed by the Social Security Administration. To get SSI, you must be 65 or older, or blind, or disabled. Children as well as adults can receive benefits, but the Social Security Administration considers the family's income and assets. When a person turns 18 years old, the family's income is no longer considered.

Services for Students with Disabilities Offices in Higher Education Institutions:

Individuals with disabilities will want to find out about disability-related support services and classroom accommodations available at colleges and universities they are interested in attending. According to Section 504 of the Rehabilitation Act, an institution of higher education receiving federal funds may not exclude an individual from participation in or deny them the benefits of any program or activity offered solely because that individual has a disability. Nearly all post-secondary institutions receive federal financial assistance. Most colleges and universities have Disability Resource Centers to assist students with disabilities.

Vocational and Technical Schools:

Vocational and technical schools are designed to prepare students for gainful employment in recognized occupations such as technician, bank teller, dental assistant, data processor, electrician, etc. Vocational training is provided so that an individual can obtain skills in a specific area of interest or increase the level of skills they have already achieved. A course of study may take anywhere from 2 weeks to 2 years to complete, with the general entrance requirement of a high school diploma, or satisfactory equivalent. These schools place great importance on placement of their graduates.

Adult Education:

Adult education programs are designed to provide instruction below the college level to any person 16 years of age or older who is no longer being served by the public education system. There are many different programs available in a variety of settings. In many states, local applied technology centers operate as part of the public school system. Secondary students may receive instruction there during the day while instruction for adults in the community is available at night.

Disability Specific Organizations:

Organizations such as the Brain Injury Association of Utah (BIAU), Learning Disabilities Association of Utah (LDAU), CHADD of Utah, National Alliance on Mental Illness of Utah (NAMI Utah) and others serving people with a specific disability often provide information and some also provide vocational assessment and training. The types of training provided may vary, but the goals of the training are usually the same: the individuals with disabilities will obtain employment and become as independent as possible. Some of them also provide support services. The Family to Family network provides support for all disabilities.

Private Providers:

Private providers operate in many different ways. Some of them receive public funding. Many different services are provided to the community through private providers. Some may receive public funding. One example in Utah is Scenic View in Provo which works with young adults to learn skills for employment.

THE TIME TO PLAN FOR THE FUTURE IS NOW!!

The time to plan for the future is now!! Depending on the age of your young person, it may be time to look into the things on this list. Even if your child is very young, you'll want to look ahead so you'll be better prepared.

Think about:

- contacting your local Utah State Office of Rehabilitation (USOR) office to establish eligibility for VR services
- setting up a college fund,
- setting up a trust fund,
- applying for Social Security Income (SSI) when your young adult turns 18,
- investigating an Impairment-Related Work Experience (IRWE) or a Plan for Achieving Self Support (PASS Plan),
- whether or not guardianship is appropriate or necessary,
- encouraging your son or daughter to participate in self-advocacy training,
- looking into HUD housing and food stamps, and
- getting your son or daughter on waiting lists for group homes, family support, and/or supported employment.

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.

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.

Other Transition Concerns for Parents



AGE OF MAJORITY

All special education rights transfer to the student at age 18 unless guardianship has been previously awarded.

At age 18 the student reaches the age of majority and is considered an adult. Parents are no longer required to be informed or to give their consent for programs or services. The law requires schools to notify students about the rights that transfer to them when they reach the age of majority by at least one year before their eighteenth birthday. As an adult, your student could decide to exclude you from participating in meetings and making decisions about adult services.

If your student is still receiving special education services until his twenty-second birthday, you will continue to be informed, and your due process rights remain in effect. This potential change in roles underscores why it is so important for him to be an active participant in developing the IEP and transition plan. It clarifies the importance of building and maintaining open lines of communication with him. (See page 79 for information on guardianship.)

“Nothing will ever be attempted if all possible objections must first be overcome.”

- Samuel Johnson

LIVING ARRANGEMENTS

“Where I am going to live?” is a question you may have asked yourself when you completed your high school education. It’s not surprising that young adults with disabilities ask the same question. A variety of living arrangements are available to adults with disabilities. The level of care and type of living arrangement should be based on the needs of the individual. Arrangements can extend from 24-hour care to living independently in the community.

Types of living arrangements can include the following:

- living with the family,
- living independently,
- living in supervised living arrangements,
- living in their own apartment,
- living in a residential care facility,
- living in a family life, and
- living in an intermediate care facility.

The type of living options available in your community depends greatly on where you live. If your young adult needs a state-supported living arrangement following high school, contact the Division of Services for People with Disabilities (DSPD). This contact should be made early because there can be a three to six year waiting list for many community residential service programs.

LIVING WITH THE FAMILY

Many young adults live with their parents while attending school, looking for a job, or working. Living at home may be an appropriate short-term option for young adults with disabilities. Some families, however, may not want to have the young adult live at home forever. Families also may not always be able to care for the young adult; thus, future living arrangements need to be discussed and planned. Young adults who live with their family should be encouraged to develop or improve independent living skills such as housekeeping, shopping, washing clothes, and budgeting.

LIVING INDEPENDENTLY

When young adults live independently, they live by themselves or with roommates in a house or apartment. In this living arrangement, little or no help is necessary. If help is needed, it is given by family members or adult service providers through visits or telephone contacts.

SUPERVISED LIVING ARRANGEMENTS

The purpose of supervised living arrangements, such as supervised apartments, is to offer a structured living situation for individuals who, because of their disability, need some support or supervision. Young adults in supervised living arrangements receive continued assistance and training in independent living skills such as meal planning, use of community resources, and money management. Supervision of the young adult is usually provided by personnel from a local adult service provider or agency. This person is trained in working with young adults who have disabilities.

RESIDENTIAL CARE FACILITY

Residential care facilities include group homes that offer help to young adults who cannot live independently, but are capable of spending time in the community with a minimum amount of supervision. Community resources are used for recreation, medical, or social services. The staff works with the young adults to develop independent living skills. Group home staff are employed by a local agency or adult service provider and are trained in working with adults who have disabilities.

PROFESSIONAL PARENT OR HOST HOME

A professional parent or host home is a private household that offers protective social living for individuals who are unable to live independently. The family offers the young adult room and board. Opportunities for participation in social, educational, and recreational activities within the community are also provided by the family life home.

INTERMEDIATE CARE FACILITY

An intermediate care facility provides 24-hour care for individuals who, through an illness or disability, require ongoing nursing and medical services. These medical services must be provided by a registered or licensed practical nurse or doctor. DSPD has a list of the various provider resources funded by them.

SELF-ADMINISTERED SERVICES – SAS

Self-Administered Services (SAS) offer an alternative to Provider Agency Services by allowing people with disabilities and their families the choice and opportunity to select providers that offer services within the home. People with disabilities and their families hire, train, and supervise employees who provide direct supports in a home setting. More information and training about how to use this model is available through DSPD or through the Family to Family Network.

EMPLOYMENT OPTIONS

There are three main kinds of employment options. They include:

- competitive employment
- supported employment, and
- sheltered workshops or work activity centers.

COMPETITIVE EMPLOYMENT

The majority of individuals with disabilities leaving school can learn to get and keep a job without any special support services. This is called “competitive employment”. Competitive jobs are found within public or private businesses or industries. Employees are paid and receive the same benefits (vacation, insurance, sick leave) as all workers, depending on whether they are considered full- or part-time. Competitive jobs are found in a number of ways – through friends, parents, relatives, agencies (Workforce Services, Vocational Rehabilitation), or newspapers. A good strategy is to use any or all of these resources to find a job. Another form of competitive employment is for individuals to own their own business (painter, seamstress, data entry, Braille service, childcare provider).

SUPPORTED EMPLOYMENT

Supported employment is a service for individuals with significant disabilities, which provides support to individuals seeking competitive employment. The job coach assists with job placement and on-the-job training and coordinates ongoing supports and other appropriate services needed to sustain paid employment. This type of employment may occur in a variety of work settings. Providing the ongoing support services necessary continues as long as the person is employed. Supported employment services may begin in school programs. Vocational Rehabilitation and the Division of Services for People with Disabilities sometimes provide supported employment services for adults. Contact these agencies directly for more information on their programs.

SHELTERED WORKSHOP OR WORK ACTIVITY CENTERS

Sheltered workshops or work activity centers are facilities that serve people with disabilities by providing supervised work and other rehabilitative activities. The goals of these facilities are to help individuals develop skills so they can be employed in the community and to employ people who are viewed as incapable of competitive employment. Some individuals and advocacy groups oppose this type of service. However, they often promote inclusive programs that result in people with disabilities working in the community alongside people without disabilities.

Parents like to think that someday when they die and are no longer able to help their children by being there, that they can leave behind some kind of inheritance that will help them. An outright inheritance may actually jeopardize the public program benefits received by sons or daughters with a disability. This needs to be taken into account when planning an estate for an heir with a disability. Some guidelines to consider include: the seven planning questions, team of qualified professionals, necessary legal documents, and funding for a trust.

For someone on an assistance program such as Medicaid (Medical Assistance), receiving an outright inheritance means the public assistance money would stop while the inherited money is used to pay for needed services or programs (such as medical care, group homes, or a day activity program). Only when the inheritance is gone does the public program money, such as Supplemental Security Income benefits, become available again.

Often, unless the family or charity provides supplementary assistance, an individual with a disability receiving monthly SSI or SSDI with medical benefits payments may experience serious challenges managing on only that amount of income. However, doing careful estate planning parents can ensure the inheritance they leave will add to and not take the place of funding received. Through careful estate planning, proceeds from the estate can be used to add to the quality of life for the heir with disabilities.

WHERE SHOULD YOU START?

There are seven important planning issues unique to families with members with disabilities which are reflected in the following questions:

1. Who will care for the child with a disability if I am physically unable to do so?
2. How can we maximize government benefit programs that currently assist families of people with disabilities? (SSI, SSDI, Medicare, Medicaid, military pensions, etc.)
3. How can we coordinate our personal resources with government benefit programs to provide the best possible lifestyle for the disabled individual, both now and in the future?
4. How can we provide sufficient resources to ensure a comfortable lifestyle without the government having claim on the inheritance?
5. How can we manage our resources so they are available for the life of the disabled person?
6. How can we ensure a dignified funeral and burial services when my son or daughter dies?
7. How can we get the rest of the family to understand and support the plans we make?

These questions are best answered with the assistance of professionals experienced in these matters. Besides an attorney, the planning team could include an accountant, a financial planning professional, and an advocate. Together the team can often better help families develop and implement appropriate estate plans for their needs. Even if you already have a family attorney, you may want to ensure that they have knowledge about disability estate planning.

One of the best ways to find legal and financial experts in estate planning for families with people with disabilities is to ask others in similar circumstances if they know or have used someone they liked. The person under consideration should be familiar with estate planning for families with a member with a disability. It takes longer to plan a will for a family including a person with a disability than a simple will, so don't be afraid to ask how much the professional's services will cost. Also, ask the professionals if they already have colleagues who work as a team to provide maximum benefits at the least cost. Remember to obtain references for a professionals working with you on this important issue.

Estate planning should be approached as a team with professionals and families working together to accomplish the following:

- Letter of intent: this is a letter by the parent regarding the child with a disability. It is an in-depth letter regarding the child – likes, habits, special communications, medical information, housing needs, etc.
- A complete analysis of resources: both family and individual, including government programs and other private resources and a plan for optimizing them.
- Appropriate execution of all legal documents: wills, trusts, transfers, etc. The appointing of a trustee, a successor trustee, and final disposition of the trust when the person with the disability dies.
- Funding of the trust: to ensure the wishes can be carried out.

When planning an estate, two categories of assets should be taken into account: those that would be listed in your will (assets subject to probate), and assets not subject to probate, such as life insurance or proceeds from an IRA (Individual Retirement Account).

In both cases it would be important not to name the person with a disability as an outright heir or beneficiary. It may be helpful to discuss potential inheritances with grandparents or other relatives. Grandparents, with all the love and good intentions in the world, but no acquaintance with the requirements of the programs upon which their grandchild is dependent, may have written an outright inheritance into their wills. Three routes can be used to accomplish this. They are:

1. Omit the person with disabilities from the will. In some states, you must state clearly it is your intent that the individual in question (when they are your daughter or son) not receive an inheritance from you. The statement of omission is sometimes accompanied by the next action.
2. Make a specific gift to an individual other than the person who has the disability with an unofficial understanding that the proceeds are to be used for the person with a disability. This cannot be an official, written agreement. If it were, the gift in question would be considered an asset of the person with a disability and jeopardize their public assistance. The informal nature of this option makes it a risky one since there are no guarantees that the gift will be used as the parents intended.
3. Establish a trust. A trust is a way to ensure an estate's proceeds, or a portion of them, are used for the benefit of the heir with a disability, enriching their life and not jeopardizing public assistance benefits otherwise available.

A trust is a complicated document that must be drafted very carefully. Trust funds, if and when spent, have to be used for the benefit of the person named as the trust's beneficiary (in this case, the son or daughter with a disability). Yet, in order that the trust funds not jeopardize their eligibility for the assistance programs they are on, the trust fund's assets cannot be considered their assets. The trust's funds are considered the trustee's assets and the trustee is legally granted total discretion not to spend – as well as to spend – any of the funds. However, when funds are spent, they must be used for the beneficiary. When developed carefully, trust funds can help parents add to the quality of their offspring's lives, even after their deaths.

For more information, contact:

NICHCY (National Information Center for Youth with Disabilities)
(800)695-0285

They provide the most up-to-date information available in the "Estate Planning News Digest".

"A Family Handbook on Future Planning", written by Richard Berkobein.

Write to:

Publications
Dept. P.O. Box 1047
Arlington, TX 76004
(817)261.6003

This publication provides families with basic step-by-step advice on developing a future plan at every stage and looks at different options.

Guardianship Associates of Utah, Inc.
180 South 300 West, Suite 202
Salt Lake City, UT 84101
801-533-0203

There are also a number of private attorneys and financial planners who can provide assistance.

GUARDIANSHIP

Guardianship is a legally authorized relationship between a competent adult (the guardian) and an adult with a disability. In this relationship, the guardian is given the duty and right to act on behalf of the person with a disability in making certain decisions affecting his or her life. When a guardian is appointed, the court gives the guardian the authority to exercise certain rights and correspondingly takes those rights away from the person with a disability. For this reason, guardianship is a very restrictive procedure and should only be used when necessary.

Guardianship may be considered for adults with disabilities who are 18 years of age and older and who, by reason of the decision of a judge or jury, are found to be incapacitated. An incapacitated person might be any person whose decision-making process is impaired by reason of:

- mental deficiency,
- physical illness or disability,
- chronic use of drugs,
- chronic intoxication,
- unusually bad judgment,
- highly impaired memory, and/or

- severe loss of behavioral control to the extent that the person is unable to care for his or her personal safety or is unable to attend to and provide for such necessities as food, shelter, clothing, and medical care, without which physical injury or illness may occur.

Regardless of an individual's disability, a parent is not automatically the guardian of a son or daughter when the child becomes 18 years old. If a parent wishes to become the guardian of his or her adult child, only a court order can make the child a ward and appoint the guardian.

A person will be made a ward only if a petition, complaint, or will is filed in a court and the court finds guardianship or conservatorship necessary to protect the individual. Upon such a finding, the person with a disability may be placed under guardianship despite the individual's objection or refusal.

The appointment of the guardian limits the civil and legal rights of the alleged incapacitated person. To ensure that rights are not limited unjustly, Utah law provides the following due process protection to the potential ward:

1. To be notified of the time and place of hearing in plain language and large type.
2. To be represented by legal counsel. If the respondent cannot afford counsel, it shall be provided at no cost to the individual.
3. To be present at all proceedings. If the respondent cannot be present, a court visitor will do an assessment. There are certain medical exceptions when a court visitor or presences in court are not required. They are: profound mental retardation, fourth stage Alzheimer's disease, and extended comatose.

When the court grants guardianship, the powers and duties of the guardian must be specified but may include the following:

- authority to determine the ward's residence, care, habilitation, and employment;
- responsibility to make sure the basic needs of the ward for food, clothing, and shelter are met;
- authority to consent to medical care needed by the ward;
- responsibility to make decisions for the ward such as whether to marry or be adopted; and/or
- responsibility to keep the ward's financial affairs in order.

The guardian is responsible for the debts of the ward only to the extent of the ward's resources. The guardian accepts no personal liability for debts incurred by the ward.

"You may be disappointed if you fail, but you are doomed if you don't try."

-Beverly Sills

Empowering Parents



“Be creative, be brave, and make up your own solutions.”

~ Madlyn Tombs, Pastor

Parents of people with disabilities have had to call upon creative resources throughout the life of their child. “Inventing the future” usually requires parents and their son or daughter to look beyond “the system”, beyond conventional answers, and requires them to consider anything that works.

Adolescence is a time of independence, a time when young adults begin to take more responsibility for meeting their own needs. Many young adults with disabilities begin to “strike out on their own” and seek less interference and involvement from their parents. Greater independence means higher risk. Risk taking is an essential component of adolescence and an important component of gaining independence.

When young adults with disabilities move from the school system into the community, their parents experience the same feelings that all parents do when it is time to “let go” and allow their kids to try things on their own. Letting sons and daughters with disabilities “try their own wings” can be more frightening because they have usually been more dependent on others.

Some parents are afraid their sons and daughters can’t make it without them. Others fear transition because change involves risk and they’re afraid their young adult may fail in some new task, be injured, or treated poorly. No parent wants to expose a young person to risk, especially one who has a higher than average chance of failing. Yet most parents know that risk-taking is essential for the long-term development of social and personal competence.

The passage from childhood to adulthood for all of us involves the ‘dignity of risk’ – the right to make mistakes and learn from them.”

Parents’ fears about physical or emotional harm are real, but protecting young people from reasonable risks robs them of an opportunity to become as independent as possible as they transition to adulthood.

The negative consequences of shielding young adults from taking risks can be more damaging than the consequences of an occasional mistake or failure. To prepare for the independence all adolescents strive for, opportunities to practice should be given prior to adolescence. A child may want to spend 2 weeks away at camp, which might terrify parents. Allowing the child to spend weekends camping with friends or spending a few nights away from home visiting a relative could gradually increase confidence in her or his independence. Breaking a desired goal into smaller steps helps build confidence and supports families as they enter this tough transition to independence.

While young adults are preparing to transition into the community, parents' need for support and information may be as great or greater than they were when their child's disability was first diagnosed. The support of other parents who are facing the same decisions and risks can be very valuable.

LETTING GO

Although it is especially difficult for you to allow and encourage your daughter with disabilities to strike out on her own, it is easier when preparations have been made in advance. You will be less traumatized if you view "letting go" as a process and use transition planning to provide an approach that lays adequate groundwork for successful independence.

As she moves toward adulthood and independence, you can encourage her to make choices and discipline yourself not to interfere. Even if you are afraid she may fail at some new task or be treated poorly by others, you must recognize that reasonable risk-taking is essential for her personal growth, ultimate well-being, and long-term happiness.

The goals and objectives of the transition IEP can include specifics that address concerns about her ability to function safely on her own. When the transition plan is being developed or reviewed, you have the opportunity and obligation to make certain those concerns are addressed. As the plan is implemented and monitored, you can assess her progress as she: makes choices; experiences consequences; evaluates outcomes and applies what she learns to new circumstances.

When you let your daughter make choices, you may experience feelings of fear, anxiety, and insecurity that match the emotional turmoil that came when she was first diagnosed with a disability. You may find it valuable to turn to other parents who are facing the challenges of transition for encouragement and support. You will find renewed strength when you share your feelings with others who understand your fears and hopes. You can sympathize and reassure one another when difficulties arise and celebrate together when positive accomplishments are made.

As you loosen your grip, you embark on a new leg of your journey in experiences with disabilities. It does not need to weaken the parent-child relationship but will change it to some degree. The love that once moved you to protect your daughter will now motivate you to support, encourage, and respect her as she maximizes her efforts toward independence.

We don't have a clue as to what people's limits are. All the tests, stopwatches, and finish lines in the world can't measure human potential. When someone is pursuing their dream, they'll go beyond what seem to be their limitations. The potential that exists within us is limitless and largely untapped.

Robert J Kriegel & Louis Patler

"If It Ain't Broke...Break It!"

Related Topics

ADVOCACY

Advocacy is pertinent to all stages of life, but for people with disabilities it has additional significance. It is initially the responsibility of parents who have children with disabilities. Depending on the extent of the disability, it is best to equip the person to be a self-advocate as soon as that is possible. The principles of advocacy are the same; whether the speaker is making a case for someone else or for himself.

Self-advocacy means standing up for your rights as a person. It means deciding what is best for you and speaking or acting on your own behalf. It often requires tremendous effort to make your voice heard by taking risks as you challenge rules or customs, acquire needed resources, and get service providers to respond to your needs.

The skill of self-advocacy can equip your son to take control of his life. He can learn from his mistakes and successes, preparing for the day when you, his parents, or school personnel are no longer available to manage his life. Parents can encourage this skill in the following ways:

- Give him opportunities to make decisions and experience the consequences.
- Teach him about his disability and how it impacts his life.
- Practice role-playing situations in which he can learn to be a self-advocate.
- Allow and encourage his independence.

You will be taking some risks as he develops this skill. By expecting and accepting the consequences of choices, wrong as well as right, he will learn from his experiences as you did from yours.

People with disabilities, their family members, and service providers can all be advocates who heighten disability awareness. Sharing information about issues like accessibility to buildings and services makes the Americans with Disability Act (ADA) a reality for those who do not recognize or understand the barriers. Ideas about accommodations and opportunities that can be created in transportation, housing, and employment will be valuable community input when it comes from people who truly understand the needs.

There are many ways to make your voice heard regarding these issues. You can do it individually by talking to neighbors, business owners, relatives, friends, and government officials to inform them of needed changes. You can serve on local or government committees, attend decision-making meetings, or support state and local legislation that provides more and better opportunities to include people with disabilities. You can also join a disability support group where you will be part of a collective voice. By informing the community about needs and reminding them about the value of people with disabilities, we increase the chance that they will be included in employment, residential, and recreational opportunities.

SUPPLEMENTAL SECURITY INCOME (SSI)

Your daughter must have a disability or be blind to be eligible for SSI. Children may be eligible for benefits depending upon the family's income and assets, but when she turns 18, the family income is no longer considered. However, the benefit will be denied if she has more than \$2,000 in accountable resources. This includes liquid assets like savings, stocks, bonds, etc., and real property beyond one vehicle she uses and the home in which she resides. If she is deemed eligible for SSI, she is automatically eligible for Medicaid.

Written applications for SSI are submitted at the local Social Security Administration (SSA) office. If you live in a metropolitan area, make an appointment to submit the application by calling their toll-free number. This can reduce or eliminate a lengthy wait. Begin this process six to eight weeks prior to her birthday. They will also send the application so you can complete it before your appointment. Bring the following to the application interview:

- Social Security card number,
- An original document to prove her age,
- Evidence of citizenship or immigration status,
- Records of earned and/or unearned income,
- Auto registration,
- Medical reports,
- IEPs for the last two years, and
- Any testing results which verify the disability.

You may also want to have written statements from others who will verify her inability to do things that others her age can do for themselves. Benefits are paid back to the month of application so if you are missing some documentation, submit the application anyway. Provide SSA with the names and addresses of doctors, hospitals, or clinics where she has received treatment. For information or assistance call your local SSA offices or their toll-free number, 1-800-772-1213. They can explain how to appeal a decision which denies her eligibility.

Whenever possible, SSI should be used as a stepping stone to economic self-sufficiency. SSA has developed programs that encourage people with disabilities to achieve a more independent and satisfying lifestyle when they take advantage of employment opportunities. Information is available from "The Red Book – A Guide to Work Incentives" (SSA Pub. No. 64-030). Benefit planning assistance is also available through Work Ability by calling 1-877-246-9675 or visiting www.workabilityutah.org.

HEALTH CARE

Another part of your son's independence is assuming some responsibility for his health care. Decisions must be made about his ability to realize when he needs health care and whether or not he can communicate adequately with health professionals. It is also recommended that you address the issues of sexuality and reproduction. Helpful information on these topics is available at www.medicalhomeportal.org.

Financial resources to pay for his health care must be identified. Medicaid may be available even if he does not receive SSI. More information can be requested by calling your local Family Support/Workforce Services Office, an agency of Utah government. Medicaid covers basic dental care

after age 21, but prior approval is required for some services. Whenever using Medicaid and when using some insurance plans, parents should learn about their pre-request plan.

For students with medical needs it is important to give careful consideration to how medical care and services will change as they become adults. For more information, you may wish to contact Utah Family Voices, Family to Family Health Information Center by calling: 801-272-1068 or 1-800-468-1160. Information on medical transition issues is also available on the Utah Medical Home website at www.medhomeportal.org.

What Help is Available?

AGENCIES PROVIDING SERVICES FOR ADULTS WITH DISABILITIES

This handbook was developed to help you identify your daughter's strengths and preferences as well as her needs. As you plan for her transition from school to adult services which have eligibility requirements you will look for programs and services that will meet those needs. This section is meant to help you with that search.

There are many agencies that provide services for transition-aged youth with disabilities. You may have problems finding an agency that provides the specific services your daughter needs or that serve people with her disability. You may also encounter a long waiting list of eligible people. Even if an agency does not have exactly what you are looking for, ask what services they do provide and if your daughter is eligible. Add the information you receive to the appropriate section of your records. Ask school personnel and other parents, agencies, and organizations about possible services or resources. It may be necessary to make many calls in search of suitable and desirable services, but it will be time well spent to locate what your daughter needs.

If you find a gap in the types of services your daughter needs, there may be other youth with disabilities and families needing these services. This is an excellent opportunity to meet with your Community Transition Council (CTC) or other groups and ask for their assistance in filling this particular gap. Contact your local school district office to reach their Transition Coordinator who can tell you if and when a CTC meets.

Access Utah Network provides information and referral about a broad range of agencies as well as product and service providers for people with disabilities. They also maintain a database of used equipment which is for sale or donation. They are able to provide detailed information and presentations about the American with Disabilities Act. Call: 801-533-4636 or 1-800-333-8824.

The Disability Law Center is a private, non-profit organization which is federally mandated to provide advocacy services to eligible clients with disabilities. They protect and advocate for the rights of individuals with disabilities and mental illness, and those seeking assistive technology devices or services under the Rehabilitation Act. Services are free of charge and available to all eligible individuals in Utah. Call: 801-363-1347 or 1-800-662-9080 – voice or 1-800-550-4182 – TTY.

Independent Living Centers assist Utahans with disabilities to live independently in their communities. Services may include assistance in obtaining modifications to a home or vehicle, adaptive equipment, personal care providers, advocacy, peer counseling, and skills training for independent living. There are four centers in Utah with some satellite locations as well. Call: 801-466-5565 or 1-800-355-2195.

Medicaid provides financial assistance with medically related costs to those who qualify. Applications are handled through the Family Support/Workforce Services Office of Utah's Human Services Department. Those who qualify for SSI may be eligible for Medicaid but still need to apply.

Work Ability Utah helps prepare people with disabilities to work. The program was designed for people who receive public benefits like Medicaid and Social Security due to a disability. Work Ability connects people with supports to help them find and maintain work. Call: 1-877-246-9675

Social Security Administration (SSA) administers Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI) and work incentives (PASS and IRWE). Call: 1-800-772-1213 between 7:00 a.m. and 7:00 p.m. Monday through Friday for information, applications, and to schedule appointments.

Utah Center for Assistive Technology (UCAT) provides accurate and up-to-date information on all aspects of assistive technology to people with disabilities and their families. They have a large display of a full range of assistive devices including computers, with staff members available for demonstrations, equipment try-outs, and customization. They also have information about possible funding sources. Call: 801-887-9500.

Utah Division of Services for People with Disabilities (DSPD) can provide information about service throughout Utah for people with disabilities. Family Support, Supported Employment, Personal Assistance, Day Training and Residential Programs are available for those who meet eligibility requirements. Services go to those with the most immediate and critical needs first, and others are placed on waiting lists. Request their booklet "A Guide to Services for People with Disabilities" from the state or regional office. It contains a general resource guide which includes locations of their offices, listings of service providers, agencies and organizations in Utah as well as national toll-free numbers. Call: 1-877-568-0084 or 1-800-837-6811.

Utah Parent Center is a private, non-profit organization which serves parents of children and youth with disabilities statewide. It provides training, support, and information that equips parents to function as equal partners in planning and accessing needed services for their children. It offers parents individual consultations; workshops and conference presentations; printed materials, resources, and information on a variety of disability issues; and information and referral to programs, services, agencies, and organizations. It also promotes collaboration by professionals of all agencies and organizations along with parents. Call: 801-272-1051 or 1-800-468-1160.

Utah Schools and the Schools for the Deaf and Blind have designated Transition Coordinators. The name and phone number is available by calling the local school district office. Call 801-629-4700 - voice, (801)466-9910 – TTY or 1-800-990-9328.

Utah State Office of Rehabilitation administers Vocational Rehabilitation programs which assist **eligible** individuals with disabilities in making career decisions, preparing for and finding suitable employment. They may provide training to develop specific vocational skills, to gain self-confidence, and to help adjust to the work setting. When appropriate, they provide medical treatment and services or assistive technology to reduce or stabilize the effects of a disability and improve abilities to participate in training or work. Call: 801-538-7530 or 1-800-473-7530.

PARENT SUPPORT GROUPS

For families living with people with disabilities, the problems that arise in getting through one day can be overwhelming. Families with a person with a disability have all the problems and obligations of ordinary families plus the added burden of the extra needs of that person. These families' lives are different than the lives of most families. Talking to people who have had to get through days much like their own provides an outlet that can't be found anywhere else.

Parents of young adults with disabilities feel that there are a lot of things they 'should' be doing. There are also a lot of things they think others, including teachers, doctors, relatives, and counselors, expect of them. Our 'to do lists' can get so overwhelming that finding time to attend a parent support group itself seems impossible. If parents look at their list of things to do they may notice that some of the things listed could be done more easily (or might have already been done) by a group of parents who share some of the same experiences.

Support groups are invaluable to many parents of youth with disabilities. Parents gain the following benefits from attending support groups:

- Support groups provide a place where you can go and talk about your feelings without being misunderstood. When parents of students with disabilities meet with other parents in the same situation it eases their sense of isolation.
- Support groups provide a place for the beginnings of organized advocacy groups.
- Support groups give parents a chance to share information, ideas, and solutions.
- A group lets its members access professionals and services that they might not have access to on an individual basis. Professionals will often speak (frequently free of charge!) to a group of parents for a couple of hours. An opportunity that, if scheduled clinically, would be half as long and very expensive.

How can you find out if a support group already exists in your area?

- Call your Parent Training and Information Center: Utah Parent Center at 801-272-1051 or toll-free in Utah at 1-800-468-1160.
- Call Access Utah Network at 801-533-4636 or 1-800-333-8824.
- Talk to your son or daughter's doctor, special educator, or VR counselor.
- Contact the county health nurse.
- Look in the yellow pages under "psychology" or the name of the disability.
- Look in the local newspaper in the upcoming events section for group meetings.
- Call the Department of Human Services, Division of Services for People with Disabilities.
- Dial 211

The Utah Family to Family Network has groups in several areas of the state and provides support in the community to parents of children with all disabilities.

If no support group exists, create your own! Find other parents facing a situation similar to yours, and meet! (See "Organizing Parent Groups" in the supplemental material in the back of this manual.) There are several clearinghouses for information that have lists of groups in each state.

The following is a list of things that have worked well in the day-to-day functioning of one support group:

- Making personal contacts with other parents is the best way to get them to come to meetings. Call and talk to prospective parents. Provide transportation for the first meeting and look at carpooling for following meetings.
- Welcome children, provide on-site childcare, or develop a pool of caregivers and pay them if possible.
- Be open to differences. Fathers and mothers, all family structures, and different types of disabilities, should all be included.
- Have parents and advocates continue to run the group. Professionals are great resources and speakers, but sometimes they intimidate families.
- Meet in a neutral place. Civic centers, public libraries, and most public buildings have meeting rooms available. Meeting in private homes may be uncomfortable for some people.
- Structure the meetings so that "something" happens. Have an agenda and accomplish it. Include a social time before or after, or on a different day. Make the meeting time work for parents' schedules."

"...What you can do is often simply a matter of what you will do...so many things are possible just as long as you don't know they're impossible."

The Phantom Tollbooth, Norton Juster, 1989



© Utah Parent Center

(801) 272-1051

(800) 468-1160

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