



TRANSITION IDEAS FOR THOSE WITH SIGNIFICANT DISABILITIES

The transition process for students with significant disabilities follows the same process as others with mild or moderate disabilities. Issues such as housing, employment, recreation need to be addressed.

- Review the Utah Parent Center's transition manual for excellent information and ideas. Look in there for examples of IEP transition goals for your child. www.utahparentcenter.org
- As you approach the transition process, you might want to consider using person-centered planning. "Person-centered planning is a process-oriented approach to empowering people with disability labels. It focuses on the people and their needs by putting them in charge of defining the direction for their lives, not on the systems that may or may not be available to serve them. This ultimately leads to greater inclusion as valued members of both community and society." (<http://www.ilr.cornell.edu/edi/pcp/index.html>) In Utah, the Department of Services for People with Disabilities (DSPD) encourages the use of such planning. The Division encourages the Person-Centered Planning process in determining the needs of persons receiving services. "Person-Centered Planning allows people with disabilities and their families to take an active role in the service planning process and have a voice in their choice of services. This process has an individualized focus and incorporates the principles of self-determination, informed choice, and equity. Input from the person and their Team (which includes the person's family members, friends, provider staff, DSPD Support Coordinator, etc.) should guide and direct this process. "
- If plans for your child include having a sibling become guardian at some point, it might be helpful to include the sibling at IEP meetings where transition is being discussed.
- If your child is not receiving DSPD money or services, be sure you have contacted the Department of Services for People with Disabilities (DSPD) and apply for services. If your child does not qualify right now, your child's name will be placed on a waiting list. Continue to work with the DSPD if your child is on the waiting list and advise them of any differences in your child's situation to see if that might affect the wait status. When your child reaches adulthood, service options will change. Also be sure you fill out and return requested information annually so your child's name is not dropped from the list. www.dspd.utah.gov intake: 1-877-568-0084
- Make contact with Utah Vocational Rehabilitation to see what types of programs and assistance is available. The school can invite a representative to the transition IEP to discuss what possible assistance can be provided. The school will ask you to sign a permission form in order for them to invite outside agencies. www.usor.utah.gov 1-800-473-7530
- Explore employment opportunities. Don't rule out some type of employment just because your child's disability is more significant. Employment of some type can provide a meaningful dimension to life; there are many types of ways to work for individuals with disabilities. Check with your school's counselor about the use of the Utah Futures website and program. The elementary school version might be easier to use depending on your child's level. www.utahfutures.org

- Self-employment is something many people with disabilities have found to be successful for addressing their needs and interests. Many times there is money available from services such as Vocational Rehabilitation to pay for training or equipment. Your family will need to help develop a business plan and advocate for this. "Self-employment offers many the freedom to work at their own pace in an environment that accommodates their special needs. As a person with a disability or a chronic health condition, you may have tried unsuccessfully to find work or you may have found that your employer is unwilling or unable to accommodate your needs. You may be looking for an option that allows you to earn a living and manage your health at the same time. Owning your own business often provides the flexibility that is necessary to those who require frequent medical attention, flexible hours, accessible work space, or other special considerations."

<http://www.workabilityutah.org/cd/02/Resources/SelfEmployment.html>

The example of a home business could be applied to many areas of interest for youth who have significant disability or health care issues. For example, young adults may have interests or preferences to bake or create jewelry. Those could all be developed into home businesses (i.e., baking dog biscuits for resale at local veterinary offices, or assembling jewelry to sell at local craft shows). http://www.nsttac.org/sites/default/files/nsttac.OSEP.teleconference.I-13_SD.pdf

- Many parents are concerned that if their child works, benefits will be lost. Call the Benefits Planning Assistance and Outreach program for help in coordinating and maximizing benefits at 866-454-8397 (toll free).
- Schedule an appointment with the Utah Center for Assistive Technology for a tour and evaluation of possible resources there. They have access to amazing computer programs and assistive devices that could help your child. 801-887-9500. www.usor.utah.gov:81/ucac
- Look into The Utah Computer Center which is a service provided under the Utah State Office of Rehabilitation http://www.usor.utah.gov:81/ucac/ucac_computer_center.htm The fundamental goal of the Computer Center for Citizens with Disabilities is to provide assistance aimed at improving the lives of children and adults living with disabilities by introducing them to the many ways in which computer technology can enhance their jobs, careers, and education.
- Explore the Utah Association of Community Services for information: www.uacs.org about day services and residential services.
- Work with other parents at your school to develop a social group to provide social opportunities for your child as an adult. Identify peer mentors and connect with other families who have youth with similar significant disabilities.
- Insure your will and trust are up to date and plans for your child after you are unable to care for him/her are clearly defined. Inheriting assets can affect your child's benefits, so this must be addressed in your trust. Be sure the attorney understands the intricacies of a special needs trust.
- If your child is unable to make decisions, guardianship should be considered and must be established when your child turns 18. Without it, you cannot make medical, financial and other decisions since your child is considered an adult. There are different levels of guardianship which the judge can grant. Also, be thoughtful about naming a successor guardian. If it will be one of your

other adult children, how will caring for the sibling with disabilities impact him/her? A very helpful site for information about guardianship is <http://guardianshiputah.org/>

- Consider how your child will participate in the community. Evaluate recreational or volunteer opportunities.
- Check with the county recreation department. There are many activities for people with disabilities. www.activityreg.com. There are other social opportunities such as Special Olympics, Splore, and Utah Independent Living Center. What will your adult child do once school is completed?
- Consider becoming involved with the Utah Caregiver Cooperative: contact Marilyn Bown at 866-404-9080 or marilynbown@aol.com.
- Check out the Utah Assistive Technology Foundation <http://www.uatf.org/index.html> which offers low cost loans for assistive technology. The mission of the UATF is to assist Utah citizens with disabilities by enhancing their independence, education, employment, and quality of life through the use of assistive technology. The UATF also helps individuals with disabilities to obtain the assistive technology devices and services they need to communicate, complete daily tasks, succeed in inclusive classrooms, work competitively, and participate in community activities.
- Explore resources at the Utah Independent Living Center www.uilc.org which offers the following services:
 - **Independent Living Skills Program**
Provides services to people with disabilities needing to gain independence in their homes, families, and communities.
 - **Peer Support and Outreach Program**
Provides outreach services and personal assistant liaison services to people increasing their participation in community life.
 - **Community Integration Program**
Provides activities and information to assure inclusion of people with disabilities in recreation pursuits and other leisure activities.
 - **Deaf Independent Living Expansion Program**
Assist people who are deaf or hard of hearing achieve greater personal and community independence.
 - **Assistive Technology Program**
Provides assistive technology related services to increase personal independence of people with disabilities including assisting consumers with accessing needed technology.
 - **Education Enhancement Program**
Assist students with disabilities ages 13 to 22 gain life skills for successful transition from high school.
 - **Nursing Home Transition Program**
Provides services and networking to people living in nursing homes who want to move into the community.
- Be creative and think outside the box when helping your child plan for a future. The time to plan is now. The transition process while your student is in school is the time to do your homework! The school team will work with you as well, but as always, parents are the child's best advocate.

QUESTIONS TO CONSIDER WHEN PREPARING FOR A TRANSITION IEP FOR YOUTH WITH SIGNIFICANT DISABILITIES:

1. Can the young adult express interests? If no, get information from parents and caregivers to develop transition plan.
2. What are special health care needs?
3. What are needs/challenges preventing the young adult from working outside the home?
4. Who can provide education/training to assist the young adult?
5. What can the young adult accomplish without assistance?
6. What else could the young adult accomplish if assistance were provided by a job coach, habilitation training specialist (HTS), or other caregiver?

(Guiding Questions for Secondary Transition Planning for Youth with Significant Disabilities, ideas from an Oklahoma working group: http://www.nsttac.org/sites/default/files/nsttac.OSEP.teleconference.I-13_SD.pdf)

EXAMPLES OF TRANSITION GOALS FOR STUDENTS WITH SIGNIFICANT DISABILITIES

http://www.nsttac.org/sites/default/files/nsttac.OSEP.teleconference.I-13_SD.pdf

Debbie(16 years old, CP, Seizures, W/C, Depression, Frequent URI)

- Education/Training: Immediately after graduation, Debbie will participate in habilitative and functional skill training through Medicaid-waiver funded services.
- Employment: After graduation, Debbie will obtain a supported employment position that allows her to work to her maximum stamina and incorporates the use of assistive technology.

Adrian (18 years old, asthma, uses a 1-2-3 Speak, mild hemiplegia)

- Education/Training: Following graduation Adrian will receive employability training at the community rehabilitation program through onsite community college Job Ready classes.
- Employment: After graduation, Adrian will work with support at the community rehabilitation program in an assembly and packaging position to prepare him for future community-based employment.

Dwayne (20 years old, W/C, Seizures, visual impairment)

- Education/Training: Within three months of graduation, Dwayne will participate in continuing education courses at the community college related to his interest in computers, food preparation or leisure activities.
- Employment: After graduation Dwayne will implement his business plan for a home-based Custom Candy Wrapping Business.

Jane D. Postsecondary Goals

Jane D. has cerebral palsy, poor fine motor skills, uses a power chair, and requires full-time assistance for daily personal needs. She is verbal and others understand her easily. Jane enjoys interacting with children, especially babies. She wants to get married and have a family. Through interviews and other types of transition assessment, Jane expressed her desire to work with children.

Education/Training: *“Jane will audit childcare/early childhood classes at the local Career Tech Center with a full-time HTS”.*

Employment: *“With the help of a full-time HTS, Jane will job shadow in 3 childcare/daycare programs”.*

Independent/Adult Living -Short-term: *“Jane will live in a group home and utilize public transportation to participate in her classes and job shadowing experiences”.*

Independent/Adult Living -Long-term: *“Jane will get married, have children, and live in Oklahoma”.*

John D. Postsecondary Goals

John D. is a 21-year-old who has a severe intellectual disability, is blind, and exhibits self-stimulatory behavior. John loves balloons and the squeaking sounds they make when they are inflated and touched, or rubbed. Due to John’s significant health care needs, he lives with his parents and has a part-time assistant who comes to his home to help with daily personal needs. John likes traveling in a vehicle. He wants to earn his own money so he does not have to rely so heavily on his parents. John’s expressive verbal skills are low, so it is difficult to get information from John. Therefore, discussions with his parents revealed John’s love of balloons, car travel, and desire to earn money.

Education/Training: *John will participate in on-the-job training at flower shops or Party Galaxy to learn how to properly inflate balloons”.*

Independent/Adult Living: *“While living at home with his parents, John will maintain a checkbook and pay for his purchases with the assistance of his parent(s) or assistant”.*

Employment: *With the help of a job coach, John will develop a home-based balloon business”.* John will participate in the development and operation of a home-based balloon business. He will not be able to do this on his own, and he will require the assistance of his parent(s), job coach, or other assistant to deliver his product. There are a number of activities in which John could participate during high school (as annual transition goals) to help prepare for his home business.

Phil P. Postsecondary Goals

Phil P. has cerebral palsy, uses an AAC device to communicate, and requires support and help for all daily care and mobility activities. Phil’s family supports his move into his own apartment, but they are worried about consistency of care for Phil, especially in terms of medical follow up. Phil has plans to go to college, but wants to try living on his own for a bit after graduation from high school, before he applies to college. Phil’s family wants to renovate their home to allow Phil private space and access. They want him to be able to handle his own health, medical, and safety needs. Phil will likely live in this adapted home when he goes to college. Phil currently has support through OK’s Developmental Disabilities Services Division (DDSD) for in-home support and job coaching.

Education/Training: *“With help from his DDSD habilitation training specialist and his family, Phil will learn how to use community supports so that he is able to interview, hire, and fire his own personal assistant, as well as access community services when necessary”.*

Independent/Adult Living: *“Phil will live independently in his own apartment, direct his own supports, schedule medical appointments, acquire various types of insurance, and access services in his community, such as local food delivery”.*

Employment: *“Phil eventually wants to be a writer, and plans to do this freelance from his home”.*

Phil may also identify supports that he needs so that he can properly identify the type of individual who will be able to best assist him with his endeavors. Phil can work on developing a list of roles for his support staff as well as interview questions to utilize when considering hire of that individual.

Here is a list of websites with some excellent information for you to explore:

TRANSITION

- <http://transitioncoalition.org/transition/index.php> Provides online information, support, and professional development on topics related to the transition from school to adult life for youth with disabilities.
- <http://www.heath.gwu.edu/modules/parents-guide-to-transition/> This is an online Parents' Guide to Transition from the Heath Resource Center.
- <http://workabilityutah.org/youth/toolkit/toolkit.php> Great toolkit to prepare youth for transition
- <http://www.ncwd-youth.info/topic> NCWD/Youth has an array of briefs, background papers, guides, manuals, and other materials to address issues for youth with and without disabilities; youth service professionals, workforce development professionals, policymakers, and many more.
- <http://www.brookespublishing.com/picturebank/> This is a site with a variety of illustrations which can be used for as a part of a plan for non-reader.
- http://sonoranucedd.fcm.arizona.edu/sites/sonoranucedd.fcm.arizona.edu/files/CAREGIVING_Roadmap_021010.pdf This is a user friendly planner for family caregivers and the individual with disabilities.
- <http://transitions.keenecommons.net/> Training and resources regarding transition are available on this site.
- <http://www.tisd.k12.mi.us/hps/pages/specedforms/pdf%20files/Transition%20Services%20-%20Helping%20Educators.pdf> This is an article by Ed O'Leary regarding transition services and gives some very specific examples of transition goals and planning.
- <http://nichcy.org/schoolage/transitionadult> This site includes information on the transition process, guardianship, disabilities and college, disabilities and employment.
- <http://www.nsttac.org/content/transition-planning-folder-mapping-out-your-childs-transition> This [planning folder](#) allows parents to map out concerns, ideas, or even courses by school year as they think about their child's transition from high school toward their post-secondary goals.
- http://www.thinkcollege.net/images/stories/TC_For_Families_07_09-1.pdf This is an article about postsecondary options for people with intellectual disabilities, including college opportunities.

- <http://www.pacer.org/tatra/> Information on transition and also includes links to podcast about intellectual disabilities and college.
- http://www.caseylifeskills.org/pages/res/res_ACLSAGuidebook.htm?#readysetfly On this site you will find a list of resources, both free and paid, for training and information about a variety of life skills needed for people with disabilities.

EMPLOYMENT

- <https://www.utahfutures.org/materials/homebrowse.html> This is an excellent site for students in Utah to explore what jobs might interest them, what it takes to live on their own, discusses various trainings. It's great to use to help student identify their interests.
- <http://www.careerinfo.net/videos.asp?id=27,&nodeid=27> This government sponsored website offers a wealth of information about careers, skills needed, etc. This particular link has videos about different careers.
- <http://www.start-up-usa.biz/resources/content.cfm?id=681> This page on the site from Virginia answers some basic questions about self-employment and people with disabilities.
- <http://www.workabilityutah.org/cd/index.php> Information found on this site includes information about incentives for working, the Ticket to Work program, self-employment, etc. is a Utah site dedicated to opening doors for work to those with disabilities and information about services available to support them.
- <http://www.pacer.org/tatra/resources/naturalsupports.pdf> The use of natural supports and employment of people with disabilities is discussed in this publication.
- <http://www.dol.gov/odep/topics/youth/softskills> This is information from the US Department of Labor with activities parents and teachers can use to help their students develop soft skills necessary for job success.
- <http://www.dol.gov/odep/topics/youth/softskills/Resources.pdf> Additional resources to explore for transition and employment.

PERSON CENTERED PLANNING:

- http://www.onestops.info/article.php?article_id=189&subcat_id=102 Starting with Me: A Guide to Person-Centered Planning for Job Seekers
- http://www.pacer.org/publications/parentbriefs/ParentBrief_Feb04.pdf This article is an excellent explanation of what person-centered planning is and how it relates to the transition process.
- http://www.mnddc.org/extra/publications/choice/Its_My_Choice.pdf The booklet found here called, *It's My Choice*, is a workbook designed to help those with developmental disabilities participate in the person-centered planning process and transition.
- <http://www.ilr.cornell.edu/edi/pcp/index.html> This is a website sponsored by the Cornell University and includes free online courses about the different aspects of person centered planning.

DAY SERVICES

- <http://www.nhutah.org/pageview.aspx?id=17486> This is information about a day service for adults with disabilities at Neighborhood House with fees based on family's ability to pay.
- <http://turncommunityservices.org> This organization offers residential and day services as well as other programs.
- www.riseinc.net Rise offers a variety of services including day, residential, employment programs, etc.
- <http://www.riseservicesinc.org/content/index.asp?page=143&nonav=no> Latitude is a program dedicated to increasing the quality of life for adults with disabilities. This program was brought together by a parent group who could not get DSPD funding for their children. Many participants in the Latitude Program have been on the DSPD waiting list for several years. This program was designed to be paid for by the individuals' social security benefits. The clients pay the monthly fee for the services we provide which include: menu planning, bus training, budgeting, shopping, job maintenance, housing search, roommate meetings, and group activities. This program is run by both parent advocates and Latitude representatives who are very keen on tailoring supports to meet individuals' needs. For more information, call: 801-995-2357

MORE RESOURCES

- <http://www.socialsecurity.gov/pubs/10026.pdf> This is a link to the guide: Social Security Benefits for Children with Disabilities.
- <http://utahpooledtrust.org/> The Utah Pooled Trust is an entity separate from the person with a disability, and is established to hold and manage assets which have been set aside for that person. This type of trust allows people with disabilities to compensate for additional needs that are not covered by the government, without jeopardizing their eligibility for benefits.
- <http://guardianshiputah.org/resources/> On this page of the Guardianship Associates is a list of some attorneys who specialize in guardianship, special needs trusts and associated issues.
- www.familyvoices.org This national organization connected with Utah Family Voices, 801-272-1068, aims to achieve family-centered care for all children and youth with special health care needs and/or disabilities. Through their national network, they provide families tools to make informed decisions, advocate for improved public and private policies, build partnerships among professionals and families, and serve as a trusted resource on health care.
- www.medicalhomeportal.org This is a good resource for information about the medical home model as well as about various medical issues related to people with disabilities.
- <http://www.fvkasa.org/index.php> Kids As Self Advocates (KASA) is a national, grassroots project created by youth with disabilities for youth. We are teens and young adults with disabilities speaking out. KASA knows youth can make choices and advocate for themselves if they have the information and support they need.