



The Young Adult Guide of the Life Stages Program

A Resource Guide for Young Adults with Tuberous Sclerosis Complex and their Families



Tuberous Sclerosis Alliance
801 Roeder Road, Suite 750
Silver Spring, MD 20910
(800) 225-6872--Toll Free
(301) 562-9890--Voice
(301) 562-9870--Fax
www.tsalliance.org
info@tsalliance.org

(Updated April 2011)

Foreword	3
Introduction	4
Section One: Legal Rights Under Disability Law	6
Disability Law Resources.....	9
Section Two: Transition Planning	13
Transition Resources.....	15
Section Three: Life and Financial Planning	17
Financial Management and Life Planning Resources.....	23
Benefits and Insurance Resources.....	32
Section Four: Assistive Technology	34
Assistive Technology Resources.....	36
Section Five: Education, Vocational Programs and Employment	39
Special Education, IDEA and IEP Resources.....	44
Postsecondary Education Resources.....	48
Employment Resources.....	54
Section Six: Housing and Independent Living	58
Residential and Housing Resources.....	64
Section Seven: Community Integration, Relationships and Recreation	67
Personal Care Assistant Resources.....	69
General Disability Resources.....	70
Community Resources.....	74
Sexuality, Family Planning, Genetic Counseling Resources.....	76
Recreation, Sports, and Leisure Resources.....	77
Travel Resources.....	79
Section Eight: End of Life Issues	81
Hospice Resources.....	82
Grief and Bereavement Resources.....	84
End of Life Resources.....	85
Section Nine: Contact Information for National Disability and Related Organizations	86
Appendix 1: Sample Telephone and Contact Log.....	90
Appendix 2: Constituent Satisfaction Survey.....	91

Foreword

The Life Stages Guide Program has been developed by the Tuberous Sclerosis Alliance (TS Alliance) to provide resource information to people with tuberous sclerosis complex (TSC) and their families about many of the non-medical challenges that are frequently experienced from infancy to adulthood. The information presented in this program is based upon the types of requests the TS Alliance frequently receives from its constituents and includes input from people with TSC and parents of children with TSC. The program includes four different guides, each addressing the topic areas and issues commonly experienced in each age range:

- The Early Years Guide (0-5 years)
- The School Age Guide (6-13 years)
- The Young Adult Guide (14-21 years)
- The Adult Guide (21 years and older)

The Young Adult Guide of the Life Stages Program focuses on those areas that are often of greatest concern from the age of 14-21 (such as moving from school to work, housing, relationships, employment, etc.). The guide is not meant to be read from cover to cover, but to be used as a reference and planning tool. Depending on the nature and severity of an individual's TSC symptoms, some of the information may be very useful, while some of the information may not apply.

We hope the information is helpful. Please use the Constituent Satisfaction Survey at Appendix 2 to let us know how we can improve future versions of the guide. This guide can also be viewed and downloaded from the TS Alliance Web site: www.tsalliance.org. Please check the Web site often as new resources and information are added regularly.

The TS Alliance recognizes that the journey for people with tuberous sclerosis complex and their families can indeed be a difficult one. For additional information and assistance, please contact us.

Tuberous Sclerosis Alliance
801 Roeder Road, Suite 750
Silver Spring, MD 20910
(800) 225-6872
(301) 562-9890
info@tsalliance.org
www.tsalliance.org

Disclaimer: The information in this guide has been compiled from recognized sources and is accurate to the best of our knowledge. The information presented should not be considered as medical, legal, financial, or other professional advice. The Tuberous Sclerosis Alliance is not responsible for any errors or inaccuracies presented.

Copyright 2011 © Tuberous Sclerosis Alliance. *The Young Adult Guide of the Life Stages Program* is provided as a service by the Tuberous Sclerosis Alliance. We encourage reproduction of this guide—in whole or in part. Permission to reproduce this guide, or any part of it, is conditioned on proper acknowledgement being given to the Tuberous Sclerosis Alliance or other noted sources. ***The Tuberous Sclerosis Alliance is dedicated to finding a cure for tuberous sclerosis while improving the lives of those affected.***

Introduction

Who will benefit from the *Young Adult Guide*?

- Individuals with TSC between the ages of 14-21
- Parents of young adult children (between the ages of 14-21) with TSC
- Other family members or caregivers who may be involved with or responsible for the care of a young adult with TSC

What is the purpose of the *Young Adult Guide*?

The purpose of the *Young Adult Guide of the Life Stages Program* is to provide helpful resource information for young adults with TSC and their families. For easy reference, the information contained in this guide is organized into several sections. Topics covered in each section are described below. To locate topics within each section, please refer to the Table of Contents.

Section One: Legal Rights Under Disability Law—Provides a brief overview of disability laws, agencies to contact for additional information or to file a complaint, disability law resources, and where to find free legal assistance.

Section Two: Transition Planning—Discusses the importance of advance planning for the transition from the teenage years to adulthood. Includes: transition planning strategies, checklists, and transition resources.

Section Three: Financial and Life Planning—Describes how to provide for an individual with disabilities after the death of his or her parents. Includes descriptions of the different types of estate planning (guardianship, wills, trusts, etc.), public disability benefit programs (Medicaid, Medicare, SSI, etc.) and ensuring eligibility for those programs, private insurance considerations (pre-existing conditions, factors to consider when selecting insurance, etc.), and daily money management tools.

Section Four: Assistive Technology—Defines assistive technology and provides contact information for the major organizations involved in assistive technology, examples of assistive technology products, and assistive technology resources.

Section Five: Education, Vocational Programs and Employment— Summarizes the educational rights of people with disabilities, including how to obtain special education services. Describes vocational programs, where to explore job opportunities, job placement and training services. Also discusses federally funded job training opportunities, online job search tools, and employment publications. Choices after high school are described as are the disability support services provided by colleges and universities. Where to find financial aid and other educational resource information is also included.

Section Six: Housing and Independent Living—Describes the types of housing and living arrangements that may be available to individuals with disabilities, ranging from situations that provide a high level of support to those situations where a person needs little or no assistance. Includes factors to consider when selecting a residential program, where to find residential financing assistance, and housing resources.

Section Seven: Community Integration, Relationships and Recreation—Describes options available for increased participation in leisure activities that may help enhance social interactions and increase community integration for the young adult with TSC. Information on relationships, sexuality, family planning and genetic counseling are included in this section. Also included are resources for adaptive clothing and equipment, beauty aids and cosmetics.

Section Eight: End of Life Issues addresses some of the issues that people with TSC and their families may face at or near the end of life. Topics addressed include hospice care, grief, bereavement and other end of life issues.

Section Nine: Contact Information for National Disability and Related Organizations—Includes headquarter office contact information (address, phone, Web address, etc.) for the major national nonprofit, disability, advocacy, and support organizations. Many of these organizations provide information and resources specific to a disability such as autism or epilepsy. Local chapters and affiliates of these organizations are usually the best source for information about the types of support and programs available to people with disabilities in your community.

Appendix 1: Telephone and Contact Log—This form may be helpful in keeping track of the information you receive when contacting different organizations.

Appendix 2: Constituent Satisfaction Survey—Share your thoughts with us about this guide. Use the survey to let us know how we can improve future editions of the guide.

Throughout this guide, contact information is listed for many different organizations and programs. *When available*, phone numbers (voice and fax numbers), TTY/TDD (for the hearing impaired) numbers, and Web site and e-mail addresses are provided.

DISCLAIMER: The information contained in this guide is provided for general information purposes only. Programs and services will vary widely by location! Resource information included in this guide (contact information, Web sites, etc.) was current at time of printing. However, due to the number of organizations and programs listed in this guide, some of this information will undoubtedly change over time.

If the Web site address listed doesn't take you to the correct site, we suggest that you use one of the Internet search engines such as Yahoo (www.yahoo.com) or Google (www.google.com) and search by the organization name.

Please also be advised this guide is not intended to provide specific financial, legal, medical or other advice. Readers are strongly encouraged to consult with the professionals in the appropriate areas (lawyers, financial planners, doctors, etc.) before making any major decisions. The TS Alliance does not promote or recommend any type of program or service, but provides this guide as a tool to help families and individuals identify the types of programs available in their area.

Section One: Legal Rights under Disability Law

ADA, IDEA 2004 and Section 504

The three most important laws that will impact children with TSC and their families are the *Rehabilitation Act of 1974 Section 504 (Section 504)*, *Americans with Disabilities Act (ADA) of 1990*, and the *Individuals with Disabilities Education Act 2004 (IDEA)*. This section of the Life Stages Guide focuses primarily on these three laws. Other disability laws are also briefly described in this section.

ADA 1990

The ADA prohibits discrimination against individuals with disabilities in employment, housing, education and access to public services (transportation, housing, etc.).

How does the ADA define “disability?”

To be protected by the *ADA*, a person must have one of the following:

- 1) A physical or mental impairment that substantially limits one or major life activities of the individual.
- 2) A record of such impairment.
- 3) A perception by others as having such an impairment.

The ADA further requires that reasonable accommodation be made so as to provide individuals with disabilities equal opportunities. Federal agencies and departments charged with enforcing the ADA include the Equal Employment Opportunity Commission (EEOC) and the Department of Justice. Specific titles of the ADA (I-IV) address specific rights with regard to employment, state and local government activities, public transportation, public accommodations, and telecommunication relay services. States may pass disability statutes so long as they are consistent with the ADA.

IDEA 2004

Under the Individuals with Disabilities Education Act 2004 (IDEA), public schools are required to make available to all eligible children with disabilities a free appropriate public education (FAPE) in the least restrictive environment to their individual needs. IDEA requires public school systems to develop appropriate Individualized Education Programs (IEPs) for each child. The specific special education and related services outlined in the IEP reflect the individualized needs of each student. Each student’s IEP must be developed by a team of knowledgeable persons, which includes the child’s teacher, parents/caregiver, special education representative and other individuals as requested by the parent or other agencies involved. The IEP must be reviewed at least annually. To learn more about your rights under IDEA, the following publications may be downloaded from the “School Issues” section of the TS Alliance Web site at www.tsalliance.org:

- *What is an IEP?*
- *Parent’s Rights: Understanding the Individuals with Disabilities Education Act 2004*
- *What is a Section 504?*

Section 504

The term “504” comes from the Rehabilitation Act of 1973 Section 504, which is a civil rights law that states a child with a disability is entitled to a free, appropriate public education equivalent to a child without a disability. This law ensures children with disabilities do not face barriers to receiving an education. Unlike the Individuals with Disability Education Act (IDEA), which is an education law that mandates a child receive the necessary educational supports and services to progress in the general education curriculum, the intent of 504 is to prevent discrimination in not providing equal access to education. Section 504 is more about accommodations than special education services.

Many children with TSC do not need special education and support services; they just need a few accommodations so they can participate in school activities, such as:

- Seizure crisis plan
- Air-conditioned classroom
- Medication administered by an adult
- Adult aide on the bus to help if seizures occur
- Allow time to make up work when absent for medical reasons
- Adapt activity level for recess, physical education class

The above are a few examples of accommodations that can be implemented on a 504 Plan. It is important to have a formal plan in place to make sure there is consistency and follow through. A 504 Plan is a good way to make everyone accountable for the support and safety of a child with TSC at school.

Unlike an Individualized Educational Plan (IEP), where children do not qualify for services unless they meet a certain criteria or category, a Section 504 can be provided if the child’s disability affects his or her access to learning. Meaning the student is entitled to accommodations under 504. Also, unlike IDEA that stops services at graduation, 504 continues on through college and beyond because it is a civil rights law. Any child who has an IEP in school is also covered under 504, so even though your child will no longer have an IEP, he/she will be eligible for protection under 504 in college. To learn more about Section 504, download the booklet entitled “*What is Section 504?*” from www.tsalliance.org under “School Issues.”

Transition Services und IDEA

The law states: § 300.43 Transition services. (a) Transition services means a coordinated set of activities for a child with a disability that—(1) Is designed to be within a results oriented process, that is focused on improving the academic and functional achievement of the child with a disability to facilitate the child’s movement from school to post-school activities, including postsecondary education, vocational education, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation; (2) Is based on the individual child’s needs, taking into account the child’s strengths, preferences, and interests; and includes—(i) Instruction; (ii) Related services; (iii) Community experiences; (iv) The development of employment and other post-school adult living objectives; and (v) If appropriate, acquisition of daily living skills and provision of a functional vocational evaluation. (b) Transition services for children with disabilities may be special education, if provided as specially designed instruction, or a related service, if required to assist a child with a disability to benefit from special education.

This law is very specific in what should take place when a student is transitioning from school to the community. In the past children with disabilities were graduating without the necessary skills to become independent. There are five areas in which school systems continue to fall short:

1. Not contacting the necessary service agencies to help students transition from school to community

2. Not involving the student in the transition process
3. Not developing a transition plan
4. Not following through with the district obligations
5. The lack of appropriateness of the transition plan developed

The school district must ensure an effort to bring agencies that may provide or pay for transition services to be part of the development of the transition plan on the IEP. This means the school district must make and document efforts to involve community agencies such as:

- Post-secondary education and training agencies
- Mental health agencies
- Human services agencies
- Social security agencies
- Housing agencies
- Transportation agencies

The school has a responsibility to link parents and students with agency resources to help students transition successfully. Schools are obligated to provide experiences based on the individual needs of the student. They must also take into consideration the interests of the students. Transition is an outcome-based process. It prepares a student to transition into post-secondary education and/or training, which will assist students to become as independent as possible within the community.

Transition should include goals in the areas of education/training, employment experiences, and independent living skills (if appropriate for that student). If the IEP team decides a student does not need goals in any of these areas, it must address why on the IEP.

IDEA 2004 §300.320(a)(7)(b)(1)(2) specifies that the IEP for every student who turns 16 years (or younger if appropriate) must include measurable post-secondary goals and the transition services needed to assist the student in reaching those goals.

The school district is required to provide transition services to every student age 16 on an IEP without exception. The State Department of Education is required to make sure the transition happens. The goals set up in the transition plan are created to include community-based programming that allows the student to try out skills, educational as well as fictional, in a real-life setting. The school district is not required to ensure that each goal of employment, post-secondary options, and independent living be achieved. But, it is obligated to provide programming intended to provide benefit to students individually. The law is intended for the transition plan to provide a variety of school and community experiences, school programs designed to assist students to successfully meet social and vocational goals, and graduations requirements. To learn more about transition go to www.tsalliance.org and click on “School Issues,” then go to publications to download the publication: *Transition from School to Community*.

The Family and Medical Leave Act (FMLA) allows covered employees to take up to 12 weeks (480 hours) of UNPAID leave if they have a serious health condition or need to care for an immediate family member (parent, son, daughter, spouse) with a serious health condition. The Act applies to any company that has 50 or more employees. Employees are eligible for leave if they have worked for the company for at least 12 months and have worked at least 1,250 hours in the prior 12 months.

In addition to the federal statutes described above, an individual may also have co-existing legal protection through the laws of their state. Contact your State Law Library for additional information about your state's disability laws and statutes.

Other Disability Related Laws

Additional federal statutes that prohibit discrimination against people with disabilities include the *Fair Housing Act*, the *Rehabilitation Act*, the *Air Carrier Access Act*, and the *Telecommunications Act*. Under the *Fair Housing Act*, it is unlawful to discriminate in any aspect of selling or renting, by denying housing because of an individual's disability. Owners are further required to make reasonable exceptions in their housing policies so as to afford equal housing opportunities to those with disabilities.

The *Rehabilitation Act* prohibits discrimination on the basis of disability in programs conducted by federal agencies, in programs receiving federal financial assistance, in federal employment, and in the employment practices of federal contractors. Its standards mirror those of the *ADA*.

Under the *Air Carrier Access Act*, air carriers (including major airlines) are prohibited from discrimination against qualified individuals with disabilities. The rules are designed to minimize the special problems that people with disabilities face as they negotiate their way through the nation's complex air travel system to and from their destination. More information regarding air travel and air travel resources can be found in the Community Integration (Travel) section of this guide.

The *Telecommunications Act* requires manufacturers of telecommunications equipment and providers of telecommunication services to ensure that such equipment and services are accessible to and usable by persons with disabilities. Telecommunication Relay Service (TRS) enables telephone conversations between people who are not hearing impaired and those who are. In addition, some local phone service providers supply basic discounted plans to people with disabilities; however, this is not mandated by law, so individuals may need to ask about availability and eligibility in their area. Contact the customer service or business office of the phone company that provides service to your area (e.g., Verizon or AT&T) to learn more about the availability of these plans.

For a detailed description of disability rights laws, visit the Disability Rights Section, Civil Rights Division of the U.S. Department of Justice Web site at <http://www.usdoj.gov/crt/ada/cguide.htm>. This summary (15 pages when printed) features descriptions of all disability laws and federal agency contact information.

Disability Law Resources

General Disability Rights Information ADA Question & Answer Booklet,	<i>ADA</i> Information Line (800) 514-0301 (voice) (800) 514-0308 (TTY)
---	---

<p>ADA Title II – Questions and Complaints about Public Transportation Services (city buses, subways, para transit services, etc.).</p>	<p>Office of Civil Rights, Federal Transit Administration</p> <p>Dept. of Transportation East Building 1200 New Jersey Avenue, SE Washington, DC 20590 (866) 377-8642 (202) 366-4043 TTY (800) 877-8339 www.ada.gov/publicat.htm</p>
<p>ADA Title II – Accessing state and local government programs, services, and activities (public education, employment, transportation, recreation, health care, social services, etc.).</p> <p>ADA Title III Public Accommodations – Provided by businesses and nonprofit service providers.</p>	<p>Disability Rights Section-Civil Rights Div. U.S. Department of Justice P.O. Box 66378 Washington, DC 20035-6738 (800) 514-0301 (voice) (800) 514-0383 (TTY)</p>
<p>ADA Title IV Telecommunications Relay Services (TRS) – Ensures people with disabilities who use telecommunication devices have access to these services 24 hours a day. The Disabilities Issues page on their Web site provides information about TRS, video description and closed captioning.</p>	<p>Federal Communications Commission Consumer & Governmental Affairs Bureau 445 12th Street, SW Washington, DC 20554 (888) 225-5322 (voice) (888) 835-5322 (TTY)</p>
<p>Wrightslaw – Provides parents, advocates, educators and attorneys with information about effective advocacy for children with disabilities.</p>	<p>Pete and Pam Wright P.O. Box 1008 Deltaville, VA 23043 www.wrightslaw.com</p>
<p>SpecialEdLaw.net – This Web site is for parents of special needs children as well as attorneys, teachers, and others who need information relating to Special Education law.</p>	<p>www.specialedlaw.net/index.mv</p>
<p>The Fair Housing Act – Publications and information.</p>	<p>Office of Housing and Urban Development Customer Service Center (800) 767-7468 (voice) (800) 877-8339 (TTY) www.hud.gov/offices/fheo/library/index.cfm</p>
<p>Family and Medical Leave Act – Provides detailed information about the act and can be printed from the Web site</p>	<p>U.S. Department of Labor Frances Perkins Building, 200 Constitution Ave., NW, Washington, DC 20210 (866) 487-2365 www.dol.gov/whd/fmla/</p>

<p>ADA Technical Assistance CD-ROM - This free CD-ROM contains a complete collection of the U.S. Department of Justice ADA materials, including: regulations, architectural design standards, and technical assistance publications.</p>	<p>U.S. Department of Justice ADA Information Line (800) 514-0301 (voice) (800) 514-0383 www.ada.gov/cdorderform/adatacd1.htm</p>
<p>American Bar Association – Consumer’s Guide to Legal Help on the Internet provides general legal information, how to get legal assistance, how to get pro bono (free) assistance and information about solving simple legal problems on your own. For general questions, contact the Service Center. Please note that legal assistance is <i>not</i> provided to individuals. But it is a good starting point for basic legal information.</p>	<p>ABA Service Center 740 15th Street, N.W. Washington, DC 20005-1019 (202) 662-1000 www.abanet.org/legalservices/findlegalhelp/home.cfm</p>
<p>Disability Rights Education and Defense Fund Inc. (DREDF) is a national law and policy center dedicated to protecting and advancing the civil rights of people with disabilities through legislation, advocacy, and education of persons with disabilities, parents of children with disabilities, advocates and lawyers. Publications are available that address various disability laws. Fees for publications range from \$10.00 to over \$100.00 per item, with discounts offered to people with disabilities.</p>	<p>DREDF-Main Office 2212 Sixth Street 2212 Sixth Street Berkeley, CA 94710 (510) 644-2555 dredf@dredf.org www.dredf.org/</p>
<p>The Council of Parent Attorneys and Advocates (COPAA) – This organization of attorneys, advocates, and parents was established to improve the quality of legal assistance for parents of children with disabilities. The site provides resources, discussion lists, advocacy tools, and information about special education policy.</p>	<p>COPAA 1321 Pennsylvania Avenue, SE Washington, DC 20003-3027 www.copaa.org/</p>
<p>The Paper Chase: Managing Your Child’s Documents Under the IDEA, written by a lawyer specializing in special education and disability law, this article helps parents organize the large amount of paperwork generated as a result of having a child with special needs. It describes which documents are important to keep and how these documents can help you tell your child’s story accurately</p>	<p>Robert K. Crabtree www.wrightslaw.org</p>

<p>to others (such as an evaluator, advocate or lawyer) to get the services and assistance he or she needs. Articles can be downloaded from the Internet for free.</p>	
--	--

Pro Bono (Free) Legal Assistance

Disability law centers, state and county bar associations, and legal aid programs may be able help individuals who need legal aid but can't afford to pay for it. Some programs serve some individuals in special circumstances (such as people with disabilities) regardless of their ability to pay. To find the Disability Law Center for your state, check the blue (state government) pages of your phone book (e.g., Maryland Disability Law Center). To find the local Bar Association for your area, check the Business Section in the white pages of your local phone book (e.g., Bar Association of Smith County). In addition, the American Bar Association Web site (listed in the chart above) offers a nationwide directory of pro bono programs and a state-by-state directory of legal aid and legal services programs.

DISCLAIMER: *The information in the legal section of the guide is provided as a service of the TS Alliance. It is meant to provide a brief overview of the major disability laws and how to obtain basic legal information. It is not meant to serve as a substitute for informed legal advice. For additional information, consult with a lawyer who specializes in disability law.*

Section Two: Transition Planning

Transition services are intended to prepare students to make the transition from the world of school to the world of adulthood. The importance of early transition planning cannot be underestimated. Throughout a child's public school years, the school district is responsible for providing the services to the student with disabilities to become a successful learner. Providing these services is mandated by the *IDEA 2004*. The transition from school to the adult system can be complicated. Rather than dealing with one agency (the public school system), the student with a disability and his family will work with many agencies (public and private) that provide these services. However, unlike services provided while the child is still under the jurisdiction of the public school system, there is no absolute entitlement to those services. Families will likely encounter different, more restrictive eligibility criteria, long waiting lists, and possibly a lack of funding that may keep a young adult from receiving services after leaving school.

Sections Five, Six and Seven cover the specifics with regard to each of these areas. This section focuses on the process of transition planning, which pulls these pieces together. Transition services and activities should provide young adults with disabilities the necessary skills to make informed choices and decisions, and gain full inclusion in society in all aspects of their lives.

An effective transition plan has the following components:

- Is designed within an outcome-oriented process, which promotes movement from school to post-school activities,
- Is based upon the student's individual needs,
- Includes instruction, related services, community experiences,
- Begins by the age of 16 or earlier if the IEP Team decides it is appropriate, and
- Contains transition goals that move the student from school to community

Transition Checklist

The following checklist of transition activities is provided as a tool that you and your son or daughter may wish to consider when preparing transition plans with the IEP team. Your child's skills and interests will determine which items on the checklist are relevant:

- Build your vision based on your child's strengths and abilities. Together, you and your child can identify the activities he or she enjoys.
- Help your child develop his/her own vision of his future. Allow your child to dream, even if those dreams may sound unrealistic.
- Identify your child's personal learning styles and the necessary accommodations to become a successful learner and worker.
- Identify your child's career interests and skills.
- Explore options for post-secondary education and admission criteria.
- Identify and begin teaching skills to your child necessary to becoming a fully participating member of a household.

- Identify your child’s interests and supports needed for future living arrangements.
- Teach your child to effectively communicate his or her interests, preferences and needs.
- Prepare your child to be able to explain his disability and the accommodations he needs.
- Teach and encourage your child to practice using informed decision-making skills.
- Investigate assistive technology tools that may increase your child’s community participation and employment.
- Broaden your child’s experiences with community activities and encourage him or her to expand his or her friendships.
- Encourage your child to learn and practice using public transportation outside of the family.
- Teach your child to learn and practice good grooming and personal hygiene skills.
- Teach your child money management and other necessary skills and support needed in this area.
- Acquire an identification card for your child and teach him or her to communicate personal information.

Investigate which benefits your child will be eligible for (Social Security, Medicare, etc.) upon reaching adulthood and apply for these as soon as possible. Identify and teach your child skills needed for independent living. With your child’s IEP team, determine whether your child will graduate with a state high school diploma, a state high school certificate at age 21, or a state high school diploma prior to age 21.

Individual Transition Team Members

The team will include the different people who will work with your child during the course of the school day. Typically, transition planning is handled by members of the IEP team and community agencies that can provide support to the student’s transition planning. It is important to include a variety of people who will bring their unique perspectives to the planning process. Other members include those typically on the IEP team (special education and general teachers, social workers, case managers, speech therapists, administrators and others as appropriate) plus transition specialists, who may be informed about resources and adult services in the community. The team draws upon the expertise of the different members to make recommendations for the student.

The student and his or her family are core members of the team. It is up to the parent to keep the team focused on the goals and on finding the appropriate services and developing a plan that will benefit the youth with disabilities. When the purpose of the IEP meeting is to discuss transition, the student must be invited to attend. If the student is physically or logistically unable to attend the meeting, then the school must take steps to make sure that the student’s preferences and interests are considered.

In addition, representatives who traditionally provide post-high school services should be involved. Within this group, not every representative will attend every meeting. However, their attendance is strongly encouraged when discussing the part of a student’s transition plan related to their expertise or services. The people included in the planning process will depend on the unique needs of your child. Each family will not use or need every type of agency or service.

However, some examples of the types of agencies that might be represented at your child’s transition planning meetings include:

- Vocational Rehabilitation (VR) Agency
- Developmental Disabilities Agency
- Independent Living Centers
- Social Security Administration (SSA)
- Department of Labor Job Services Agencies
- School to Work Opportunities Act (STWOA) Programs
- Community Representatives (such as religious leaders, directors of county recreation programs, etc.)
- Local Disability Organization Representatives
- Adult Education Representative
- Potential Employers

This is only a partial list of the types of agencies and service providers that may participate in the actual planning process or serve as a consultant to the team for specific areas. Families need to be creative in searching for services that may be appropriate for their child as he/she moves into adulthood; such identified service providers should be included in the planning process where appropriate.

Whether a student has a disability or not, the greatest challenge for parents of post-secondary students is learning when and how to be supportive while still encouraging self-determination and independence.

Information for this section of the guide was gathered from *Transition from School to Community*, found under “School Issues” at www.tsalliance.org.

Transition Resources

<p>Transition From School to Community—This publication provides a easy to understand guide in transition planning and can be down loaded free of the TS Alliance Web site.</p>	<p>TS Alliance 801 Roeder Rd. Suite 750 Silver Spring MD, 20910 www.tsalliance.org (800) 225-6872</p>
<p>Transition Planning for Success in Adult Life, Parent Brief-Winter 1996, (4 pgs).</p>	<p>National Transition Network http://ici2.coled.umn.edu/ntn/pub/briefs/tplanning.html</p>
<p>Transition Planning: A Team Effort, NICHCY Transition Summary #TS10, 1999 (22 pgs). Provides information on how students, families, school personnel, and service providers can work together to help students make a smooth transition. This document focuses on creative transition planning and services that use all the resources that exist in communities, not just the agencies that have traditionally been involved.</p>	<p>National Information Center for Children and Youth with Disabilities (NICHCY) P.O. Box 1492 Washington, DC 20013 (800) 695-0285 (voice/TTY) (202) 884-8200 (voice.TTY) nichey@aed.org www.nichcy.org</p>

<p>Travel Training for Youth with Disabilities #TS9, this transition summary (also available from NICHCY) focuses on training people with disabilities to use public transportation safely and independently. It describes the components of a successful training program, specific skills that travelers need to ensure their safety and issues that arise with specific disabilities (such as physical or cognitive impairments).</p>	<p>National Information Center for Children and Youth with Disabilities (NICHCY) P.O. Box 1492 Washington, DC 20013 (800) 695-0285 (voice/TTY) (202) 884-8200 (voice.TTY) nichcy@aed.org www.nichcy.org</p>
<p>The Adult Life Stages Guide—Written by parents for parents of young persons with disabilities. This guide is particularly helpful for students who will be making the transition from high school to adult life in the not too distant future.</p>	<p>Southeastern Regional Resource Center (SERRC) P.O. Box 244023 Auburn University Montgomery Montgomery, AL 36124 edla.aum.edu/serrc/fulllife/fulllife.htm</p>
<p>Transition: Planning for Life After High School, published by the Autism Society of America, this 4 pg. guide provides a good overview of the transition planning process. Information presented can be applied to all disabilities.</p>	<p>Autism Society of America 7910 Woodmont Avenue, Suite 300 Bethesda, MD 20814-3067 (301) 657-0881 (voice) (301) 657-0869 (fax) www.autism-society.org</p>
<p>The Road Ahead: Transition to Adult Life for Persons with Disabilities, (2002) This book provides strategies and ideas for improving the lives of people with disabilities, from assessment and instructional strategies, to career development, supported living and postsecondary education. Cost: \$32.95.</p>	<p>Training Resource Network P.O. Box 439 St. Augustine, FL 32085-0439 (866) 823-9800 (voice) (904) 823-3554 (fax) customerservice@trninc.com www.trninc.com/roadahead.htm</p>

Section Three: Life and Financial Planning

This section of the *Young Adult Guide of the Life Stages Program* provides an overview of the various life and financial planning issues related to having a disability or having a child with a disability. Some of the decisions that will need to be made may include: determining whether guardianship or some other legal option is the best for your child; how to access federal benefits; how to select private insurance when there is a pre-existing condition (a medical condition not covered by insurance); or how to assist a person with a disability who is capable of managing all or a portion of their money matters in a way that provides the right balance of independence and safeguards to ensure against those resources being exploited or wasted.

This section is organized into four subsections that address these areas and other factors to be considered by a young adult with a disability and the family when addressing financial concerns:

1. **Life Planning:** life and financial or estate planning, guardianship, trusts, wills and resources
2. **Public Disability Benefits Programs:** SSI, SSDI, Medicaid, Medicare and resources
3. **Private Insurance Considerations:** what to consider when selecting insurance, pre-existing conditions, where to get help in finding insurance, and insurance resources
4. **Daily Money Management:** tools and resources

Please be aware this section of the guide provides basic resource and information only and is not meant as a substitute for legal or financial planning advice. Agencies and organizations listed as resources may be for-profit, non-profit, or may operate as social service agencies, health organizations or privately held business concerns. Be sure to investigate an organization before investing time or money in it. Individuals with TSC and their families should work with a lawyer and/or a certified financial planner experienced in special needs planning as appropriate before making any financial or legal decisions. Prices of resources cited were current at time of printing. However, we recommend that you contact the organization directly for current price, content and availability of resources prior to ordering.

Life Planning

Life planning for people with disabilities and their families encompasses more than just financial planning. While the financial component represents a large portion of planning for the future, successful life planning encompasses many steps that will help ensure that the best interests of an adult with a disability are represented after their family members are gone. The recommended steps in life planning are listed below:

*Recommended Steps to Life Planning**

1. Determine the needs of the individual with a disability in the following areas: vocational, housing, medical, educational, recreational, legal, daily living, emotional needs and other concerns. Both present and future needs should be carefully considered. Where needed, consider how much family members, friends and others are willing and/or able assist an individual now and in the future. Life planning professionals (who, for a fee) can help with this step and others in this checklist. To the maximum extent possible, involve the adult with TSC in developing and implementing each of the life planning steps.
2. Write a "Future Care Plan," also known as a letter of intent. This describes your hopes and expectations in writing and provides guidance for future care providers.

3. Recommend future advocates or guardians: people who will visit your child (as appropriate) and make sure your wishes are carried out.
4. Create a family financial plan that addresses the needs of the person with special needs while also providing for the financial objectives of the other family members.
5. Select a combination of resources that will provide adequate funds for that person's lifetime. This will include government benefits, family assistance, settlements, inheritances, savings, investments and life insurance.
6. Work with an attorney who specializes in *special needs estate planning*. Have the proper wills and special needs trust established so resources now and in the future protect government benefits and provide supplemental income.
7. Choose a number of successor trustees from relatives and friends or select a corporate trustee to manage the trust funds in the future.
8. Meet with all persons involved to review the plan.
9. Store the life plan, financial plan and other legal documents in a safe place, preferably in a binder or folder that holds all the documents together.
10. Review the plan at least once a year. Update the future care plan, financial plan and legal documents as necessary.

**Source: Life Planning Institute of New Jersey, LLC, Oakland, NJ*

Financial and Estate Planning

Estate planning is important for determining what resources will be available to an adult family member with a disability after his or her family is gone. A person's estate is what he/she owns or possesses, such as a home, car, money in savings or checking accounts, stocks and bonds, and other personal possessions. Estate planning is the process of planning how these possessions will be divided and distributed when the person dies. Individuals and their families need to be aware that an inheritance may cause an individual with disabilities to become ineligible to receive government benefits. Any inheritance of \$2,000 or more will jeopardize eligibility for all needs-based government benefits.

In addition, other financial needs-based benefits that the family may want to protect in the estate plan include food stamps, public housing and legal aid. Eligibility requirements for these benefits vary from state-to-state.

The nature and severity of an individual's disability will affect the nature of the estate plan that must be developed. If the disability does not affect the person's ability to manage his or her financial affairs, the primary influence on planning the estate should be whether that individual receives, or may one day need to depend on, government benefits such as Supplemental Security Insurance (SSI), subsidized housing, personal attendant care or Medicaid.

If an adult with a disability is *not* eligible for or is not receiving government benefits, families may be able to leave their adult child money outright as they would to someone who did not have a disability. But there is still the need to plan for that individual's future. If there are concerns that the adult with a disability may not responsibly handle an inheritance, then utilizing a trust is likely the best way to plan for the future.

For an adult with a cognitive disability or mental illness, the need to create a special estate plan is more obvious. Mental illness and cognitive disabilities often impair a person's ability to manage his or her own financial affairs, while simultaneously increasing financial need. As a result, steps must be taken to ensure that there are assets available after the death of the parents to help the adult with disabilities, while also protecting the assets from his or her inability to manage them. Future legal planning falls into three main categories: guardianships, trusts and wills.

Guardianships

A guardianship, or conservatorship depending on the state, is a legal action that grants an adult legal power to make decisions for another person. It is a legal means of protecting adults who cannot take care of themselves, make decisions in their own best interest, or handle his/her assets. When the court determines a person is incapable of handling either his/her personal and/or financial affairs and appoints a guardian, the person with a disability is referred to as the guardian's "ward." Guardianships are supervised by the court.

Generally, the natural guardianship of a minor child terminates when the person turns 18 or, in some states, upon marriage if the individual marries before age 18. It is important to realize that, legally, an adult is presumed competent unless otherwise deemed incompetent by a court of jurisdiction after a competency proceeding. In other words, once the child reaches the age of 18, the parent is no longer the child's legal guardian regardless of a disability.

Some young adults with disabilities may not be able to give reasoned and well-informed consent when making a decision. To protect them from people who may exploit their inability to make informed choices, individuals with disabilities and their families need to familiarize themselves with the various legal options available to them. Depending on the severity of the person's disability, setting up a guardianship may be an option. However, bear in mind that guardianships can be relatively inflexible as compared to less intrusive options such as trusts (described later in this section). When considering the different types of financial planning tools that are available, families will need to consider some of the following questions:

- Is the person with TSC able to work? If so to what extent?
- Is the individual able to manage small amounts of money on a monthly basis?
- Does the individual need residential care now or in the future?
- Can the individual live with a friend, relative or group home in the future?
- What are the estimated costs of these arrangements?
- What are the person's recreation, leisure and social needs?
- Does the person's disability involve the possibility of deteriorating health and more involved health care needs and costs?
- What will the transportation costs for this individual be now and in the future?

The following is a brief description of the types of guardianships that are generally available.

- A **Guardian of the Person** is responsible for monitoring the care of the ward. The guardian may, but does not have to, be a relative such as a brother, sister or cousin. It may be a good friend of the family. The guardian need not use his/her own money for the ward's expenses, provide daily supervision of the ward, or even live with the ward. However, the guardian must attempt to ensure that the ward is receiving proper care and supervision, and the guardian is responsible for decisions regarding most medical care, education and vocational issues. For highly unusual decisions not anticipated at the time of the original guardianship hearing, the guardian should ask the court for instructions. The court must make decisions involving intrusive forms of treatment, such as administration of anti-psychotic medication, sterilization, and the withdrawal of life-

prolonging treatments. Generally, the guardian is required to report annually on the status of the ward.

- A **Guardian of the Estate** or **Conservatorship** should be considered for persons with disabilities who are unable to manage their finances and who have income from sources other than benefit checks or have other assets and/or property. The guardian or conservator is responsible for handling the ward's financial resources but is not personally financially responsible for the ward from his or her own resources. The guardian or conservator must file an annual accounting of the ward's funds with the court.
- A **Limited Guardianship** may limit the guardian's decision making to certain areas, such as decisions about medical treatment, to allow the ward to continue making his/her own decisions in all other areas. The benefit of a limited guardianship is that the guardian's responsibilities can be tailored to fit the ward's special needs in the least restrictive manner. Further, under a limited guardianship, the ward has not been declared incompetent. A sibling or another concerned family member may be able to make the decisions in only those areas where help is needed.
- A **Temporary Guardian** or **Conservator** may be appointed in an emergency situation when certain decisions must be made immediately. Generally, a permanent guardianship or conservatorship must be requested along with the temporary appointment. State law dictates the duration of a temporary appointment.

A *letter of intent* is an important accompanying document for guardianships. A letter of intent describes the person's disability history, his/her current status and what future needs may be. This document is important as it provides guidance to the trustee with regard to the family's wishes for the family member with TSC in the future. To the maximum extent possible, involve the adult in the writing of this letter, so that the letter truly represents his or her interests. Completing the letter of intent should be done as soon as possible and updated regularly to reflect any changes in a person's health status or situation. This ensures the letter is ready at any moment, should a parent become ill, become disabled or die. Although it is not legally binding, it provides direction for the person(s) who will care for the adult with special needs in the future.

Guardianships and Moving to Another State

When a ward moves to another state, the guardian is required to open up a guardianship of the person or estate in the new state. Once the guardianship has been opened in the new state, the guardianship in the home state will be closed. The guardian will be required to give the court a final status report, which includes information regarding where the ward is living, with whom he or she is living, and what services he or she is receiving or is anticipated to receive in the new state. If a guardianship of the estate is in place, the guardian will be expected to give a full and final accounting. Furthermore, some states require that the guardian get permission from the court prior to moving the ward to another state. If the guardian is the parent and the parent moves, the court will usually ratify the move after it has taken place. If the guardian is not the parent, a court that requires prior approval for all out of state moves may sanction the guardian for failing to obtain permission in advance.

Families who are considering moving should inquire with their local probate court as to whether specific court permission is required. This is especially important when parents die and a sibling becomes the guardian and wants to move his or her brother or sister to his or her home state to be closer to them. Please note that minors whose parents (either natural or adoptive) are their guardians are not "wards" of the state. The term "ward" is specific to someone who is under the supervision of the probate court and usually refers an adult with a disability, but could refer to a minor child where the parent is not serving as guardian.

Alternatives to Guardianships

Parents, family members, and/or other potential caregivers must carefully consider the young adult's individual circumstances, including strengths and weaknesses, needs and interests, before deciding to seek guardianship. If the person is capable of making some but not *all* decisions, some of the less intrusive alternatives to guardianship listed below may be considered:

- A **Representative Payee**, often times a family member, friend or nonprofit agency, can be named to manage the funds of a person with a disability who receives government benefits checks, such as SSI and SSDI. Benefits checks are sent to the representative payee who spends the funds for the benefit of the individual with the disability. The representative payee has authority only over income from the particular check(s) for which she/he is payee. In this situation, a person with a disability would still make *personal* decisions.
- A **Durable Power of Attorney for Property** is useful for individuals with mild or moderate disabilities and who are capable of choosing another person to handle their money. The power of attorney (POA) is a legal document that grants one person the legal authority to handle the financial affairs of another. If executed before incapacity, a "durable" POA continues the authority in the event the individual becomes disabled or incapacitated.

Individuals with TSC and their families need to be aware that many states have their own statutory form that must be completed when establishing a POA. Other states allow individuals to design their own unique POA. To learn more about POA requirements in your state, contact the state attorney general's office to ask about statutory POA, visit your public library, or consult with a local attorney.

There are advantages and disadvantages to using a Power of Attorney. The person with a disability still has the legal authority to make decisions. For example, they can commit to a contract that is not in their best interest and can be held to that contract. Also, the person can withdraw the POA at anytime and can remove the agent verbally or by the physical act of destroying the POA. Consequently, a person with a history of mental illness, or other severe disabilities, may, remove his/her agent at a time when an agent is most needed.

- A **Durable Power of Attorney for Health Care**, also known as a **Health Care Proxy**, should be considered for individuals who are disabled and who can make some, but not all, health care decisions. This is a legal document that enables a competent individual (the "principal") to designate a health care agent to make health care decisions should the individual become incompetent to make them. The health care agent can be permitted to make all health care decisions, including decisions about life-sustaining treatment, which may eliminate the need for a guardian.

The proxy or power of attorney must be a written document that is signed by the principal, age 18 or older, and properly witnessed. The principal may revoke the document at any time and in any manner that demonstrates specific intent to terminate the power. Depending on state law, the document generally becomes effective according to the principal's wishes or upon a doctor's written certification of the principal's incapacity. A benefit of this type of planning tool is that a POA is inexpensive, quick and can be accomplished without court intervention or permission. Another benefit is that the individual with a disability has someone to assist him or her with decisions yet has not lost any rights in the process.

- An **Appointment of Advocate and Authorization** is a customized power of attorney that allows an individual with a disability to designate an agent to advocate on his/her behalf with

administrative agencies such as the Department of Developmental Services, the Department of Human Services, Medicaid, local education authorities and any other state or federal agency from which an individual is receiving services. The agent can be granted specific powers, such as access to rehabilitation and school records, and has the authority to release records, approve placement or services, attend meetings and generally advocate on behalf of the individual who is disabled. The document must be in writing and notarized.

- A **Joint Bank Account** can provide a structure for adults who can manage their money with a higher level of independence. It allows for budgeting and money management. Direct deposit arrangements can be made with most banks for an adult's benefits checks, such as Social Security or SSI payments. In addition, a **permanent withdrawal rider** can be arranged with the bank, authorizing the bank to send a specified amount of money on a regular basis to a specified party, such as the landlord, or to the person with a disability for spending money.

As individuals and their families consider the different legal planning tools which will work best for their situation, keep in mind that the Social Security Administration (SSA) will only speak with a representative payee with regard to a person's benefit checks but *will not* speak with an agent who has been designated as a durable power of attorney for health care or with an advocate appointed for the individual with a disability.

These examples of the types of guardianships and alternatives to guardianship are not an exhaustive list. Additional options may be available depending on where you live. Sources for life and future planning materials may include your state Developmental Disabilities Council, Protection and Advocacy and Mental Health Service Agencies, Legal Service Agencies or commissions, and/or your local chapter of The Arc, as well as other resources listed in the chart on the next page. Many of these community agencies publish financial planning guides and other resources specific to their state.

Trusts

Trusts may be an appropriate alternative to the appointment of a guardian of the estate or conservatorship in some circumstances. A trust is a far more flexible and effective estate-planning tool than a guardianship. Trusts can also be an effective means of protecting an individual's eligibility for benefits while addressing the ongoing needs of that person.

A trust is a legal plan for placing funds and other assets in the control of a trustee for the benefit of an individual with a disability. A trust may also make it possible for the beneficiary to receive the advantage of extra income without losing valuable state and federal benefits. Trusts, for the benefit of a person who is disabled, should be established with the help of a lawyer experienced in wills and trusts and familiar with laws relating to government disability benefits. A trust set up without regard to the eligibility laws may disqualify a person from SSI, Medicaid, and other important benefits.

There are different types of trusts, but a **special needs trust** is a planning device that avoids the loss of assets meant to supplement the life of the adult with a disability. A special needs trust provides the individual with a disability with the goods and services he or she needs from an adequate share of an estate while still preserving that person's eligibility for government benefits, and the care and support these benefits can provide. Income from the trust should supplement, not replace, such benefits as SSDI or SSI.

For example, special needs trusts can be set up to pay for items such as special services, assistive devices, transportation, clothing, recreation activities, books, CDs, DVDs, and other personal items that would not be covered by government benefits. Families may wish to instruct the trustee with regard to shopping, running errands, and attending religious and social events. The trust may address the specific equipment

(e.g., lift-equipped vans) and service needs of the individual, such as personal aides or assistants. These might include someone who will help them get in and out of a vehicle or help bathe and dress them. The primary advantage a special needs trust offers over a direct gift or inheritance is that, if arranged properly, the assets in the trust do not actually belong to the beneficiary. However, the beneficiary has a beneficial interest in all of the assets held in the trust. The trust holds title to the property; therefore, any and all benefits received by the individual are not jeopardized.

Wills

A will declares how the estate will be distributed after the death of the parents and allows the parents or caregivers to select a guardian for their child with a disability upon their death. When creating a will, families need to be aware that individuals with disabilities who receive assets in excess of \$2,000 may jeopardize their continued eligibility for all needs-based government benefits. There may also be instances where the adult with TSC needs his or her own will. Prior advance legal planning will ensure the assets are distributed according to the wishes of the adult with TSC after his or her death.

Whatever life and financial planning tools are selected for the future, families should be sure to consult with qualified professionals before making any final decisions. Referrals from friends or your local bar association can be a good starting point for finding a lawyer who specializes in disability issues. Certified financial planners can be found through insurance companies or brokerage firms, such as Metropolitan Life and Merrill Lynch, which provide special-needs financial planning services. Some companies may also provide medical claims management as part of the services they offer. Contact information for Metropolitan Life and Merrill Lynch are listed in the chart below. Local offices can be found in your local Yellow Pages, usually listed under “Financial Planning Consultants.”

Every family and young adult with a disability has different needs, making it impossible to recommend a “one-size-fits-all” solution. Careful thought and consideration with professionals trained in life, legal, financial and estate planning will ensure that the needs of the young adult with a disability and their siblings will be provided for based on their parents’ wishes. It is a big decision. Be sure to explore all options and resources available before finalizing the plan. A well-written estate plan can minimize taxes, preserve eligibility for government benefits, and adapt to unforeseen circumstances.

Some individuals with disabilities may not need any help managing all or part of their financial affairs. Others may need additional support.

Daily Money Management

Utilizing money management tools, such as joint bank accounts, direct deposit of social security checks and automatic electronic bill paying, may provide the extra assistance an adult with disabilities may need to manage his or her financial affairs somewhat independently. In addition, arrangements may be made with the bank so the individual receives a certain amount of money from his or her account each month or week as needed for spending money.

Financial Management and Life Planning Resources

<p>Daily Money Managers (DMMs) provide a range of services that may include: balancing checkbooks, bill paying, preparing and delivering bank deposits. While not meant to take the place of social workers, lawyers or financial planners, etc. DMMs can provide money management services for people who may be unable to perform these</p>	<p>American Association of Daily Money Managers (AADMM) P.O. Box 8857 Gaithersburg, MD 20898-8857 (301) 593-5462 (voice) (301) 668-5760 (fax) Info@AADMM.com</p>
--	--

<p>tasks themselves. Fees vary, based on services provided.</p>	
<p>The Patient Advocacy Foundation acts as a liaison between the patient and their insurer, employer and/or creditors to resolve insurance, and/or debt crisis matters relative to their diagnosis through case managers, doctors and attorneys. The free, online “National Financial Resource Guidebook for Patients: A State-by-State Directory” includes resources that address housing, utilities, food, transportation needs and where to find interim funds to pay certain types of medical costs.</p>	<p>The Patient Advocacy Foundations 753 Thimble Shoals Blvd., Suite B Newport News, VA 23606 (800) 532-5274 (voice) (757) 873-8999 (fax) www.patientadvocate.org/patient.htm help@patientadvocate.org</p>
<p>Future Planning Resources – This resource list from The Arc includes government agencies, publications regarding estate planning, guardianship financial and future planning resources by state. It also includes an extensive bibliography of publications that address these topics.</p>	<p>The Arc of the United States Publications Department 1010 Wayne Avenue, Suit 650 Silver Spring, MD 20910 (301) 565-3842 (voice) (301) 565-3843 (fax) www.thearc.org/page.aspx?pid=2716&txtSearch=future+planning</p>
<p>Future Planning: Making Financial Arrangements with a Trust (Berkobien & Varnet). This article, written in Q&A format, describes the importance of careful financial planning and the types of trusts available.</p>	<p>The Arc of the United States Publications Department 1010 Wayne Avenue, Suit 650 Silver Spring, MD 20910 (301) 565-3842 (voice) (301) 565-3843 (fax) TheArc.org/faqs/trustqa.html</p>
<p>Special Needs Trust Helps Ensure Support, Care—Written by the law firm of Spain, Spain and Varnet.</p>	<p>Spain, Spain & Varnet, P.C. 33 North Dearborn St., Suite 2220 Chicago, IL 60602 (312) 220-9112 (voice) (312) 220-9261 (fax) www.altonweb.com/cs/downsyndrome/spaintrust.html</p>
<p>“After We’re Gone, A Program for the Lifetime Care of Persons with Disabilities”</p>	<p>Life Services for the Handicapped, Inc. 352 Park Avenue, South, Suite 703 New York, NY 10010 (212) 532-6740, (800) 995-0066 (voice) disabledandalone@aol.com</p>
<p>Estate Planning News Digest – Written by estate planners for family members planning for the needs of those with disabilities. This 23–pg. digest provides an overview of the process by which families can create specialized wills and trusts to</p>	<p>To access online: www.nichcy.org/pubs/newsdig/nd18.htm. Or contact, NICHCY at (800) 695-0285 and request their News Digest entitled, “Estate Planning” #NDI8.</p>

provide for their adult children in the future. It describes how to develop a special needs will, how to protect eligibility for government benefits, and how to ensure that future caregivers have an in-depth understanding of the person with a disability.	Merrill Lynch provides special needs financial services and programs for people with disabilities and their families. Services also include medical claims management for those with long-term health care needs.
Merrill Lynch provides special needs financial services.	Merrill Lynch Special Needs Financial Services (877) 456-7526 (Voice) www.totalmerrill.com/TotalMerrill/pages/SpecialNeedsFinancialServices.aspx
Metropolitan Life Insurance Company provides special needs financial services.	MetLife Special Needs Planning (877) 638-3375 (Voice) www.metlife.com/individual/investment-products/financial-planning/special-needs-planning.html#overview

Public Disability Benefits Programs

There are three ways a child can get benefits from Social Security or SSI. They are:

1. **SSI Benefits for Children**—These are benefits payable to the parents of children with disabilities under the age of 18 who have limited income and resources.
2. **Social Security Dependents Benefits**—These are benefits payable to children under the age of 18 as dependents of a parent who are collecting retirement or disability benefits from Social Security, or as survivors who had been collecting such benefits. Although children under the age of 18 who are eligible for these benefits might be disabled, the Social Security Administration (SSA) does not consider their disability to qualify them for dependent or survivor benefits. Note: A child can continue receiving dependents or survivors benefits until age 21 if he or she is a full time student.
3. **Social Security Benefits for Adults Who Have Been Disabled Since Childhood**—A Dependent’s benefits stop when the child reaches 21 if he or she is a full time student (see note on previous page). However, these benefits may continue to be paid (to the child or guardian) into adulthood if the child who has a disability qualifies. To qualify for these benefits, an individual must be the child or survivor of someone who is getting Social Security retirement or disability benefits and that individual must have a disability that began prior to age 22. Although most of the people getting these benefits are in their 20s and 30s (and some even older), the benefit is considered a “child’s” benefit because it is paid on the basis of a parent’s Social Security earnings record.

How Does My Child Qualify?

To qualify for disability benefits from the SSA, an individual must have a physical or mental condition that results in “marked and severe functional limitations.” The condition must be expected to last at least 12 months or result in the child’s death. The child must not be working at a job the SSA considers to be “substantial.” (In 2009, “substantial” was considered to be monthly earnings of \$1,650 or more).

How Do I Apply?

To apply for Social Security benefits, you may call and make an appointment with a SSA representative or visit your local Social Security office (listed in the blue pages of your phone book, under “Federal

Government”). Make copies of all documents you submit to the SSA. Parents should have their child’s social security number (SSN) and birth certificate when they apply. Be sure that the applicant’s name and social security number appear on each page or form you complete for your child. The SSA will often want to see original documents; however, it is advisable to retain the originals for your records and give them copies for their files. Bring dates and specific information regarding any treatments and services the applicant has received, as well as names, addresses and phone numbers of service providers (doctors, nurses, clinicians, etc.). List prescribed medication names, dosage amounts, and the name of the physician who prescribed the medication.

In addition, if your child is under age 18 and applying for SSI, the SSA will ask you to describe how your child’s disability affects his or her ability to function on a day-to-day basis. You will also be asked to provide copies of your child’s medical records to substantiate your claim. In addition, SSA may ask for names of teachers, day care providers, and family members who can provide information about how your child functions. School records should also be brought to the interview. The SSA may require additional information when applying for benefits. Contact your SSA office for details about the information they require.

The SSA assesses the effects of the condition or combination of conditions on your child’s ability to perform daily activities by comparing your child’s functioning to that of other children the same age who do not have impairments. To do this, they consider such questions as:

- What activities is your child able or not able to perform?
- Which activities are limited in comparison with those of same-age peers?
- What type and amount of help does your child need to complete age appropriate activities?

Ultimately, the SSA will consider evidence from a variety of sources with knowledge of your child’s condition and or his or her ability to function in determining whether your child is eligible for benefits. These sources include, but will not be limited to, the doctors, teachers, counselors, therapists, social workers and other professionals who treat and work with your child.

How Long Does it Take to Receive Benefits?

It is not uncommon for a claimant to wait 6-12 months for a decision on an application for disability benefits. Some of the disability categories in which the SSA can presume your child is disabled include mental retardation, cerebral palsy, and total blindness or deafness.

What If My Application is Denied?

When a decision is made that affects eligibility for benefits, the applicant will receive a letter explaining the decision. Applicants who disagree with a decision have the right to appeal it within 60 days. In counting the 60 days, the SSA presumes that you receive the letter five days after it was mailed, unless you can show that you received it later. If you do not appeal on time, your appeal may be dismissed. This means you may not be eligible for the next step in the appeal process and that you may also lose your right to any further review. You must have what the SSA determines as a “good reason” if you wait more than 60 days to request an appeal. If you file an appeal after the deadline, you must explain the reason you are late and request that the SSA extend the time limit. Representatives in your local Social Security office can explain this further and help you file a written request to extend the time limit. There are four steps to the appeal process:

1. Reconsideration – a written request to have a decision reviewed

2. Hearing by an Administrative Law Judge
3. Review by the Appeals Council
4. Federal Court Action (if no agreement is reached in steps 1-3)

Many claimants who receive denials file appeals. More than half of the claimants who request a hearing before an Administrative Law Judge will receive favorable decisions awarding benefits. It can take a great deal of time and effort to pursue an appeal. Perseverance and persistence are crucial. Every applicant has the right to be represented by an attorney or the person of his or her choice in any dealings they have with the SSA.

Medical Benefits (Medicaid and Medicare)

Medicaid is a federal-state assistance health care program that pays medical bills of people with low-incomes and limited assets. In most states children who receive SSI benefits qualify for Medicaid. In many states, Medicaid comes automatically with SSI eligibility. In other states, individuals must apply for it. The Centers for Medicare & Medicaid Services describes eligibility requirements at www.cms.gov/MedicaidEligibility/02_AreYouEligible_.asp. For more information about Medicaid, contact the Health Care Financing Administration (HCFA) at (800) 227-8922 or visit www.hcfa.gov/medicaid/medicaid.htm. Or contact your local Social Security office or your state or county social services office for more information.

Medicaid can be very important to an individual with disabilities because SSI and Medicaid eligibility is often necessary to receive other services. For example, group homes, community residences and some rehabilitation services are funded in several states by SSI or Medicaid benefits. Other benefits that may be covered include independent case management, individual and family support services (including respite and attendant care), vocational services, protection and advocacy services, and residential services. In some instances, after a certain dollar amount has been spent, some “buy-in” or “spend down” programs (they vary from state to state) offered through Medicaid may pay a portion of prescription or other medical costs regularly incurred by the person with a disability.

Given the range of services that are presently available through SSI and Medicaid and those which may become available in the future, it is important that families and their estate planners are aware of the financial-need requirements to qualify an individual for these two programs.

Even very wealthy families don't want to shut the door on eligibility for Medicaid and the safety net it provides. For instance, if an adult child is covered by a private health insurance, often the coverage in private policies for people with disabilities is very minimal. A child may currently have private medical insurance, but upon the death or retirement of the parent, his or her medical coverage may terminate.

Be aware that because Medicaid is administered by the states, there are 50 different interpretations of the federal guidelines. This is especially true in the issue of nursing homes, community-based services and long-term care.

OBRA '93 and Federal Medicaid Rules: In August of 1993, Congress passed the Omnibus Budget Reconciliation Act (OBRA '93), which changed the Medicaid rules pertaining to the transfer of assets and made it possible for a person who is disabled and under the age of 65 to remain eligible for Medicaid even if he or she receives money or assets in excess of \$2,000 from a direct inheritance, lawsuit, divorce settlement or other financial windfall, if that windfall is placed in a qualifying trust. The new law also contains another noteworthy exception that allows parents who are in need of nursing home care to transfer their assets to an OBRA “Payback” Trust for the sole benefit of a child or grandchild who is disabled.

Under the old law, a person could not qualify or re-qualify for Medicaid if he or she transferred assets to another person within a certain time frame of applying for Medicaid. This meant that persons with disabilities who rely on Medicaid, and parents of persons with disabilities in need of Medicaid-funded nursing home care had to spend down their assets to \$2,000 or wait 30 months to qualify for Medicaid.

Disadvantages of OBRA '93

- Congress extended the so-called “look-back period” (the look-back period begins from the date the individual is both in the nursing facility (or receiving home and community-based services) and he or she applies for Medicaid sponsorship in the cost of nursing facility care) for the transfer of assets from 30 months to 36 months for outright gifts and to 60 months for transfers to most trusts.
- Congress eliminated a person’s ability to disclaim any inheritance. OBRA '93 treats disclaimers as a transfer of an asset and a person will lose his or her eligibility for Medicaid if he or she disclaims an inheritance.

Advantages of OBRA '93

- A person with disabilities under the age of 65 who receives funds can remain eligible for Medicaid by transferring his or her funds to an irrevocable “OBRA '93 Payback Trust.” The trust is called a “payback” trust because if there are any funds left in the trust when the beneficiary dies, the state is entitled to be paid back for the full amount of Medicaid monies paid on behalf of the beneficiary.
- Parents who require long term nursing care can transfer their own funds to an OBRA Payback Trust for the sole benefit of a child who is disabled and become eligible for Medicaid without a waiting period. This exception is especially reassuring for parents who worry about what will happen to their son or daughter with disabilities if all of their money had to be spent on their own nursing home care.

These two exceptions carved out by OBRA '93 offer exciting planning opportunities for lawyers working with people with disabilities and their families in the areas of guardianship, personal injury, divorce, estate planning and elder law planning.

It is important that people with disabilities and their families not confuse the OBRA '93 “Payback Trust” with the special needs trust. Not *all* persons who are disabled can qualify for an OBRA '93 Trust. Please note that these trusts do not replace the need for families to write an estate plan (see the options discussed previously in this section of the guide) that enables a family member with a disability to benefit from an inheritance and remain qualified for government benefits. There is no “pay back” requirement in a traditional special needs trust. Consult an attorney for more information about OBRA '93 trusts.

Medicare is a federal health insurance program for people 65 or older and for people who have been getting Social Security disability benefits for two years. Because children, even those with disabilities, do not get Social Security benefits until they turn 18, no child can qualify for Medicare coverage until he or she is 20 years old.

Veterans Benefits

Benefits are available to individuals who are veterans or whose parents or spouses are veterans. Benefits may include monthly cash payments, education assistance, health care, and vocational rehabilitation assistance. To see if you or a family member qualifies, contact your local Veterans Administration Office or their headquarters office at (800) 827-1000 or visit www.va.gov/

Working and Continuing to Receive Benefits

SSA has different incentive programs that allow recipients to work for a limited amount of time or under special circumstances without losing their benefits. There are Social Security and SSI rules that can help young people receiving disability benefits who want to go to work (called incentives). Different rules apply to different programs. For example, there may be help with work expenses or with rehabilitation or training, or students with disabilities may exclude a certain portion of their income when counting their income for SSI programs.

There are also specific programs that have been implemented to provide additional incentives. For example, the *Ticket to Work Act* (see description of this program in the Employment section of this guide, under the *Federally Funded Job Training, Placement and Employment Programs*) allows more beneficiaries to work without losing benefits or medical coverage. The SSA Web site has a special section entitled “The Work Site” (www.ssa.gov/work) or call (866) 968-7842) to promote the employment of beneficiaries with disabilities. Contact your local Social Security office for more information about work incentive programs and provisions.

This information offers only a brief summary of government benefits and related laws. Individuals and their families are cautioned to not assume that all lawyers and financial planners are familiar with these benefit programs. Be sure when selecting a lawyer and/or financial planner that he or she is not only familiar with basic estate planning techniques, but is also knowledgeable about the methods used to prevent the state from taking the child’s inheritance upon the death of their parents.

Changes Affecting Private Insurance Plans and Issuers*

In the past private insurance was a difficult maze to walk through. There were lifetime caps and preexisting conditions issues. There have been extensive changes to the U.S. healthcare system. Below is a summary of these changes.

President Obama signed into law the Patient Protection and Affordable Care Act on March 23, 2010 and the Health Care and Education Affordability Reconciliation Act on March 30, 2010 (collectively, the “Act”). The Act will result in extensive changes to the U.S. healthcare system. This Advisory focuses on the Act’s impact on private insurance plans and issuers.

Health benefit and market reforms include:

- **No Lifetime or Annual Limits.** Effective six months after enactment, the Act prohibits group health plans and health insurance issuers from establishing lifetime limits on the dollar value of benefits for any participant or beneficiary. The Act also prohibits annual limits beginning January 1, 2014. Prior to that date, the Act permits only “restricted annual limits,” a term that will need to be defined by the Secretary of Health and Human Services (the “Secretary”). The restrictions and prohibitions on lifetime and annual limits apply only to services classified as “essential health benefits,” as defined below.
- **Coverage for Essential Health Benefits.** Effective January 1, 2014, health insurance issuers that offer health insurance coverage in the individual or small group market must ensure that such coverage includes the “essential health benefits” package. These “essential health benefits” will be determined by the Secretary and will include ambulatory patient services, emergency services, hospitalization, maternity and newborn care, mental health and substance use disorder services, prescription drugs, rehabilitative and facilitative services and devices, laboratory services, preventive and wellness services and chronic disease management, and pediatric services including oral and vision care.

- **Coverage of Preventive Health Services.** Effective six months after enactment, the Act requires group health plans and health insurance issuers to provide, at a minimum, coverage for certain specified healthcare services. Group health plans and health insurance issuers cannot impose any cost-sharing requirements for these healthcare services. The covered health care services are: (1) evidence-based items or services recommended by the United States Preventive Services Task Force; (2) immunizations recommended by the Advisory Committee on Immunization Practices of the Centers for Disease Control and Prevention; (3) with respect to infants, children and adolescents, evidence-informed preventive care and screenings provided for in the comprehensive guidelines supported by the Health Resources and Services Administration; and (4) with respect to women, such additional preventive care and screenings not described in (1) as provided for in comprehensive guidelines supported by the Health Resources and Services Administration.
- **Coverage for Preexisting Conditions.** Effective six months after enactment, the Act prohibits excluding children from coverage on the basis of a preexisting medical condition in all group plans and plans in the individual market. This prohibition will be extended to adults beginning 2014. Additionally, the Act calls for a creation of a temporary high-risk pool within 90 days after enactment to provide health coverage to persons with preexisting conditions. The pool will be effective until January 1, 2014.
- **Guaranteed Availability of Coverage.** Effective January 1, 2014, each health insurance issuer that offers health insurance coverage in the individual or group market in a given state must accept every employer and individual in that state that applies for such coverage.
- **Guaranteed Renewability of Coverage.** Effective January 1, 2014, health insurance issuers that offer health insurance coverage in the individual or group market must renew or continue in force such coverage at the option of the plan sponsor or the individual, as applicable.
- **Extension of Dependent Coverage.** Effective six months after enactment, the Act requires group health plans and health insurance issuers to provide dependent coverage for unmarried children of participants until the age of 26. The Act directs the Secretary to promulgate regulations defining dependents eligible for such coverage.
- **Antidiscrimination Provisions.** Effective six months after enactment, the Act prohibits plan sponsors of group health plans from discriminating against full-time employees based on hourly or annual wages, or favoring of higher-wage employees. Effective January 1, 2014, the Act prohibits discrimination based on health status, medical condition (including mental illnesses), claims experience, receipt of healthcare, medical history, genetic information, evidence of insurability (including conditions arising out of acts of domestic violence), disability, and any other health status-related factor determined by the Secretary. In addition, premium variations in individual and small group markets will be restricted. Premiums can vary with respect to a particular plan or coverage only according to: (1) whether the plan or coverage covers an individual or family; (2) rating area, as established in accordance with the Act; (3) age; and (4) tobacco use. The Act directs the Secretary to define the permissible age bands for rating purposes in consultation with the National Association of Insurance Commissioners (NAIC).
- **Prohibition on Rescissions.** Subject to certain exceptions for fraud and intentional misrepresentations by an enrollee, a group health plan and a health insurance issuer cannot rescind a plan or coverage with respect to an enrollee once the enrollee is covered under such plan or coverage. This prohibition goes into effect six months after enactment of the Act.

- **Prohibition on Excessive Waiting Periods.** Effective January 1, 2014, group health plans and health insurance issuers offering group or individual health insurance coverage are prohibited from imposing coverage waiting periods that exceed 90 days.

With respect to the benefit and market reforms described above, the Act grandfathers requirements for certain existing individual and group health plans, generally for a period of six months.

Rate Review Reforms

- **Review of Increases in Premiums.** The Act directs the Secretary to establish a process for the annual review of unreasonable increases in premiums for health insurance coverage, beginning with the 2010 plan year.

Documentation and Reporting Reforms

- **Development and Utilization of Uniform Explanation of Coverage Documents and Standardized Definitions.** Within 12 months after enactment, the Secretary must develop standards for group health plans and health insurance issuers to use in providing consumers with information regarding their benefits and coverage. In developing the standards, the Act directs the Secretary to consult with the NAIC, a working group composed of representatives of health insurance-related consumer advocacy organizations, health insurance issuers, healthcare professionals, patient advocates including those representing individuals with limited English proficiency, and other qualified individuals. The standards for the summary of benefits and coverage must include, among other things, (1) uniform definitions of standard insurance terms and medical terms so that consumers may compare health insurance coverage and understand the terms of coverage (or exception to such coverage); (2) a description of the coverage, the exceptions, reductions, and limitations on coverage; (3) the cost-sharing provisions, including deductible, coinsurance, and co-payment obligations; (4) the renewability and continuation of coverage provisions; (5) a coverage facts label that includes examples to illustrate common benefits scenarios, including pregnancy and serious or chronic medical conditions; (6) a contact number for the consumer to call with additional questions and an internet web address where a copy of the actual individual coverage policy or group certificate of coverage can be reviewed and obtained. Group health plans and health insurance issuers must comply with the new standards with 24 months after enactment.
- **Quality Reporting Requirements.** Within two years after enactment, the Secretary must develop reporting requirements for use by group health plans and health insurance issuers with respect to plan or coverage benefits and healthcare provider reimbursement structures that (1) improve health outcomes through implementation of activities such as quality reporting and care compliance initiatives, (2) implement activities to prevent hospital readmissions; (3) implement activities to improve patient safety and reduce medical errors; and (4) implement wellness and health promotion activities. For purposes of the reporting requirements, wellness and prevention programs may include personalized wellness and prevention services (e.g. smoking cessation and weight management), which are coordinated by a healthcare provider, a wellness and prevention plan manager, or a health, wellness or prevention services organization.
- **Reporting of Medical Loss Ratio.** Beginning with the 2010 plan year, health plans will be required to report to the Secretary the percentage of premiums they spend on reimbursement for clinical services, known as the medical loss ratio (“MLR”). Effective January 1, 2011, if the MLR does not fall within the parameters specified by the Act, the Act requires payment of rebates to enrollees.

In addition to the reforms outlined above, the Act includes certain reinsurance provisions, including the creation of a reinsurance program for early retirees and a reinsurance program to protect against anti-selection.

*Source: For more details, see the Healthcare Reform Update entitled *The Role of Reinsurance in Establishing the New Regime* written by Eric D. Fader and Mohana Terry (Edwards Angell Palmer & Dodge Law Firm).

Benefits and Insurance Resources

<p>SSA – Provides information about eligibility and application requirements. The SSA Web site provides answers to frequently asked questions, forms, and online tools to help determine eligibility for certain benefit programs.</p>	<p>Health and Human Services in the U.S. Government Section. www.ssa.gov (800) 816-0822</p>
<p>Benefits for Children with Disabilities – SSA Publication # 05-10026, August 2001. Written primarily for the parents and caregivers of children with disabilities and adults disabled since childhood. It illustrates the kinds of Social Security and Supplemental Security Income (SSI) benefits a child with a disability might be eligible for and explains how the SSA evaluates disability claims for children.</p> <p>Benefits for Children with Disabilities – SSA Publication # 05-10026, August 2001. Written primarily for the parents and caregivers of children with disabilities and adults disabled since childhood. It illustrates the kinds of Social Security and Supplemental Security Income (SSI) benefits a child with a disability might be eligible for and explains how the SSA evaluates disability claims for children.</p>	<p>Health and Human Services in the U.S. Government Section www.ssa.gov (800) 816-0822</p>
<p>Centers for Medicare & Medicaid Services (CMS) Web site – For information about the State Children’s Health Insurance Program (SCHIP)</p>	<p>CMS 7500 Security Blvd. Baltimore, MD 21244-1850 (410) 786-3000 (voice) www.cms.hhs.gov/schip</p>
<p>State Health Insurance Assistance Program – To locate the program in your state visit the Web site.</p>	<p>www.medicare.gov/contacts/Related/Ships.asp</p>
<p>Guide to Disability Income Insurance – Explains the various sources of disability income, what disability income insurance is, and what it covers. It includes a worksheet to evaluate personal sources of disability income, as well as a checklist of policy features that can be used to compare disability income insurance policies.</p>	<p>Health Insurance Association of America www.healthinsuranceproviders.com/health-insurance-association-of-america-hiaa</p>

<p>Federal Programs for Adults with Autism – This guide, while written for adults with autism, has useful information for people with other types of disabilities as well. It describes major federal programs, how to apply, how claims are processed, and eligibility requirements. While not a substitute for the information provided by the SSA, it provides a good summary of SSA’s programs.</p>	<p>Autism Society of America 7910 Woodmont Avenue, #300 Bethesda, MD 20814-3067 (301) 657-0881 (voice) (301) 657-0869 (fax) www.autism-society.org info@autism.org</p>
<p>National Organization of Social Security Claimants’ Representatives (NOSSCR) is an association of attorneys and paralegals who represent social security claimants. They refer individuals to an attorney in their area who can provide legal representation to assist in obtaining SSDI or SSI benefits. The attorney will charge a fee, but generally only if they win the case. The site includes a list of answers to frequently asked questions about disability benefits.</p>	<p>NOSSCR 6 Prospect St. Midland Park, NJ 07432-1691 nosr@worldnet.att.net www.nosscr.org (800) 431-2804</p>

Section Four: Assistive Technology

Technology is fast becoming an integral part of everyday life for persons with and without disabilities. As a result, assistive technology may have the potential to enhance the quality of an individual's life. This section of the guide includes the following information with regard to assistive technology:

- What is assistive technology?
- The federal definition of assistive technology and assistive technology projects
- Examples of assistive technology products
- Assistive technology resources

What is Assistive Technology?

Assistive technology means any special device or equipment that helps people with disabilities in daily life—electronic communication aids, speech synthesizers, print enlargers on a computer, etc. Equipment or strategies may be high or low tech; the key is determining the functional limitation of the disability and to find an appropriate accommodation.

The Federal Definition of Assistive Technology and Assistive Technology Projects

The Federal Definition of Assistive Technology. The potential of assistive technology was recognized through the enactment of *Public Law 100-407, the Technology-Related Assistance For Individuals with Disabilities Act (The Tech Act)*. The definition of assistive technology that was included in P.L. 100-407 was modified slightly in the federal regulations for the *Individuals with Disabilities Education Act (IDEA – P.L. 101-476)* to make the definition more applicable to children with disabilities:

Assistive technology means any piece of equipment or product or system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve the functional capabilities of children with disabilities. (Federal Register, August 19, 1991, p. 41272)

The IDEA also requires that assistive technology devices and services be considered when developing Individual Education Programs. Furthermore, the Department of Education has enhanced access to assistive technology because schools are obligated to provide assistive technology at home or in other environments where an IEP team determines that a student needs assistive technology to benefit from his or her educational program. The need for assistive technology must be considered, like other needs, on a case-by-case basis.

To support the need for assistive technology, parents and professionals should document precisely how the student would benefit educationally. For example, documentation may include a specific example such as: “Mary usually takes 1 hour to do 8 math problems. With a calculator, she can do the same number of problems in 20 minutes.” For more information on IEPs, see Section Five of this guide.

Assistive technologies can include mechanical, electronic, and microprocessor-based equipment; non-medical and non-electronic aids; and specialized instructional materials, services and strategies that people with disabilities can use either to:

- Assist them in learning
- Make the environment more accessible

- Enable them to compete in the workplace
- Enhance their independence or otherwise improve their quality of life

In addition to providing assistive technology services under the IDEA, the Technology Related Assistance for Individuals with Disabilities Act, Public Law 100-407 (often referred to as the “Tech Act”) provides the avenue for all individuals with disabilities to explore the use of assistive devices and to access services. Pursuant to the passage of the *Tech Act*, projects in all 50 states have been funded. Services may vary by state, but generally will provide the following types of assistance:

- Access to computerized information on the use of assistive technology
- Demonstration centers where people with disabilities may go to try different pieces of equipment
- Consultants to help individuals make informed decisions about equipment
- Referral services
- Training to both individuals with disabilities and others

Assistive Technology Projects. Federal and state funded projects are operated either in the State Vocational Rehabilitation Services Office, the Department of Education, the University Affiliated Program, or by a coalition of agencies providing service at the state level. The State Department of Education should be able to help you locate the project in your state. Or contact the National Institute on Disability and Rehabilitation Research at (202) 205-5000 and ask them to refer you to the assistive technology project in your state.

Individuals and employers can get help in identifying appropriate assistive technology and/or accommodations in the workplace by contacting the Job Accommodation Network (JAN) at (800) 526-7234. Consultants can provide information about accommodations, devices and strategies. Calls to JAN are confidential.

In addition, many colleges and universities have incorporated the use of technology into the support services they provide to students with disabilities. These services are usually provided through office of disability support services, learning resource centers or computer labs.

Additional Sources of Funding and Access to Technology

The Easter Seals centers provide technology services and equipment to people with disabilities. To locate the Easter Seals services near you, visit their web site at www.easter-seals.org. Some local Elks Club Lodges provide financial assistance to young people. Find your local Elks Lodge at www.elks.org/lodges/default.cfm.

Local businesses and offices all use computers and may also be an excellent source of reliable, highly usable technology. The speed with which the technology changes in various fields requires them to upgrade their systems fairly frequently. Some businesses will donate equipment that they are no longer using to an individual or organization. Friends, relatives, and business contacts (banks, real estate agents and manufacturing firms) may know of companies or organizations that regularly donate computer or other technology to others in the community.

Finally, most local libraries are equipped with computers that can be used by the general public. Some may also provide special equipment for people with disabilities to make their computers more accessible. Contact your local library to find out how to reserve time on a computer and/or how to find out if special adaptive equipment is available in your area.

Examples of Assistive Technology Products

When people think of assistive technology, they often think of sophisticated computers or electronic devices. While those types of tools exist, it is important to recognize that assistive technology applications can range from very high-tech to low-tech solutions. A high-tech example of assistive technology would include complex computer software or hardware or electronic aids, while low- or no-tech applications may include adapted spoon handles, Velcro fasteners, or making use of existing environmental conditions that do not involve the use of devices or equipment.

For more information about assistive technology and the types of products and services available under this very broad category, check out the resources listed below. Some of these organizations and/or Web sites maintain product and service listings of companies that sell various assistive technology products. Please note that TS Alliance does not recommend or endorse these companies and organizations, but provides this chart as a resource for your information. Be sure to thoroughly research any company and their products prior to ordering or sending money.

Please note that portions of this section of the guide were excerpted from the following publications: *News and Notes from the Family Center on Technology and Disability*, and the *Assistive Technology for Individuals with Learning Disabilities Fact Sheet*, published by the Learning Disabilities Association. To obtain a copy of these publications, contact these organizations directly (listed in chart below).

Assistive Technology Resources

<p>State Assistive Technology Projects – To find the assistive technology project in your state</p>	<p>National Institute on Disability and Rehabilitation Research (NIDRR) 400 Maryland Avenue, S.W. Washington, DC 20202-2572 (202) 205-8134 (voice) (202) 205-4475 (TTY)</p>
<p>ADA Technical Assistance Program – For information, materials, technical assistance or training on the ADA contact the toll-free number or visit their Web site to locate the Disability and Business Technical Assistance Center (DBTAC) nearest you.</p>	<p>ADA Technical Assistance Program (800) 949-4232 (V/TTY) www.adata.org</p>
<p>Job Accommodation Network – A free consulting service that provides assistance to individuals and employers in identifying appropriate assistive technology and/or accommodations in the workplace.</p>	<p>Job Accommodation Network (JAN) (800) 526-7234 (voice) (877) 781-9403 (TTY) www.askjan.org/</p>
<p>Assistivetech.net – This site provides increased access to information on assistive technology devices, services and disability-related resources, links to a broad range of topics and discussion groups where people can discuss ideas and share information.</p>	<p>Georgia Tech Center for Assistive Technology & Environmental Access 490 Tenth Street, NW Atlanta, GA 30332-0156 (800) 726-9119 (Voice) (404) 894-4960 www.assistivetech.net</p>
<p>Rehabilitation Engineering and Assistive Technology</p>	<p>RESNA</p>

<p>Society of North America (RESNA) – This nonprofit membership organization’s goal is to improve the potential of people with disabilities to achieve their goals through the use of technology. Membership includes consumers and rehabilitation professionals. They are currently operating a Technical Assistance Project, which helps callers identify the program in their state that is responsible for providing information, training, and technical assistance on assistive technology.</p>	<p>1700 North Moore Street, Suite 1540 Arlington, VA 22209-1903 (703) 524-6686 (voice) (703) 524-6639 (TTY) (703) 524-6630 (fax) info@resna.org www.resna.org</p>
<p>Ability Hub – The purpose of this Web site is to help users find information on adaptive equipment and alternative methods available for accessing computers. Site is maintained by Dan J. Gilman, who is a member of RESNA and has a disability. They will respond to brief e-mail requests pertaining to the content of the Web site. More in-depth consulting and/or training is available for an additional fee.</p>	<p>AbilityHub c/o The Gilman Group, LLC P.O. Box 6356 Rutland, VT 05702-6356 (802) 775-1993 (voice) (802) 773-1604 (fax) info@abilityhub.com www.abilityhub.com</p>
<p>Apple Computer – Manufactures computers for people with disabilities. Users of the Web site can search the online database for specific hardware and software solutions that meet their needs.</p>	<p>Apple Computer, Inc. National Special Education Alliance Worldwide Disability Solutions 20525 Mariani Ave., Suite 36SE Cupertino, CA 95014 (800) 692-7753 (voice) www.apple.com/accessibility/specialneeds@apple.com</p>
<p>Microsoft Accessibility Technology for Everyone – This site includes information about assistive technology as it relates to Microsoft’s software products. The site allows users to search for products by disability type (such as language or learning).</p>	<p>Microsoft Accessibility Technology (800) 642-7676 (800) 892-5234(TTY) www.microsoft.com/enable/default.htm</p>
<p>Half the Planet – This nonprofit organization supports the application of technology to promote the values of the ADA. Their online TechAccess Database allows users to search for technologies based on disability or life area focus or by articles on a particular topic.</p>	<p>Half the Planet 1875 Eye Street, NW 12th Floor Washington, DC 20006 (202) 429-6810 (voice) (202) 429-6813 (fax) www.halftheplanet.com suggestions@halftheplanet.com</p>
<p>Tech Connections – Sponsored by the UCP Center for Rehabilitation Technology, this site provides an overview of assistive technology resources, including a list of state assistive technology projects, disability resources and a newsletter. The “Quick Reference Series” cover topics such as computer workstations and mouse alternatives.</p>	<p>Tech Connections 490 Tenth St. NW Atlanta, GA 30318 (877) 835-7335 (voice) techconnections@crt.gatech.edu www.techconnections.org</p>

<p>News & Notes – From the Family Center on Technology and Disability newsletter.</p>	<p>Family Center on Technology and Disability Academy for Educational Development 1825 Connecticut Avenue, NW, 7th Floor Washington, DC 20009-5721 www.fctd.info fctd@aed.org</p>
<p>Assistive Technology for Individuals with Learning Disabilities Fact Sheet</p>	<p>Learning Disabilities Association 4156 Library Road Pittsburgh, PA 15234-1349 (412) 341-1515 (voice) (412) 344-0224 (fax) info@ldaamerica.org www.ldaamerica.org/pdf/assistive_tech.pdf</p>
<p>Disabled Children’s Relief Fund (DCRF) provides children with disabilities with assistance in obtaining assistive devices such as wheelchairs, braces, walkers, etc. They also grant small awards for assistive devices, rehabilitative services, or for efforts to bolster compliance with existing laws that benefit children with disabilities. Parents may submit applications for an individual child. DCRF focuses on helping children who do not have adequate health insurance, especially the physically challenged. Contact DCRF for application, eligibility and deadline requirements.</p>	<p>DCRF P.O. Box 7420 Freeport, NY 11520 www.dcrf.com</p>

Section Five: Education, Vocational Programs and Employment

A child's teenage years can be confusing as he or she move towards and prepares for adulthood. It is important that parents work with the school system to ensure their child obtains the services he or she is legally entitled to as a middle and high school student. Once a young adult completes school, based on his or her strengths and interests, there are different educational and vocational options depending on what is available in your community. While adulthood may be many years away, it is important for families to plan as far in advance as possible.

During this time, the family and the young adult with TSC will begin to make a series of decisions that will determine the types of programs and activities he or she will pursue as an adult. Transition planning in IDEA states that it begins at age 16 or earlier if the IEP Team decides it is needed. Because of the complex issues of TSC, transition planning should start as early as middle school. This section of the guide provides a brief overview of what special education services are and how to get them during the middle school and high school years. It also describes specific educational and vocational options that may be available to a young adult after finishing school, including resources that can be utilized during the public school years and beyond. For easy reference, this section is organized into the following subsections:

- Developing a Vision of Your Child's Future with Your Child
- Your Child's Educational Rights During the Public School Years
- Special Education, IDEA and IEP Resources
- The Importance of Education and Training After High School
- Educational Choices After High School
- Educational Rights After High School
- Financial Aid
- Post-Secondary Education Resources
- Vocational Opportunities After High School
- Finding a Job
- Service Providers and Types of Vocational Programs
- Employment Rights
- Federal Employment and Support Programs
- Online Job Search Tools
- Employment Publications
- Employment Resources

Developing a Vision of Your Child's Future with Your Child

When looking for employment, a vocational program, or other type of day activity, it may be helpful for you and your child to think about and write down his or her vision for the type of job or other program that would provide the greatest satisfaction. In other words, what are your child's interests, capabilities and vocational goals? Chances are, no one educational or vocational program will meet every need, however by considering the "ideal fit" early in the process, you and your child can look for the program or programs that come closest to that vision. Sharing this vision with counselors, service providers and others may also help in identifying a program that is a good match for the individual. As you develop this vision, some of the questions and options you and your child will want to consider include:

- What are my child's skills and interests?
- What type of education or training would prepare my child for future employment?
- Does my child enjoy being around people?
- What type of learning environment does my child prefer (classroom setting, one-on-one training, etc.)?
- What type of work environment does or would my child most enjoy (office, factory, retail, outside, etc.)?
- Is college an option?
- Is college an option with supports or pre-college support?
- What types of activities does my child like to participate in?
- Is employment an option?
- Is employment an option with supports?
- What type of vocational or day program would he or she enjoys the most?

As you and your son or daughter begin to consider the various vocational and educational options available, they may find that some service providers are unfamiliar with tuberous sclerosis complex. For example, they may not know that an individual with TSC may experience both seizures and emotional problems. Some programs may be equipped to deal with seizures or emotional problems, but not both. The TS Alliance has created various publications (*Teacher's Guide to TSC*; *Transition from School to Community*; information sheets, and newsletters) to help educate the general public, medical professionals, service providers and others about tuberous sclerosis complex. These publications can be downloaded from www.tsalliance.org or you can call (800) 225-6872 to receive a copy.

Your Child's Educational Rights During the Public School Years

Obtaining Services Under the IDEA. As discussed in Section One of this guide, the Individuals with Disabilities Education Act (IDEA 2004) is the legal means by which your child *may* be able to receive special education and other services. This law gives *eligible* children with disabilities the right to receive special education services and assistance in school. Special education is instruction that is specifically designed to meet the unique needs of children who have disabilities and is provided at no cost to the parents. Special education can include special instruction in the classroom, home, hospitals or other settings.

The IDEA provides a definition of a “child with a disability.” In general, the term “child with a disability” means a child:

- With intellectual disability, hearing impairments (including deafness) speech or language impairments, visual impairments (including blindness), serious emotional disturbance, orthopedic impairments, autism, traumatic brain injury or other health impairments or specific learning disabilities; and
- Who, by reason thereof, needs special education and related services.

According to the IDEA, the disability must affect the child’s educational performance. Determining eligibility takes into account whether the child has a disability that fits into one of the categories such as those listed above and whether that disability affects how the child does in school. The disability must cause the child to need special education and related services.

Special education is a set of services and supports provided to children with disabilities to help them progress in the general education curriculum. The Individuals with Disabilities Education Act 2004 (IDEA 2004) is an education law designed to ensure that children with disabilities are not only exposed to the general education curriculum but progress in it also through a free appropriate public education (FAPE).

When your child is diagnosed with TSC, the medical issues can be overwhelming and dealing with the school is the last thing you want to do. It’s bad enough that you practically have to earn a medical degree to understand everything going on with your child medically, but you also must understand what your child needs educationally. The school should know what is going on with your child -- they are the experts right? Wrong! You are the expert. Many teachers and administrators are not familiar with disabilities in general, let alone in the area of TSC.

Just because your child has TSC does not mean your child will automatically receive help in school. The law is very specific a child’s disability and it must adversely affect learning or he/she will not qualify to receive help in school. To further complicate matters, under the Individuals with Disabilities Education Act of 2004, the child must meet a certain criteria to even qualify. So, just because your child has a disability does not mean the school has to provide any kind of support or help.

If your child is not currently receiving special education services, and you think he or she may need these services, the first step is to find out if your child has a disability as defined by the *IDEA*. To do this, ask the school to evaluate your child. Call or write the Director of Special Education of the local school district or the principal of your child’s school. Let them know that you think your child has a disability and needs special education help. Ask the school to evaluate your child as soon as possible. The public school may also think your child needs special help. If this is the case, then the school must evaluate your child at no cost to you. To better understand how to request an evaluation download a copy of *Parent’s Rights* document from www.tsalliance.org under “School Issues.” This publication will walk you through the process and provide you with sample letters to request an evaluation.

If a child has more than one disability he/she will qualify under the disability that most adversely affects learning, or he/she can be identified under multiple disabilities. If your child has intellectual disabilities and autism, he/she could be identified under either depending on which is affecting learning the most. Is the developmental delay affecting his/her learning more than the autistic behaviors? If one does not outweigh the other, then you might want your child evaluated for multiple disabilities.

The school typically doesn’t know how a TSC diagnosis will impact learning, because TSC affects everyone differently. The school does not have to recognize the disability if they feel it is not affecting your child’s learning. If your child is passing with Cs and Ds, the school will probably not want to test.

You will then have to push to get them to understand for example it might take your child two or three hours a night just to do homework. Most school systems will only evaluate a child if he/she is failing.

Because the school system is not an expert in TSC, it doesn't always understand your child is struggling and not just being lazy or not putting forth the greatest effort. Moreover, many times there are no outward signs of TSC. Since many regular educators don't understand disabilities, they feel if they don't see any visible signs of a disability, none must exist. If you are in this position, the first step is to write a letter requesting your child be evaluated for a disability under IDEA 2004. Put as much information in the request letter as possible describing the areas your child is struggling. Once you have requested the evaluation, the school will do one of three things:

1. Send you a "permission to evaluate form"
2. Refuse to evaluate until they do interventions
3. Refuse to evaluate

The school does not recognize your letter as a request to evaluate your child, even if that is what you stated in your letter. They will only recognize their "permission to evaluate form." Once you have signed that form, the school is required to evaluate your child within 60 calendar days (this is not school days) from the day you gave your consent to evaluate. School systems choose to only recognize their state-approved parent request form. So, when writing your letter makes sure you give them a specific date to respond. To get the 60-day time frame going, you must sign their form stating that you suspect you child of having a disability under IDEA 2004.

The school can also state that it wants to do a Response to Intervention Model (RTI) first. The school has authority to choose the RTI process to determine whether a child has a specific learning disability. It first determines if the child responds to *scientific, research-based intervention*. The problem with this type of intervention is that the 60-day time frame does not start until after the RIT process is completed. Sometimes it will be a full school year before the school will move forward with testing. That means your child may experience a year of failure and/or struggle before you can get them help. The idea of the RTI Model is not a bad practice if the school system is trained in the RTI process and the interventions they are using are in fact evidence-based research. These are the questions to ask:

1. How long are you planning on doing the RTI?
2. Am I involved in this process?
3. How are you going to collect data on the outcome of the RTI?
4. What is the evidence-based research to back the RTI you are using?

If the school system refuses to evaluate your child, you have no choice but to exercise your rights as a parent of a child with a disability. You want to proceed with the most un-adversarial approach, such as asking for a meeting with the person who runs the special education programs in you school district, who is sometimes called the "Special Education Director." If you don't know who this person is, go to your school district's Web site and look for who is in charge of Special Education. If you do not have access to a computer contact the TS Alliance at 1-800-225-6872 to ask for the Advocacy Department, and we will assist you in finding the contact for Special Education.

What if You Disagree with the School Evaluation?

When a school district provides an evaluation for a child with a suspected disability, it has to follow appropriate procedures as discussed in the previous pages. What parents need to understand is that the school psychologist must know how your child is currently affected with TSC and what changes may occur in the future due to the progression of TSC in the brain. The psychologist will not provide an evaluation that is as thorough and extensive as your child's neurologist. Sometimes the school psychologist and your doctor's recommendations do not agree.

The first question would be, then why do we even bother with the school's evaluation? Remember, even though you have a diagnosis of TSC, it does not mean the school has to recognize the disability. The first step to getting them to recognize your child has a disability is through their evaluation process. Unfortunately, the school system and medical system do not always agree on what a child needs. When the school system's evaluation comes back, and you disagree with the results, there are steps you can take as a parent to get the school to take into consideration your doctor's evaluation.

Under IDEA 2004, parents are entitled to an Independent Educational Evaluation (IEE) at the school district's expense. The law recognizes that when a school psychologist works for a school system, he/she is not always a free agent or as unbiased as needed to support the specific educational needs of your child. Basically, this means the school pays the psychologist, which may sway the outcome of the evaluation. Legally it is not supposed to but sometimes it does. IDEA 2004 took this into consideration and as a safeguard parents have the option of an IEE.

If you believe the evaluation is not appropriate for your child, you can request an IEE. I strongly suggest you request that verbally at the evaluation meeting and later in writing. Your signature is very important the school cannot do anything without your written consent. So, make sure that you agree with everything before you sign anything. This will save misunderstandings later on down the road.

Developing an IEP Plan

If a child is found eligible for special education services, you and the school will work together to design an educational program for your child. This will be done through a planning tool called the Individual Education Program (IEP). To get a more detailed document on IEPs, download *What is an IEP?* from www.tsalliance.org under "School Issues."

An IEP is a written statement of the educational program designed to meet a child's individual needs. Every child who receives special education services must have an IEP. Each IEP includes the following information:

- **Present levels of educational performance**—describes how your child is currently doing in school, including how the disability affects his or her progress.
- **Annual goals**—describes what you and the school team think your child can reasonably accomplish within the school year. It may include short-term objectives and major milestones.
- **Special education and related services to be provided**—includes any supplementary aids and services (such as communication devices or other types of assistive technology) that will be provided to your child.
- **Participation with non-disabled children**—how much of the school day will your child be educated separately from non-disabled children? For example, will he or she participate in extracurricular activities and lunch?

- **Participation in state and district-wide assessments**—describes any modifications needed when student achievement tests are conducted.
- **Dates/location**—describes when and where services will be provided, how often they will be provided, and how long they will last.
- **Transition needs**—transition planning (moving from childhood to adulthood) must begin by age 16 (see Section Two: Transition Planning for more information).
- **Measuring progress**—describes how school personnel will measure your child’s progress against annual goals, how parents will be informed of their child’s progress, and whether that progress is enough to enable your child to achieve his or her goals by the end of the year.
- **Schedule for updates**—must be updated annually or when anyone from the IEP Team feels it’s needed

Note: Some information for this section of the guide was excerpted from Briefing Paper #LG1 entitled, “Questions Often Asked by Special Education Services,” published by the National Information Center for Children and Youth with Disabilities (NICHCY), and “A Guide to Disability Rights Laws,” published by the U.S. Department of Justice. For contact information for these resources, see the chart below.

Special Education, IDEA and IEP Resources

<p>A Guide to Disability Rights Laws – Provides an excellent overview of disability laws along with relevant statute citations users can refer to for additional information.</p>	<p>Disability Rights Section Civil Rights Division U.S. Department of Justice P.O. Box 66738 Washington, DC 20035-6738 (800) 514-0301 (voice) (800) 514-0308 (TTY) www.usdoj.gov/crt/ada/adahom1.htm</p>
<p>NICHCY Briefing Paper – “Questions Often Asked by Parents About Special Education.” This publication helps parents learn about the <i>IDEA</i> and how students with disabilities access special education and related services.</p> <p>NICHCY “Related Services for School-aged Children with Disabilities.” This publication looks exclusively at the related services as identified by the <i>IDEA</i> including occupational and physical therapy, speech therapy, transportation and special health services.</p>	<p>NICHCY P.O. Box 1492 Washington, DC 20013 (800) 695-0285 (voice) nichey@aed.org http://nichey.org/</p>
<p>How to Write a Successful IEP – A step-by-step guide for developing Individual Education Plans.</p>	<p>Incentive Publications Nashville, Tennessee www.incentivepublication.com</p>
<p>Transition from School to Community – A guide to understanding Transition planning for children with TSC. This guide can be downloaded from the Webs site.</p>	<p>TS Alliance 801 Roeder Rd. Suite 750</p>

	Silver Spring, MD 20910 www.tsalliance.org (800) 225-6872
Accommodations for Students with Disabilities in High School. This brief produced by the National Center on Secondary Education and Transition, addresses legal considerations, examples of instructional and assessment accommodations, and state-reported levels of use of accommodations. NCSET also provides other publications that address education and transition issues.	Nat'l Center on Secondary Education and Transition Institute on Community Integration (UAP) University of Minnesota Pattee Hall, 150 Pillsbury Drive, SE Minneapolis, MN 55455 (612) 624-2097 (voice) (612) 624-9344 (fax) ici.umn.edu/ncset/
School Psychology Resources Online – This Web site provides resource information for parents, psychologists and educators about various learning disabilities including: Autism, mental retardation, ADD, etc.	www.school.psychology.net
Wrightslaw – The Special Ed Advocate Newsletter – this online newsletter provides helpful information about and skills needed to best advocate for your child. Web site also includes various special ed publications, libraries, and a bookstore. Pete Wright is a lawyer who represents children with special needs.	www.wrightslaw.com/subscribe
SpecialEdLaw.net – This Web site is a resource for parents of special needs children, as well as attorneys, teachers and others with a need for information relating to special education law.	www.specialedlaw.net
KidNeeds.com – provides resources for special needs children and their families for different types of disabilities, growth, development and technology.	KidNeeds.com World Headquarters 29-01 216th Street Bayside, NY 11360 (866) 543-6333 info@KidNeeds.com www.kidneeds.com
Schwab Learning – This site is dedicated to helping kids with learning differences be successful in learning and life. Site includes resource information on identifying and managing learning differences, tools to use to plan and progress.	Schwab Learning 1650 South Amphlett Blvd. Suite 300 San Mateo, CA 94402 (650) 655-2410 or (800) 230-0988 (voice) (650) 655-2411 (fax) webmaster@schwablearning.org www.schwablearning.org
Life Beyond the Classroom: Transition Strategies for	Paul H. Brookes Publishing

<p>Young People with Disabilities – This guide describes how to plan and design successful transition programs for students with disabilities. While primarily geared toward practitioners, instructors, service providers and vocational counselors, parents will also find the information helpful. Author: Paul Wehman.</p> <p>Steps to Independence: Teaching Everyday Skills to Children with Special Needs – A practical training guide for parents and teachers of children with special needs.</p> <p>Developing Personal Safety Skills in Children with Disabilities – Addresses areas such as self-esteem, assertiveness, dealing with strangers, what to do when lost and sexual abuse.</p>	<p>P.O. Box 10624 Baltimore, MD 21285 (800) 638-3775 (voice) (410) 337-8539 (fax) custserv@brookespublishing.com www.p.brookes.com</p>
---	--

The Importance of Education and Training after High School*

As different options for the teenager moving into adulthood are considered, the importance of education and training cannot be underestimated. Gaining additional education and/or training may help an individual feel better about him- or herself. Technology is changing the world of work. Staying current with these changes makes an employee more valuable to an employer. Most job promotions require additional training or education. Jobs and employers’ requirements may change and therefore it is important to maintain job skills.

Unfortunately, as in other areas of life, there are prejudices in the workplace. Some employers still want to limit individuals with disabilities to low-paying, service jobs. There’s nothing wrong with these jobs, but for individuals who want higher-paying positions with greater variety, they will often need to have more skills than their non-disabled peers. That will require more education and training. Even if the individual with TSC isn’t sure what he or she wants to do, sometimes education is its own reward. It generally lends itself to a more enjoyable life and may lead that person to a job that they hadn’t considered before.

**Excerpted from “Why You Need Education and Training,” from the iCan News Service.*

Educational Choices after High School

After leaving high school, there are different postsecondary educational and training options available to adults with disabilities. Be sure that you and your child explore all available options in your community. The final choice will depend on his or her strengths, interests, and the severity of the disability. Some examples of different educational programs for young adults are listed below:

- **Training Offered by Disability-Specific or Advocacy Organizations** such as local chapters of The Arc (formerly the Association for Retarded Citizens) and the United Cerebral Palsy Association (UCP) may provide vocational assessment and training services. These organizations provide services to people with a wide range of disabilities and are not limited to mental retardation or cerebral palsy as the name might indicate. Programs will vary, but many of these agencies provide training and job experience to adults with disabilities (in addition to other support services). In some instances, the state vocational rehabilitation counselor may refer a person to an organization of this type to provide job training and placement services. The goal is to help the individual find a job and become as independent as possible. Contact the headquarters

office (a list appears in Section Seven of this guide) to find the chapter or affiliate nearest you to learn more about programs offered in your area.

- **Adult Education Programs** provide instruction below the college level to individuals 16 years of age or older who are no longer being served by the public education system. Training may be home economics, industrial arts, or for certain trades such as automobile repair or carpentry. Programs may also be available to prepare individuals for the Graduate Equivalent Degree (GED) or to teach English as a second language (ESL). For more information, contact your high school, or the Adult Education Department of your local school district.
- **Vocational, Trade and Technical Schools** prepare students for jobs such as a bank teller, air conditioning technician, dental assistant, data processor, electrician, medical secretary, administrative assistant or welder. Programs can range from two weeks to two years and usually require a high school diploma or GED. Trade and technical schools typically offer job placement services for their graduates. For additional information, contact your high school guidance counselor and/or a vocational counselor at your state vocational rehabilitation agency.
- **Pre-College Programs** are offered to students with learning disabilities and/or ADD to prepare them for the academic and personal challenges of college. Many programs take place in the summer and focus on improving skills such as using college texts, improving memory, and taking notes. Programs vary by college. Contact the Heath Resource Center (see Postsecondary Resource Chart on the next page) for a copy of the article entitled “Summer Pre-College Programs for Students with Disabilities.”
- **Distance Learning** takes advantage of technology and easy access to the Internet. Many colleges, universities, and other training providers make their courses and programs available over the Internet. These programs offer scheduling flexibility and the ability to learn from home (or other off-site location) using a personal computer and modem. Contact the university or college to see if it offers a distance learning program in your field of study. For a clearinghouse of distance learning programs, see the Web site, *Distance Learning on the Net*, listed in the chart on the next page.
- **Universities, Colleges, Community and Junior Colleges** offer opportunities for individuals to continue their education and earn a degree or certification. Many community colleges often offer low cost programs, including vocational and occupational courses. Be sure to inquire about the specific support services offered to students with disabilities (see *Educational Rights After High School*, below).

Educational Rights After High School

After exiting the public school system, a person with disabilities over the age of 21 is not guaranteed the same services in adulthood that were mandated by the IDEA. However, their educational rights are protected through Section 504 of the Rehabilitation Act of 1973. This legislation states that any institution (such as a college or university) that receives federal funds may not exclude an individual from participation or deny him or her the benefits of any program or activity the institution offers solely because that individual has a disability.

Many educational institutions, including private schools, receive some type of federal funding. Therefore, if they receive federal aid, they should be prepared to make accommodations for people with disabilities. Many college campuses have an Office for Students with Disabilities or Disability Support Services. Support services which may be provided include note taking, using a computer in class, course pre-registration, additional time to complete assignments, specialized counseling, mentoring and support

groups. Services will vary greatly by school or program. After your child selects the programs or schools he or she is most interested in, contact them directly to learn about the support services provided to students with disabilities.

Financial Aid

There are different types of financial aid for people with disabilities. The challenge is in locating the scholarships and other programs that your son or daughter may be eligible for.

The United Cerebral Palsy Association (UCP) has assembled a fairly comprehensive list of scholarships for people with disabilities. More than 100 of these scholarships and funding sources are listed on their Web site. Please contact these agencies directly to find out about application procedures, deadlines and eligibility requirements. Established as a public service several years ago, FinAid has become one of the most comprehensive collections of information about student financial aid on the Web, including a Fast Web Scholarship Search function at <http://finaid.org>.

Be sure to visit your local public library and your local college's financial aid office to find sources of money for college and other educational programs in that exists your community.

Postsecondary Education Resources

<p>Learning How to Learn: Getting Into and Surviving College When You Have a Learning Disability</p>	<p>www.greatschools.org</p>
<p>Summer Pre-College Programs for Students with Disabilities lists programs that help students with disabilities prepare for their college career and enhance their college performance.</p> <p>Creating Options: A Resource on Financial Aid for Students with Disabilities, Heath Resource Paper.</p>	<p>The George Washington University HEATH Resource Center 2134 G Street, N.W. Washington, D.C. 20052-0001 askHEATH@gwu.edu www.heath.gwu.edu</p>
<p>LD Resources - Resources for people with learning disabilities, including many for college and adult literacy. A free e-mail newsletter that includes articles about learning disabilities is also available.</p>	<p>www.ldresources.org</p>
<p>A list of scholarships for people with disabilities</p>	<p>www.disabled-world.com/disability/education/scholarships/</p>
<p>Parke Davis Epilepsy Scholarship Award – Entering graduate students who have epilepsy and who demonstrate potential for high academic achievement are eligible.</p>	<p>www.epilepsy-scholarship.com</p>
<p>Entry Point – A program of the American Association for the Advancement of Science (AAAS) offering internship opportunities for students with disabilities in Science, Engineering, Mathematics, and Computer</p>	<p>Lauren Summers AAAS Project on Science, Technology & Disability 1200 New York Avenue, NW Washington, DC 20005-3920</p>

Science. The program includes opportunities in private industry and government agencies. Mentoring and assistive technology is available which may help to facilitate the entry and advancement of individuals with disabilities into competitive employment. Contact for eligibility and deadline requirements.	(202) 326-6649 (voice/TDD) (202) 371-9849 (fax) www.entrypoint.org lsummers@aaas.org
Christopher Reeve Paralysis Foundation Fellowship Awards – Artists and writers with physical disabilities are eligible to apply for one-month fellowships at the Vermont Studio Center. Fellowships are awarded on the basis of creative merit. Applications must be received by June for consideration.	Vermont Studio Center Box 613 Johnson, VT 05656 www.vermontstudiocenter.org (802) 635-2727 (voice) (802) 635-2730 (fax) info@vermontstudiocenter.org
Distance Learning on the Net – Provides descriptions of distance education Web sites and links to other distance learning and education resources.	www.hoyle.com
Frequently Asked Questions About Section 504 and Post Secondary Education.	www.pacer.org/text/pride/504.htm
Why a Section 504 Plan in High School is Different from a 504 Plan in College	www.okc.cc.ok.us/okahead/home/transition.html
Questions and Answers on Disability Discrimination under Section 504 and Title II.	www.ed.gov/offices/OCR/qa-disability.html
College Students and Disability Law , by Stephen Thomas. This comprehensive article addresses <i>Section 504, ADA</i> , qualifying as a ‘person with a disability’ admission accommodations, and dismissal. Includes guidelines for higher education practitioners and legal references.	www.ldonline.org

Vocational Opportunities After High School

People with disabilities work in a variety of settings every day. Vocational and rehabilitation options for people with disabilities range from positions that provide high levels of assistance to full competitive employment. Often the challenge is not in performing the job, but in finding the job or program that best suits an individual’s interests, strengths and personality.

For some people, participating in a vocational, educational or other type of activity can be empowering and may provide a purpose for living. Experience provided through work, job training or other enrichment activities may add to the quality of life and increase a person’s self-esteem. Additionally, social interactions with co-workers and others may enhance a person’s integration into the community. Many individuals with disabilities want to and are able to work if given the proper supports.

Finding a Job

To begin the process of learning more about the various vocational opportunities available to your child, start with your State Department of Rehabilitation Services. State vocational and rehabilitation (VR) agencies coordinate and provide a number of services for people with disabilities who are looking for a job. These services may include counseling, skills evaluation, training, job placement, coaching, and support. Services provided vary by state, but most agencies will assign a vocational counselor to work with an individual with a disability to identify and locate employment options that best suit their capabilities, needs, and interests. The state VR agency will also be able to help an individual determine the services and programs for which they qualify.

State VR agencies work with nonprofit organizations and private employers that provide a range of employment support services options in a variety of settings. You can find your state or local VR agency by checking in the state government pages of your phone book or do an Internet search.

Vocational counselors can provide more information about opportunities in a specific geographic area. As awareness of what people with disabilities achieve in the workplace grows, many large, private companies and federal agencies have implemented programs that actively recruit candidates with disabilities. Specific resources to locate these companies are listed in the “Online Job Search Tools” section on page 53.

How to Qualify for Vocational Rehabilitation Services

To be eligible for vocational rehabilitation services, an individual must have a physical or mental impairment that keeps him or her from working. The person must also need vocational services in order to get or keep employment and must be able to benefit from these services. A counselor at the State Department of Vocational and Rehabilitation Services will make this assessment. People with certain conditions automatically meet the definition of having a disability: They include individuals who:

- Receive SSI or SSDI
- Have moderate or severe mental retardation
- Who are blind or deaf
- Have epilepsy, if *not* seizure-free for two years

However, some states do not use the same criteria for disability as the Social Security Administration. Therefore, an individual may be eligible for vocational and rehabilitation services from the state even if they have been denied social security benefits. Contact your state Department of Vocational Rehabilitation to find out more about eligibility requirements.

Service Providers and Types of Vocational Programs

Service Providers. People with disabilities now have more options than ever before for achieving job satisfaction and becoming a productive member of the work force. Nonprofit Community Rehabilitation Programs (CRPs) exist around the country and provide a variety of training and employment services for people with disabilities. Many of these agencies provide job training and employment support. Some are affiliated with a national disability organization such as The Arc, Autism Society, Autism Speaks, Goodwill Industries International, United Cerebral Palsy (UCP), the Epilepsy Foundation, Easter Seal Society, and the International Jewish Vocational Services, and some are independent organizations. Each of these community-based agencies has been created to meet the vocational needs of adults with

disabilities in their community. Services are provided to people with all types of disabilities, whether mild or severe, and are usually not limited to the specific disability noted in the name of the organization.

Local chapters of national disability organizations are excellent resources for disability-related programs that exist in the community. Many of these organizations may also provide job training and job placement services in your area. For example, adults who live with seizures may obtain employment assistance such as job search training, job development, job clubs, and follow up services after finding a job from the Epilepsy Foundation. The Epilepsy Foundation also offers a range of materials to help people through the job-search process.

The International Association of Jewish Vocational Services (IAJVS) through its Jewish Vocational Services network is another national nonprofit organization with many years of experience in providing employment and training services to people with disabilities. IAJVS affiliates also provide vocational and rehabilitation programming in supported work environments for people with cognitive, emotional or physical disabilities. Services may include training, job search assistance and on-site job coaching. Services are provided to individuals with disabilities regardless of religious affiliation. To locate a chapter or local affiliate of the UCP, IAJVS, Epilepsy Foundation or other disability organization in your area, contact the national office of these organizations (listed in Section Seven of this guide).

There are also private, for-profit providers of vocational services. Families should check with their vocational counselor or their local disability advocacy organization to learn of the availability of these programs in their area.

Types of Vocational Programs. Programs will vary greatly between organizations and by location, so it is best to research the programs that will provide the vocational experience that best suits your child's needs before making a selection. Depending on where you live, there may be many programs available, while other locations may have more limited options. In addition to knowing about the different programs in your community, plan to visit them to see how they are managed. Your vocational counselor or rehabilitation specialist should have access to the information about the programs that are available in your area. Listed below are some of the more common types of employment options that may be offered in a community.

- **Day Activity or Personal Enrichment Programs** are day habilitation programs for individuals whose primary focus is *not* employment. These programs may enhance the quality of life by providing experiences and growth in such life areas as recreation, personal care, socialization, daily living skills and mobility training. Programs are designed to maximize the independent functioning of the participants through training in a variety of areas.
- **Work Activity or Work Enhancement Programs** provide experience and low paid work while offering individualized employment skills training. Participants may be given the chance to work in different settings on various tasks in order to increase their skills. Work is performed in an integrated setting and/or in the community when possible. The goal of the training is to teach fundamental work skills and habits and is often the first step in gaining experience that may enable an individual to move to more challenging work and increase future independence. Often behavioral supports are offered for people who require this type of assistance.
- **Facility-Based Employment** usually includes jobs in industrial settings performing work on subcontracts with community businesses in such areas as assembly, packaging, bulk mailing, and manufacturing. A higher level of supervision and support is provided than in a supported or competitive employment situation. Experience from these types of jobs may prepare an individual for more independent employment options in the future.

- **Supported Employment** places an individual in a job that matches their strengths, needs, and preferences with the job requirements. This type of employment may offer partial or full community integration as well as social and economic empowerment. Job training, coaching, supervision and other support services based on individual need are provided either at or away from the work site, which are necessary to assure satisfactory job performance. Jobs are often in service industries such as administrative support, food, mail or janitorial or grounds maintenance services. Some positions may be in a retail environment. Support services may gradually be reduced as the individual becomes more skilled in the job.
- **Competitive Employment** positions match employees with a job that best suits their interests and capabilities by working with individual employers in the community. Individuals placed in these positions are usually required to perform the job with little additional supervision or support. However, the service provider may provide assistance with job placement and with training required before starting the job.

Employment Rights

The Americans With Disabilities Act (ADA) is a federal law that prohibits discrimination on the basis of disability in the areas of employment, housing, public accommodation, transportation, and telecommunication services. *Title I of the ADA* states that employment practices cannot discriminate against a person with a disability who is qualified for the job. A person with a disability who is able to complete the essential functions of the job is considered qualified. The law also requires an employer to provide, “reasonable accommodations” or modifications to a work environment to guarantee the person can effectively perform their job, such as providing wheelchair accessibility. To learn more about Title I rules for employment visit www.thearc.org. Or, contact the Equal Employment Opportunity Commission (EEOC) office nearest you. Contact information listed on the Employment Resource Chart that appears later in this section. Additional ADA Resources can be found in Section One: Your Rights Under Disability Law.

Federal Employment and Support Programs

There are various federally funded employment and support programs available to people with disabilities. Some examples of these programs are described below. In addition to the contact information listed for each program, your school guidance counselor and or your vocational/rehabilitation counselor may have additional information about these and similar programs that may be available in your area.

- **Ticket to Work** is a nationwide initiative that offers SSA disability beneficiaries more choices in obtaining the services they need to help them go to work. To qualify, an individual must be a SSA disability beneficiary. This program provides assistance with finding employment, vocational rehabilitation and other support services from public and private providers.

The SSA will provide disability beneficiaries with a ticket they may use to obtain the services they need from an Employment Network of their choice. For more information about *Ticket to Work*, contact Maximus (the organization that will be managing this program) at (866) 968-7842 or visit their Web site at www.yourtickettowork.com.

- **Project Employ** is a joint initiative of the Office of Disability Employment Policy and the Society for Human Resource Management in partnership with other employers to promote and expand employment opportunities for people with significant cognitive disabilities such as mental retardation, autism, and psychiatric disorders by working with groups such as Goodwill Industries International, Inc., Association for Persons in Supported Employment, Administration on Developmental Disabilities and others. Employer partners include companies such as AT&T,

Marriott Foundation, General Electric, IBM and Southwest Airlines. While programs vary by state, Project Employ provides career development skills and training through a network of employment training and placement providers. For more information about Project Employ, see the Employment Resource Chart at the end of this section.

- **Federal Contracts** under the federal employment program, the Javits-Wagner-O’Day Act (Public Law 92-28) provides people with disabilities training and work opportunities in a wide range of employment situations at federal sites and military installations across the country. Services and products provided under this program are purchased by federal agencies. Many of these positions offer competitive wages, benefits and opportunities for job growth and mobility. These 55 work opportunities are available through organizations affiliated with NISH (formerly National Industries for the Severely Handicapped) that have these types of contracts. For a list of agencies in your area that provide these types of employment opportunities and other vocational services, see the contact information in the “Employment Resource Chart” at the end of this section.
- **The Job Accommodation Network (JAN)** is a free consulting service of the U.S. Department of Labor Office of Disability Employment Policy that provides information about job accommodations, the Americans with Disabilities Act and the employability of people with disabilities. JAN is *not* a job placement service; however, it does provide services that assist people with disabilities become informed about their educational rights, acquire accommodation options, and learn about other government and placement agencies. For contact information, see the “Employment Resource Chart” at the end of this section.
- **Association of University Centers on Disabilities (AUCD)** hosts a nationwide network of interdisciplinary centers advancing policy and practice for and with individuals with developmental and other disabilities, their families and communities. One center per state (some states have more than one center) provides a wide range of community outreach and assistance in the areas of special education, employment and housing programs. All centers are part of universities or medical centers and serve as a link between the university and community. Services provided by each center will vary. For example, some provide more services to adults or children with disabilities. In some instance, centers may work with the local Developmental Disability Planning Council in providing services and information. To learn more about the services provided by the center nearest you, see the “Employment Resource Chart” at the end of this section.
- **Developmental Disability (DD) Planning Councils** are assisted by the U.S. Department of Health and Human Services (HHS) and provide information on disability-related organizations in your state. The information offered by each council differs by state. To find the DD council in your state, visit www.acf.dhhs.gov/.

Online Job Search Tools

There are hundreds of job search tools available on the Internet, with new ones added everyday. The list below is not meant to be a comprehensive list, but to provide selected sites to help young adults and their families get started with their job search.

- **The Career Center** sponsored by the American Association of People with Disabilities (AAPD) can be accessed through their Web site. The center provides a link to the Job Options network, which allows users to search from a nationwide job bank. The center also provides helpful tips on resumes and interviewing, a job alert e-mail service, and a direct link to employers’ Web sites. www.aapd-dc.org

- **Job-hunt.org** links to more than 2,000 job search sites. Sites are organized by job category and geographic location. It also provides advice on developing an online resume and how to avoid the most common mistakes in searching for a job online. www.job-hunt.org
- **Job Access** works with companies, government and nonprofit agencies to employ people with disabilities. www.jobaccess.org
- **Able to Work** is a consortium of 21 corporations, including Microsoft and Pitney Bowes, dedicated to expanding employment opportunities for persons with disabilities. The site has job postings for several corporations. www.able2work.org
- **The U.S. Department of Labor** maintains a Job Links area on its web site that lists companies and federal agencies by state that actively recruit people with disabilities. In many instances this list provides a headquarters location. Contact the agency directly to learn more about the opportunities available in your area. www.dol.gov and type in job links in the search engine.
- **Careers and the Disabled** is an online publication that features corporations and government agencies that are actively recruiting persons with disabilities. The focus is on jobs for people with disabilities at the undergraduate, graduate or professional levels. www.eop.com
- **USA Jobs** is a comprehensive database of job openings in various branches of the federal government. www.usajobs.opm.gov
- **Monster Jobs** is a general employment site that contains a broad array of job postings from across the nation. Users can search by job category and geographic area. The Monster’s Career Center (in the Resources Section of the site) provides career advice, resume help and interview tips. www.monster.com

Employment Publications

Mainstream is a national nonprofit organization dedicated to improving competitive employment opportunities for people with disabilities by providing specialized services and acting as a bridge between people with disabilities, employers and service providers. Mainstream publishes a quarterly magazine *Employment in the Mainstream* (available in print and online) and also responds to individual requests for assistance by telephone, fax or e-mail. It also provides some job placement support and assistance in the Dallas, Texas, and Washington, D.C. metropolitan areas. For contact information, see the “Employment Resource Chart” below.

Employment Resources

<p>State Vocational/Rehabilitation Offices Consult your local phone book, under State Government (blue pages), vocational and rehabilitation agency. For a list of Voc/Rehab agencies for all 50 states.</p>	<p>www.workworld.org/wwwwebhelp/state_vocational_rehabilitation_vr_agencies.htm</p>
<p>How to Choose a Provider—A Guide from CARF, published by the Commission on Accreditation of Rehabilitation Facilities, this not-for-profit accrediting body establishes customer-focused standards to measure and</p>	<p>CARF 4891 E. Grant Rd. Tucson, AZ 85712 (520) 325-1044 (voice/TTY) (520) 318-1129 (fax)</p>

<p>improve the outcomes of services provided to persons with disabilities. This guide provides a detailed list of questions to ask providers when selecting Adult Day Services and/or Employment and Community Services.</p>	<p>www.carf.org</p>
<p>The Work Site – Established by the Social Security Administration’s Office of Employment Support Programs to promote the employment of social security beneficiaries with disabilities. Contains information on Social Security Disability Insurance (SSDI), the Ticket to Work and other work incentive programs.</p>	<p>(866)-968-7842 (voice) www.ssa.gov/work</p>
<p>Association for Persons in Supported Employment (APSE) improves and expands employment opportunities, services and outcomes for people with disabilities</p>	<p>APSE 1627 Monument Avenue Richmond, VA 23220 (804) 278-9187 (voice) (804) 278-9377 (fax) www.apse.org</p>
<p>NISH (formerly National Industries for the Severely Handicapped) maintains a list of Community Rehabilitation Programs (CRPs). Many of these agencies provide jobs on federal contracts in addition to providing training and employment for people with disabilities. Contact NISH or on the Web site, click on “CRP Locator” for the agencies nearest you.</p>	<p>NISH 2235 Cedar Lane Vienna, VA 22182 (703) 560-6800 (voice) (703) 849-8916 (fax) info@nish.org www.nish.org</p>
<p>Epilepsy Foundation (EF) – Provides many services including employment assistance through 45 local foundations nationwide. The JobTech Program provides various services onsite with vocational rehabilitation providers and other partners.</p>	<p>The Epilepsy Foundation of America 4351 Garden City Drive Landover, MD 20785-7223 (301) 459-3700 (voice) (800) 332-1000 (voice) www.epilepsyfoundation.org</p>
<p>UCP (formerly United Cerebral Palsy) provides a range of services to people with disabilities and their families including many resources for finding a job. 39 UCP affiliates across the country provide services including employment assistance. Enter your zip code to enter the Web site. This links you to the affiliate in your area and information about the services provided</p>	<p>UCP National 1660 L Street, NW, Suite 700 Washington, DC 20036 (800) 872-5827 (voice) (202) 776-0414 (fax) (202) 973-7197 (TTY) www.ucpa.org</p>
<p>The JVS network provides employment, training and services to individuals with</p>	<p>Contact them to find the local JVS nearest you Or on their Web site, click on your state or region.</p>

<p>disabilities from all faiths and backgrounds.</p>	<p>International Association of Jewish Vocational Services 1845 Walnut Street, Suite 640 Philadelphia, PA 19103 (215) 854-0233 (voice) (215) 854-0212 (fax) www.iajvs.org</p>
<p>Pacer Center – Provide many services to people with disabilities and their families. See “Employment Strategies for Youths & Adults with Disabilities” section on their Web site.</p>	<p>Pacer Center 8161 Normandale Blvd. Minneapolis, MN 55437 (952) 838-9000 (voice) (952) 838-0199 (fax) (952) 838-0190 (TTY) pacer@pacer.org www.pacer.org</p>
<p>Project Employ – Request contact information for the Project Employ Center(s) in your state.</p>	<p>Employment Training Administration, Department of Labor (202) 693-2723 www.dol.gov/dol/odep/public/program/projecte.htm chafkin-randee@dol.gov</p>
<p>Job Accommodation Network (JAN) provides resources for people with disabilities, employers, and rehabilitation professionals about job accommodations and employment rights.</p>	<p>Job Accommodation Network P.O. Box 6080 Morgantown, WV 26506-6080 (800)-526-7234 (voice) (304)-293-5407 (fax) www.askjan.org jan@jan.icdi.wvu.edu</p>
<p>Mainstream – Links people with disabilities, employers and services providers. Publishes a quarterly magazine, <i>Employment in the Mainstream</i> (online and print versions) and local job placement service for dislocated workers in Washington, D.C., and Dallas, Texas.</p>	<p>Mainstream, Inc. 6930 Carroll Avenue, #240 Takoma Park, MD 20912 (301) 891-8777 (voice) (301) 891-8778 (fax) www.mainstream-mag.com wlink@mainstream.org</p>
<p>Association of University Centers on Disabilities (UCDs) is a nationwide network of university and medical centers that provide a variety of services and information to people with disabilities and their families. Services vary by center.</p>	<p>Association of University Centers on Disabilities 8630 Fenton Street, # 410 Silver Spring, MD 20910 (301) 588-8252 (voice) (301) 588-2842 (fax) www.aucd.org</p>
<p>Description of federal laws prohibiting discrimination under the <i>Americans with Disabilities Act (ADA)</i>. Web site includes a Q&A section about discrimination laws and how to file a charge. Filing a charge must be done with 180 days of the alleged</p>	<p>U.S. Equal Employment Opportunity Commission 1801 L Street, NW Washington, DC 20507 (202) 663-4000 (800) 669-4000 (to be connected to the EECO office nearest you) (800) 669-6820 (TDD)</p>

<p>discriminatory act. Site also links to local EEOC offices (alphabetical by city).</p>	<p>www.eeoc.gov</p>
<p>Centers act as “one-stop” central resource on ADA issues in employment, public services, public accommodations and communications and provide publications, training, and technical assistance on ADA-related topics. Goal is to partner with others in their community to increase awareness of the ADA.</p>	<p>Disability and Business Technical Centers (800) 949-4232 (Voice/TTY) www.adata.org</p>
<p>National Institute for Literacy encourages the provision of high quality educational services for adults with disabilities. Resources include publications and America’s Literacy Directory (ALD), which refers potential students to local literacy programs that help in studying for the GED, learning English as a second language, and math.</p>	<p>America’s Literacy Directory 1775 I Street, NW, Suite 730 Washington, DC 20006-2401 (202) 233-2025 (voice) (202) 233-2050 (fax) (800) 228-8813 (toll-free directory line) www.nifl.gov/nifl (home page) www.literacydirectory.org</p>
<p>ERIC Clearinghouse on Higher Education – Provides information for students about post-secondary education options. FAQ section of Web site includes sections for students with disabilities and where to find financial aid.</p>	<p>ERIC Clearinghouse on Higher Education (ERIC HE) 1 Dupont Circle, NW #630 Washington, DC 20036 (202) 296-2597, (800) 773-3742 (voice) (202) 452-1844 (fax) www.eriche.org</p>
<p>National clearinghouse on postsecondary education for individuals with disabilities. Offers many resources Articles are available in print and can also be downloaded from Web site. Site has FAQ section addressing best schools for students with disabilities and where to find financial aid.</p>	<p>Heath Resource Center 2121 K St., NW, #220 Washington, DC 20037 (202) 973-0904 (voice) (800) 544-3284 (voice) www.heath.gwu.edu</p>

Section Six: Housing and Independent Living

As a result of the movement toward integrating people with disabilities into the community, there are more residential options and related support services available than ever before. Yet this doesn't mean finding an appropriate housing program is easy. This portion of the guide describes the various types of living situations and programs that may be available to people with disabilities in their community.

Prior to reviewing the information in this section, it may be helpful for the young adult and his/her family to think about and write down what their vision is for the type of housing situation that would best serve the needs of the person with TSC.

In other words, in a perfect world, what features or characteristics are most important to the person with TSC and his or her family? Chances are, no one program will meet every need; however, by considering this early in the search, an individual and/or family member may be better prepared to choose the option that comes closest to their vision.

This section is divided into the following subsections:

- Types of Residential Programs – Supported and Assisted Options
- Financing for Housing Related Supports
- What to Look for in a Residential Program
- Other Housing Options
- Getting Started/How Do I Qualify for these Programs?
- Residential and Housing Resources

Please note that various areas of the country define residential programs differently. These descriptions are provided as a starting point to assist young adults and their families in exploring the types of programs that may be available in the community. Options may range from those that provide a high level of assistance to those with minimal supports, such as those found in supervised apartments and group homes, to heavily regulated Medicaid-funded facilities.

The residential programs described in this section may or may not be available in your area. Families need to educate themselves about the types of residential options available in their community. Researching the available programs and asking the right questions will help you to make an informed decision.

While each state has access to the same federal funding, states vary widely in the types of services offered and how much is supplemented with state funds. In addition, services may be offered by the state, non-profit community-based organizations, or private sector agencies. No matter how many different providers are offering services to an adult with disabilities, there is a maximum monthly amount that will be paid by federal and/or state funds to cover the cost of these services. Learn as much as possible about the different options available in your community, starting years in advance if possible. Many programs have long waiting lists, so the sooner an appropriate program or living arrangement is identified, the better.

In addition to the resources listed in the chart at the end of this section, local chapters of national disability organizations such as The Arc, Autism Society, Autism Speaks and United Cerebral Palsy can help to identify the different options in the community. Contact information for the headquarters offices of these organizations can be found in Section Seven at the end of this guide.

Types of Residential Programs

Examples of the residential programs frequently used by people with disabilities are described below. Be aware that not every option will exist in every community. Depending on where you live, there may be the opportunity to combine various services that will create a good fit for your child. The ideal situation is when the family and provider(s) design residential supports around an individual's unique needs. Because the demand for these programs is usually far greater than what is available in the community, finding an "ideal" fit is usually difficult, if not impossible. The goal should be to locate the situation that fulfills as many of your child's requirements as possible. Contact your local service providers and/or some of the resource organizations listed in the chart at the end of this section for more information.

24-Hour Care Homes and Nursing Facilities

Twenty-four hour care facilities provide round-the-clock supervision and assistance with all daily living activities. Most frequently they provide a residential environment for those individuals with the most severe health problems and disabilities. They can be state-operated or privately owned and operated facilities. The quality of care can range from excellent to below average. As with any program considered, it is important to investigate it thoroughly before choosing it as an option. A thorough client assessment, which usually includes a psychological assessment and health and medical examination, is required for placement in a 24-hour care home.

Supervised Group Living

Supervised group living, commonly referred to as group homes, is usually a group situation in a single family home that serves several individuals with disabilities. Homes are staffed by trained professionals who assist individuals based on their levels of need and may include personal care skills, meal preparation and housekeeping. Often, residents may live at the home during the week and visit their families on the weekends. The home may or may not be specific to a certain type of disability (such as autism or cerebral palsy) but may house individuals with different types of disabilities. In some instances, especially where there are not many residential options, parents of children with TSC and parents of children with other types of disabilities may want to join forces and combine their resources and efforts to establish a community group living situation that can be used by their young adult children.

Supervised Apartments

Supervised apartments offer a situation where an individual lives in an apartment, possibly with a roommate or alone, with minimal assistance. This choice may work well for individuals who prefer to live with fewer people, but still require some supervision and assistance. Usually a staff person visits once or twice a week to provide any assistance that may be needed. Often, a supervised apartment setting can provide the first step for an individual who wants to prepare to move to a more independent living arrangement in the future.

Skill Development Homes/Adult Foster Care

In Skill Development Homes, sometimes referred to as adult foster care, an individual lives in a home with a family and other people with or without disabilities. Unlike foster care for younger children, adult foster care is meant to be as permanent as possible. Families who provide foster care to adults receive money from the federal government but are not necessarily trained or expected to teach independent

living skills. Adult foster care may be best suited to individuals who do not need extensive supervision and assistance.

Independent Living and Independent Living Centers

Independent living for people with disabilities means living like everyone else: having opportunities to make decisions that affect one's life and the ability to pursue activities of one's own choosing. Independent living should not be defined in terms of living on one's own, being employed in a job fitting one's capabilities and interests or having an active social life. These are aspects of living independently. Independent living has to do with self-determination. It means having the right and the opportunity to pursue a course of action. And it is having the freedom to fail and learn from one's failures just as people without disabilities do. There are, of course, individuals with certain mental impairments that may affect their ability to make complicated decisions or to pursue complex activities. For these people, independent living means having every opportunity to be as self-sufficient as possible. Independent living is not easy and it can be risky, but people with disabilities do not have to do it all on their own.

Independent living centers are nonprofit service organizations run by people with disabilities and offer a variety of services to help people live independently, including:

- **Information and Referral** – Providing information about accessible housing, transportation and employment opportunities and lists of people available to serve as personal care attendants.
- **Independent Living Skills Training** – Providing skills training to assist people to learn skills that will enable them to live independently, such as how to access public transportation, manage a personal budget, or deal with insensitive or discriminatory behavior in the general public and other subjects.
- **Peer Counseling** – Offering a service in which people with disabilities can work with others with disabilities and who are living independently in the community. The goal is to solve problems that sometimes occur for people with disabilities.
- **Advocacy** – Providing consumer advocacy for the individual with disabilities to obtain necessary support services from other agencies in the community. This involves center staff, board members, and volunteers initiating activities to make changes in the community that make it easier for all persons with disabilities to live more independently.
- **Other Services** – Offering a number of other services depending on the needs of consumers and the availability (or lack of) other services in the community. Examples of these other services may include public information, equipment repair, and recreational activities.

Respite Care

For families of a person with a disability, respite care is a support service that may be required from time to time. Some community-based programs offer respite care that may be as simple as providing a substitute caregiver for a few hours each week. Others provide more major interventions, like temporarily placing the individual in a special respite home. For example, some Epilepsy Foundation affiliates provide respite care for individuals who experience frequent and debilitating seizures. Care is typically provided for an agreed upon time. To find out if there is an affiliate in your community that provides this service, visit www.epilepsyfoundation.org/aboutus/affiliatelookup.cfm.

In addition, the National Respite Locator Service helps individuals, parents and caregivers find respite services in their state and local area. Contact information for this service is listed in the Residential and Housing Resource Chart at the end of this section.

Financing for Housing Related Supports

Some support services that enable an individual with a disability to live as independently as possible may be funded by federal or state benefit programs. Families need to be aware there will be a maximum amount paid per month by federal and state benefits. So while different service providers may provide various residential and/or other support services to your child, the total amount of money available remains the same and will be divided, as appropriate, between providers. Some potential funding sources to consider may include:

- Medicaid pays for personal care attendants, case management, therapeutic services, medical care, technological and physical aids, and may pay for case management services. In many instances, it depends on the state.
- The state's Medicaid Home and Community-Based Services Waiver is usually administered through the Department of Social Services or their Developmental Disabilities office, and could pay for a range of support services, including service coordination and case management. In a few states (including California, Colorado, Florida, Illinois, Maryland, Michigan, Rhode Island and Wisconsin), Medicaid has approved a Community and Supported Living Arrangement Waiver, which may fund an even broader array of support services.
- The state funds residential services that might now be used to finance group homes and apartments, but which could pay for individualized and flexible supports for a person to live in his or her own home.
- Private funding sources may include money contributed by local civic groups, the person or family.
- Other funds administered by the State Developmental Disabilities or Social Services Offices.

What to Look For When Selecting a Residential Program

Philosophy – What is the agency's vision and mission? Does the program seek to empower individuals by providing choices for them in their daily lives? How does the agency ensure the staff behavior supports this mission?

Programs Offered – How does the agency work to improve the quality of its programs? Is the agency able to develop new supports for people who don't "fit" into existing programs? How are homes selected and matched with who will live in the house or other setting?

Location & Convenience – Is the program located close to the person's job, supported employment or other day activity? Some agencies provide both residential and employment support services. Is it possible to choose (or mix and match) day or support services at another location from another service provider? Is it located close to family and friends? Is there access to public transportation? Is it close to other community activities a young adult may want to participate in (church, recreation, etc.)?

Size and Staffing – Smaller is usually better, but not always. More importantly, are individuals empowered or able to make their own decisions? Look at the ratio of staff to clients when comparing providers. Ask about the wages, benefits and training provided to staff. Also ask about staff turnover and how quickly vacancies are filled. Ask about the experience of the executive director or president and how long the person has held the position.

Human Rights/Abuse Records – Has the agency ever been cited for violations? If so, ask what they were for. The local chapter of The Arc or other disability groups can frequently share an agency's history in

this area. The regional state regulatory agency may also be a source of information, but may not be as candid.

Financial Solvency – Some programs are funded and managed better than others. Compare providers’ financial stability before making your final selection. Do they have reserves, a foundation, etc.? Do they receive funding from a variety of sources?

These are just a few of the many factors that need to be considered when selecting a residential arrangement or program. In addition to considering whether a program meets most of your child’s preferences and needs, it is important to determine whether the program provides a supportive environment and is well managed. The best way to determine this is to visit your top choices, talk with the administration, staff and consumers who are receiving their services. If possible, talk with others who have utilized the agency’s services as well.

As families begin to consider the various residential options available in the community, they may find that some service providers are unfamiliar with TSC. For example, they may not know that an individual with TSC may experience both seizures and emotional problems. Some programs may be equipped to deal with seizures or emotional problems, but not both. The TS Alliance has created various publications (information sheets, books, newsletters, etc.) to help educate the general public, medical professionals and others about TSC. Please contact the TS Alliance or visit www.tsalliance.org if you would like copies of these materials to assist in educating service providers in your community.

Before making the final selection, be sure that the person with TSC, family members (as appropriate) and any other advocates (case managers, counselors, etc.) meet with the residential team to discuss the needs and expectations of the young adult who will be receiving services. When the provided services have been agreed upon, get them in writing with signatures. Once a person is accepted into a program, be sure to keep notes of all conversations (including staff person’s name), the issue(s) discussed and any follow-up actions agreed upon at meetings and in conversations.

Other Housing Options

The federal government provides housing assistance through the U.S. Department of Housing and Urban Development (HUD) to people who have low incomes primarily through two programs:

- **The Section 8 Tenant-Based Rental Assistance Program** provides vouchers or certificates to subsidize rent. Under this program, a person provides 30 percent of his or her own income toward rent, and the certificate or voucher pays the difference to the landlord. It offers the most flexibility in terms of where a person can live and what kind of living arrangement he can select. However, the number of available vouchers is limited and the waiting list is extremely long.
- **The Section 8 Project-Based Rental Assistance Program** offers assistance (subsidies) to landlords who agree to provide housing for people with disabilities. The demand for this type of housing is also greater than the number of available units.

How Do I Qualify for Public Housing or the Section 8 Programs?

Eligibility for public housing programs is determined by the gross family income minus certain allowed deductions for dependents and certain medical expenses. An individual may qualify as a “family” if he/she is living on his/her own and may be eligible for this program if he/she has very low or no income. The application process can take up to a year and, as the demand is greater than the supply, the wait may take another year or longer. However, it may be an option worth pursuing.

Low income is defined as 80 percent of the median (midpoint) income for the county or metropolitan area and very low income as 50 percent of the median. Since median income varies from area to area, families may find that they are eligible in one area but not another. Current income limits are available online in PDF format from HUD at www.huduser.org/portal/datasets/il/il10/index.html. The information on this site provides eligible income levels based on the number of people in the household.

Section 8 was created to allow very low income (defined as 50 percent or less of local median income) families and individuals to rent on the private market using vouchers that cover a portion of the monthly rent. Individuals interested in this program can start by contacting their local Housing Agency (HA). The HA for your area can be found at: www.hud.gov/renting/phpprog.cfm. This site also provides information about how the application process works and the information you will need to provide as part of your application.

§ 811 – Supportive Housing For Persons with Disabilities

HUD provides funding to nonprofit organizations to develop rental housing with supportive services for very low-income adults with disabilities, and provides rent subsidies for these projects to help make them affordable. The Section 811 program allows persons with disabilities to live as independently as possible in the community by increasing the supply of rental housing with the availability of supportive services.

How Do I Qualify for Section 811?

In order to live in Section 811 Housing, a household, which may consist of one unmarried qualified person must be very low income (see definition above) and at least one member must be 18 years old and have a disability, such as a physical or developmental disability or chronic illness. Contact your local housing agency to find nonprofit organizations that participate in this program.

Getting Started

Listed below are excellent resources that should be explored early in your search for an appropriate residential program or setting. Contact information is listed in the Residential and Housing Resource Chart that appears at the end of this section.

- **The www.Arclink.org** provides detailed information on home- and community-based services. Users can search by state, zip code and the type of service provided.
- **Local Chapters or Affiliates of National Advocacy Groups**, such as a chapter of The Arc, United Cerebral Palsy, the Epilepsy Foundation of American, or the National Alliance for the Mentally Ill. Check your local phone listings or contact the headquarters office listed in Section Nine of this guide.
- **State, County or City Social Services Offices**. Check local phone listings under government listings, often listed under the Department of Health, under the Developmental Disabilities Administration or Department of Mental Retardation or Developmental Disabilities. The counselor or liaison working with you should be able to provide a list of programs in your area.
- **State Councils on Developmental Disability Programs** (see contact information in chart below) foster community integration of people with disabilities in housing, jobs, education and society.
- **Parent Organizations and Parent Information Training Centers** such as those affiliated with the Pacer Center (see contact information in chart below) and other local parent/advocacy groups may be able to provide information about local housing options. Networking with other parents who have found housing for their young adult child with disabilities may also be helpful. Higher

functioning adults with disabilities who are currently living independently may provide an opportunity for roommate situations or mentoring (sharing advice with individuals who are just starting to live independently).

- **University Centers on Disabilities (UCDs)** provide services to people with disabilities and their families and may work together with the local Developmental Disability Council. Services vary by center, but it may be a helpful resource if you live near a teaching university or college.
- **National Associations** that represent private or nonprofit service providers such as ANCOR or NISH. These agencies themselves don't provide residential services, but may be able to refer you to agencies in your community that do.
- **HUD** provides a wide range of information about federal housing resources for people with disabilities and fair housing laws such as the Fair Housing Act and Title II of the Americans with Disabilities Act.
- **Some realtor sites** offer searches for “accessible homes” or homes under a certain dollar amount on their site. Most realtor offices can provide additional information such as price history, neighborhood searches and access to public transportation. Check your local telephone listings.

Residential and Housing Resources

<p>Arclink.org – Provides detailed information on home and community-based services. Search by state, zip code and service provided. Includes a Provider Search function, “Know the System” (by state) section and a suggested list of questions to ask service providers.</p>	<p>www.thearclink.org (800) 433-5255 (voice) info@thearc.org</p>
<p>How to Choose a Provider: A Guide From CARF, published by the Commission on Accreditation of Rehabilitation Facilities, this accrediting body establishes customer-focused standards to measure the outcomes of services provided to persons with disabilities. Provides a list of questions to ask providers about their assisted living programs.</p>	<p>CARF 4891 E. Grant Rd. Tucson, AZ 85712 (520) 325-1044 (voice/TTY) (520) 318-1129 (fax) www.carf.org</p>
<p>Developmental Disability (DD) Councils (one per state) can refer you to disability programs in your state. Services will vary by state but may include programs that foster community integration of people with disabilities in housing, employment and education. Some DD councils work closely with UCDs listed below.</p>	<p>National Assoc. of Developmental Disabilities Councils 1234 Massachusetts Avenue, NW #103 Washington, DC 20005 (202) 347-1234 (voice) (202) 347-4023 (fax) www.naddc.org mgray@naddc.org</p>
<p>Association of University Centers on Disabilities – A national network of programs affiliated with teaching hospitals and universities that provide programs for people with disabilities. Programs vary by center.</p>	<p>Association of University Centers on Disabilities 8630 Fenton Street, Suite 410 Silver Spring, MD 20910 (301) 588-8252 (voice) www.aucd.org</p>

<p>Parent Advocacy Centers for Educational Rights – Parent Training and Information Centers and Community Resource Centers (one per state) help to expand opportunities and enhance the quality of life for people with disabilities. They may also provide housing information.</p>	<p>Pacer Center - Alliance Coordinating Office 8161 Normandale Blvd. Minneapolis, MN 55437 (952) 838-9000 (voice) (952) 838-0190 (TTY) (952) 838-0199 (fax) www.pacer.org</p>
<p>NISH (formerly, National Industries for the Severely Handicapped) maintains a nationwide listing of over 600 Community Rehabilitation Programs (CRPs) that provide a wide variety of services to people with disabilities that <i>may</i> include residential services, group or community homes. Once in the site, click on <i>CRP Locator</i>. Click on the state within a map of the U.S. Note: Not all CRPs provide residential services.</p>	<p>NISH 2235 Cedar Lane Vienna, VA 22182 (703) 560-6800 (voice) (703) 849-8916 (fax) www.nish.org info@nish.org</p>
<p>ANCOR – This association represents private providers of services and supports to people with disabilities. <i>ANCOR Directory of Members 2001</i> lists over 600 agencies that provide residential services and supports in 48 states & D.C. Includes contact information, the types of services provided, and the number of individuals who receive services.</p>	<p>ANCOR 1101 King Street, # 380 Alexandria, VA 22314 (703) 535-7850 (voice) (703) 535-7860 (fax) www.ancor.org</p>
<p>ResCare – A for profit service provider for people with developmental and other disabilities in 32 states, D.C. and Puerto Rico that enables people with disabilities to live and work in the community.</p>	<p>ResCare 10140 Linn Station Road Louisville, KY 40223 (502) 394-2478 (voice) www.rescare.com</p>
<p>National Accessible Apartment Clearinghouse (NAAC) maintains a national database of accessible apartments. Information includes property name and address, the community’s accessible features and the features of each individual unit.</p>	<p>NAAC 201 N. Union Street., # 200 Alexandria, VA 22314 (800) 421-1221 (voice) (703) 518-6191 (fax) clearinghouse@naahq.org www.forrent.com</p>
<p>HUD – A “People with Disabilities” page on the Web site compiles all of the disability-related housing information from this federal agency in one place.</p>	<p>U.S. Department of Housing and Urban Development 451 7th St. SW Washington, DC 20410 (202) 708-1112 (voice) (202) 708-1455 (TTY) www.hud.gov</p>
<p>Independent Living Centers (ILCs) are typically non-</p>	<p>National Council on Independent Living (NCIL)</p>

<p>residential, private, non-profit, consumer controlled, community-based organizations providing services and advocacy by and for persons with all types of disabilities. They assist individuals with disabilities within their communities by assisting with access to housing, employment, transportation, health and social services. The NCIL provides resources regarding independent living and a national directory of Centers for Independent Living.</p>	<p>1916 Wilson Blvd., Suite 209 Arlington, VA 22201 (703) 525-3406 (voice) (703) 525-4153 (TTY) ncil@ncil.org</p> <p>To find the ILC in your state: www.ncil.org</p>
<p>Housing Center for People with Disabilities – this Web site is managed by the Technical Assistance Collaborative (TAC) and provides information and news updates regarding affordable housing policies and programs for people with disabilities. Helpful sections on this site include Housing News Headlines, Opening Doors, and HUD Programs, and Federal Housing Policy and Legislative Updates.</p>	<p>Technical Assistance Collaborative One Center Plaza, Suite 310 69 Boston, MA 02108 (617) 742-5657 (voice/TTY) www.tacinc.org E-mail: info@tacinc.org</p>
<p>Respite Care: Time Out for Families, published by the Epilepsy Foundation. This guide helps families become informed consumers and find the type of respite care that best meets their needs. Cost: \$14.95. Contact the Epilepsy Foundation. Can also be ordered online.</p>	<p>Epilepsy Foundation of America 4351 Garden City Drive Landover, MD 20785-7223 (800) 332-1000 (voice) www.efa.org</p>
<p>National Respite Locator Service (a program of the ARCH Respite Network and Resource Center) helps individuals, families and caregivers find respite services in their state. The service is also useful when a family moves or travels to another state. Links to special needs (eldercare locator service, adult day services, etc.).</p>	<p>National Respite Locator Service ARCH National Respite Network and Resource Center Chapel Hill Training-Outreach Project 800 Eastowne Drive, Suite 105 Chapel Hill, NC 27514 (888) 671-2594 (voice) (919) 490-4905 (fax) www.chtop.com/locator.htm</p>

Section Seven: Community Integration, Relationships and Recreation

Quality of life activities, friendships, and romantic relationships often bring the most enjoyment to an individual's life. The information presented in this section is meant to provide a starting point to assist young adults with TSC and their families in pursuit of activities that will help contribute to living a well balanced, healthy and more fulfilling life.

This section includes information and resources to assist young adults with TSC in connecting with others and in gaining greater independence. It also addresses some of the secondary concerns that arise as a result of TSC, such as skin disorders, the need for special clothing and adaptive equipment.

This section of the guide addresses the following topics:

- Staying Healthy
- Skin Disorders Associated with TSC
- Adaptive Clothing and Equipment
- Personal Care Assistants
- General Disability Resources and Information (publications, Web sites, magazines, etc.)
- The Importance of Social Relationships
- Recreation, Travel, Sports, and Leisure Activities

Staying Healthy

Eating a balanced diet, exercising regularly, and getting regular medical and dental checkups are basic steps to ensure the person with a disability stays healthy. It is also strongly recommended that the individual with TSC keep a list of all the medications he or she is currently taking with him or her at all times. It is important for medical professionals to have this information in the event of an emergency.

Some individuals may also find it helpful to keep a diary or journal to help sort through the experiences, feelings, obstacles and successes that are all part of living with a disability.

The information in this guide focuses on non-medical issues confronted by young adults with TSC and their families. If you need assistance in keeping track of the medical issues associated with your child with TSC, you may want to contact the TS Alliance for a copy of the TSC Journal or Adult Journal. The purpose of these journals is to help families and individuals keep track of doctor visits, medications, and other information related to medical care. To obtain the journals, contact the TS Alliance at (800) 225-6872, or download PDF versions from www.tsalliance.org.

Skin Disorders Associated with TSC

Some individuals with TSC experience certain types of skin discoloration or pigmentation as one of their symptoms. Although most skin disorders associated with TSC are not curable, an experienced dermatologist or plastic surgeon may be able to remove troublesome lesions with favorable results. Additionally, with continued research, the future looks bright for new, more effective skin treatments for skin disorders associated with TSC. There are different companies that sell cosmetics for concealment

and de-pigmented skin, such as www.covermarkusa.com, www.lindaseidel.com, and www.dermablend.com.

Adaptive Clothing, Shoes and Equipment

Finding clothes and equipment that are easy-to-wear, stylish, and affordable may help add to a young adult's confidence and better enable him or her to focus on living an active and healthy life. The following vendors sell different types of special needs clothing and incontinent supplies: www.easyaccessclothing.com, www.speciallyforyou.net, www.decentexposures.com, www.hdis.com, and www.gopeach.com.

Personal Care Assistants

What is a Personal Care Assistant?

Personal Care Assistants (PCAs) are people hired by you or your family to assist you with your activities of daily living. For example, they may provide assistance with your dressing, bathing, feeding and other personal needs. PCAs can be skilled or unskilled workers who come into your home and assist with your personal and household needs. They may work for a home health care agency or be hired independently depending on personal choice and state requirements. PCAs do not have specific and set ways of doing tasks, but instead take directions from you. For many people with disabilities, the key to being able to live independently is securing and maintaining attendant care. The concept of independent living is based on the notion that an individual with a disability has the right to make his or her own decisions and to have control over the direction of his/her life. Directing your own care with the assistance of a personal care attendant is a prime example of this concept in action.

Finding a Personal Care Assistant

One way to obtain a personal care assistant is to contact your state department of Human Services and request a caseworker if you do not already have one. Let them know you want to look into home health care services and PCAs. There are many different programs and classifications based on priority and medical need that are considered, so be sure to inform them clearly about your situation. Once the right program is selected, your caseworker will come to your home to assess your environment and your needs. To do this, the caseworker will ask questions about what type of care and assistance (bathing, feeding, transferring, etc.) you require. Once the assessment is completed, you will be asked to choose a home health care agency. There are both good and bad home health care agencies, so you'll have to do your homework. Before interviewing for the position, ask the agency about their hiring guidelines, specifically how they check the background and qualifications of the assistants they hire, training the assistants receive and the costs.

Another way to hire an assistant is to place an ad in your local newspaper. Prior to placing the ad, you'll need to determine whether you want the assistant to work full- or part-time, run errands, transport you to the store or other locations, and perform light housekeeping duties and cooking in addition to meeting your personal care requirements. Whether you hire an assistant through an agency or on your own, it's important for you to thoroughly investigate the individual's references and background and to ensure the person is someone you feel comfortable with.

Discuss the job tasks in detail, including the time required for each task. Be specific about bowel and bladder care, dressing, transfers and bathing requirements. Be sure to ask about their personal history, driving record and alcohol and drug use/abuse. Transportation is also important. Will the person use his/her own transportation to come to work, or will he/she use public transportation? Be sure to have a back-up plan in the event of transportation problems. Hours required, pay, time off and weekend or

evening requirements (if needed) should also be discussed. Also let a candidate know how he/she will be paid (such as a state agency, insurance company or directly from you).

How Do I Pay For a Personal Care Assistant?

In some cases, funding for personal care services may be provided by Medicaid or Medicare. Check with your state Medicaid Office for more information about eligibility requirements. However, if your income exceeds the level set by your state, private insurance may offset the cost. Check with your insurer as different policies have different requirements and offer different levels of coverage.

This section addresses the topic of personal care assistants in a very general way. You may want to do additional reading before beginning your selection process. Depending on where you live there may be different assistant options available to you. Check the resources listed below for additional information about finding a personal care assistant.

Personal Care Assistant Resources

<p>Managing Personal Assistants, A Consumer Guide, published by the Paralyzed Veterans Association, addresses recruiting, hiring, training, keeping and firing PCAs. Also addresses funding resources and tax information (70 pages). Can be downloaded from the Web site.</p>	<p>www.pva.org/NEWPVASITE/publications/pubs/PersAsst.htm</p>
<p>Hiring and Management of Personal Care Assistants for Individuals with Spinal Cord Injury covers locating, hiring and training personal assistants. Can be downloaded from the Internet and includes forms, checklists and resources (26 pages).</p>	<p>www.tbi-sci.org/pdf/pas.pdf</p>
<p>Caregivers and Personal Assistants: How to Find, Hire and Manage the People Who Help Your (Or Your Loved One!), Author: Alfred H. DeGraff.</p>	<p>Check your local bookstore or www.amazon.com.</p>

General Disability Resources

The amount of information generated by and for the greater “disability” community is vast, depending on you or your child’s area of interest. Many resources have been developed—many by people with disabilities themselves—to facilitate greater community integration and empower people with disabilities to lead more fulfilling lives. This exchange of information has been greatly enhanced by the popularity of the Internet. Finding the right fit in employment, education and housing (addressed in previous sections of the guide) will go a long way toward successful participation in the community. Some of the more popular general disability resources listed below may provide additional support as your family faces its own challenges. Please note that contact information for the major national disability advocacy organizations appears in Section Eight of this guide.

General Disability Resources

<p>TS Alliance Online Support Community. In partnership with Inspire, the TS Alliance provides a social network for people with TSC and their families to connect with others facing similar challenges.</p>	<p>Visit tsalliance.inspire.com to join.</p>
<p>Disability Resources is a nonprofit organization that reviews hundreds of resources available to people with disabilities. The newsletter, <i>Disability Resources Monthly</i> (DRM) and the “DRM Web Watcher” (an online subject guide to disability resources on the Internet) provide comprehensive information on a wide range of topics, in an easy-to-access format.</p>	<p>Disability Resources, Inc. Dept. IN Four Glatter Lane Centereach, NY 11720-1032 (631) 585-0290 (voice) www.disabilityresources.org To subscribe, e-mail: pubs@disabilityresources.org</p>
<p>BLURT – This site, hosted by the Epilepsy Foundation of America (EFA) is for teens who experience seizures. It includes message boards, personal stories, chat rooms and other features.</p>	<p>Epilepsy Foundation of America 4351 Garden City Drive Landover, MD 20785-7223 (800) 332-1000 (voice) www.efa.org/blurt</p>
<p>Facts for Families – Fact sheets developed by the American Academy of Child & Adolescent Psychiatry (AACAP) provide concise and up-to-date information on issues that affect children, teenagers, and their families. Fact Sheets cover many topics, including autism, learning disabilities, psychiatric medications, long-term illness, substance abuse, mental retardation, talking to your kids about sex, etc.</p>	<p>AACAP 3615 Wisconsin Avenue, NW Washington, DC 20016-3007 (202) 966-7300 (voice) (202) 966-2891 (fax) www.aacap.org/publications/factsfam/index.htm</p>
<p>Our Kids – Adult Support for Parents and Caregivers of Teens and Adults with Disabilities Information, resources, electronic mailing lists for caregivers of teens and adults. Various disability topics are covered.</p>	<p>www.ourkids-kids.org/OKAdults/default.html</p>
<p>Band-aids & Blackboards – This site addresses those issues encountered when growing up with a disability with sections for teens, kids and adults.</p>	<p>www.faculty.fairfield.edu/fleitas/contents.html</p>
<p>Family Voices – Families from throughout the U.S. who have children with special needs. Their “Family Voices Leadership Handbook” (23 pgs.) describes the public systems that support the health care needs of children. It also explains commercial health plans and various laws</p>	<p>Family Voices 3411 Candelaria NE, Suite M Albuquerque, NM 87107 (505) 872-4774 or (888) 835-5669 (voice) (505) 872-4780 (fax)</p>

and provides an overview of government policy.	www.familyvoices.org kidshealth@familyvoices.org
No Easy Task – This Web site combines a mix of health and family informational web sites that offer information on diseases, conditions, symptoms, treatments, forums, chats, personal stories, support, family life and pets. Includes a section on Young Adult and Teen Issues.	www.noeasytask.com
TeenGrowth.com – This Web site is tailored towards the health interests and general well being of teens, offering a secure environment to search for information on topics such as alcohol, drugs, family, friends, school and sex. Also publishes a free weekly e-mail newsletter.	www.teengrowth.com feedback@teengrowth.com
Ability Online – a computer network where children and youth with disabilities connect to each other as well as their friends, family members, caregivers and supporters.	Ability Online Support Network 104-1120 Finch Avenue West Toronto, Ontario M3J 3H7 Canada (416) 650-6207 (voice) (416) 650-5073 (fax) system.manager@ablelink.org www.ablelink.org
Beyond All Barriers E-Zine – this online magazine written by and for teens with disabilities. Includes a chat room, message board, advice columns, legislative decisions and conferences.	<i>newmobility.com</i> – Online resource for disability culture. Sections include a bookstore, message board, chat and links to other disability-related sites. www.newmobility.com
Reach Out Magazine – This online magazine serves as a meeting place for people with disabilities all over the world. The site contains live chat, personals, message boards and a free members only mailing list.	Reach Out Magazine 3090 Sheridan St. PMB# 207 Hollywood, FL 33021-3730 (954) 985-0319 (voice) www.reachoutmag.com
Special Needs Project – Provides books about disabilities, that serve individuals, families and professionals with a large collection of disability-related materials, including titles about Autism and ADHD.	Independent Living and Full Inclusion. Special Needs Project 324 State Street, Suite H Santa Barbara, CA 93101 (800) 333-6867 (voice) www.specialneeds.com
Children With Disabilities: Understanding Sibling Issues, NICHCY News Digest #ND11. This 17 pg. digest focuses in particular on how a child's disability can affect siblings in the family with many of the articles	NICHCY P.O. Box 1492 Washington, DC 20013 (800) 695-0285 (voice/TTY)

<p>written by siblings themselves.</p>	<p>nichey@aed.org www.nichey.org</p>
<p>The Sibling Support Project – A national program dedicated to the interests of brothers and sisters of people with disabilities. Its primary goal is to increase the availability of peer support and educational opportunities for siblings of individuals with disabilities.</p>	<p>Don Meyer Director, Sibling Support Project The Arc of the U.S. 6512 23rd Avenue, NW, Suite 213 Seattle, WA 98117 (206) 297-6368 (voice) www.thearc.org/siblingsupport</p>
<p>Families and Disability News – this newsletter is published by the Beach Center at the University of Kansas. They also publish other publications on a variety of disability related topics, including transition to adulthood.</p>	<p>Beach Center on Disability The University of Kansas Haworth Hall, Room 3136 1200 Sunnyside Avenue Lawrence, KS 66045-7534 (785) 864-7600 (voice) (785) 864-7605 (fax) beach@dole.lsi.ukans.edu www.beachcenter.org</p>
<p>Everyday Warriors – An online gathering place for people of all ages with disabilities and their caregivers. Special sections devoted to issues confronting kids and teens with disabilities.</p>	<p>www.everydaywarriors.com</p>
<p>National Rehabilitation Information Center (NARIC) – this information center includes results of federally funded disability and rehabilitation research projects, an extensive document collection and searchable database. Information Specialists help consumers locate information.</p>	<p>NARIC 4200 Forbes Blvd., Suite 202 Lanham, MD 20706 (800) 346-2742 or (301) 459-5900 (voice) www.naric.com</p>
<p>On a Roll – A weekly radio show that addresses the lives and issues of people with disabilities. For a list of radio stations that carry the show, check their Web site or contact them. The Web site lists “channels” that provide information and human interest stories focusing on such topics as employment, money, relationships and travel from the perspective of a person with a disability.</p>	<p>iCan, Inc. 870 Bowers Street Birmingham, MI 48009 (248) 594-4226 (voice) (877) 275-4226 (toll-free voice) iCare@icanonline.net www.ican.com</p>
<p>Disability Worldwide – A weekly program broadcast by FM stations and over the Internet. Hosted by Jean Parker, disability rights activist. People with disabilities and experts in their fields who discuss the full spectrum of issues related to advancing human rights of people with disabilities around the world.</p>	<p>For a description of the show and to order cassette tapes of previous shows: www.rfpi.org/disabilityradio/index.html For a schedule and stations carrying the show: www.rfpi.org/quarterly-sked.html</p>

<p>Disabilities-R-Us – This Internet chat site was created by and for people with physical disabilities, although everyone is welcome. Site includes a chat room, message board, answers to frequently asked questions and an extensive 11-page list of disability links.</p>	<p>Disabilities-R-Us http://members.tripod.com/~disabled</p>
<p>Parent Advocacy Centers for Educational Rights (PACER CENTER) – These individual centers (one per state) help to expand opportunities and enhance the quality of life for people with disabilities and their families. Adults and families will find useful info from the Web site (e.g., employment, disability rights, emotional & behavioral issues, etc.).</p>	<p>Pacer Center 8161 Normandale Blvd. Minneapolis, MN 55437 (952) 838-9000 (voice) (952) 838-0199 (fax) E-mail: pacer@pacer.org www.pacer.org www.pacer.org/national/parentinfous.htm</p>
<p>Cooking Made Easy – This Web site provides information and assistance for people with developmental disabilities who want to cook independently. Includes easy-to-follow recipes and other helpful cooking and food preparation information.</p>	<p>Eileen Laird Cooking Made Easy P.O. Box 2117 Boone, NC 28607-2117 E-mail: Eileen@cookingmadeeasy.org www.cookingmadeeasy.org</p>
<p>Mealtime Manual for People with Disabilities by Judith Lannefeld Klinger, Howard Institute of Rehabilitation Medicine, publisher, Slack, Inc.</p>	<p>Check with your local library, bookstore or www.amazon.com.</p>

The Importance Social Relationships*

Relationships that foster a sense of belonging and intimacy seem to play a vital role in maintaining health or surviving serious illnesses. Relationships with friends are completely different than those with parents. Friendships are more symmetrical and involve sharing and exchanging. Friendships are important to young children, but there is a change at the beginning of adolescence—a move to intimacy that includes the development of a more exclusive focus, a willingness to talk about oneself and to share problems and advice. Through individual friendships, young people find support and security, negotiate their emotional independence, exchange information, put beliefs and feelings into words and develop a new and different perspective of themselves. The importance of quality of life activities, engaging social relationships and close interpersonal bonds in human life cannot be underestimated. A lack of healthy friendships can create mental health problems for individuals with or without disabilities.

Spending time with people who share the same interests and activities may lead to the development of the friendships and relationships that are so important to an individual’s mental health. The organizations and resources listed on page 74 are provided as a starting point to help young adults with disabilities meet new friends and form new relationships.

Local Chapters of Advocacy Organizations

Local chapters and affiliates of organizations such as United Cerebral Palsy (UCP), The Arc, Epilepsy Foundation and others may provide events and opportunities for social interaction with peers. Contact information for the headquarters of these organizations can be found in Section Eight of this guide.

Clubs and Social Groups

Teens and those moving into adulthood may want to consider pursuing special interests or hobbies through local clubs or social groups. Often, shared hobbies or interests bring people together and provide opportunities for friendships to develop. Participating in different recreation or activities may also provide the chance to make new friends. Many leisure, recreation and travel resources for people with disabilities are listed later in this section of the guide.

Parents of teens may also want to consider forming a social group for the young adults with disabilities in their community. Groups of this type can facilitate socializing among those similar in age and with similar interests. By working with other parents of young adults in your area, it may be possible to find enough interested families who are willing to organize and plan different social events such as: a pizza night; bowling; going to the movies or the beach; or any other activities that interest the teens in the group. Local churches or community centers may be willing to let the group use space in their building (for little or no charge) on a regular basis if available. For more information about forming a group of this type, see the contact information for the Work Study Group listed in the resource chart below.

There may also be opportunities available through your county parks and recreation department, and or local community centers. Check in your local phone book in the blue pages under County or City Government, Department of Parks and Recreation. For what is usually a nominal fee, many county departments of recreation offer classes on a wide variety of topics and field trips to theaters, historical locations, and other points of interest.

Civic and Community Organizations

The YMCA/YWCA and other organizations often provide the chance to participate in activities that improve the community while getting to know others.

Religious and Spiritual Groups

Many local churches, synagogues or mosques host teen and young adult social groups and activities for people who want to socialize with members of the same faith.

*Portions of this section were excerpted from the following sources: *Social Relationships, Connectedness, and Health: The Bonds that Heal*, A Summary of a Presentation by Lisa F. Berkman, Ph.D., Harvard School of Public Health, NIH Record, May 22, 1997, *The Importance of Friendship*, Authors: Shucksmith, Hendry, Love & Glendinning, The Scottish Council for Research in Education, Research in Education, No. 52, Spring 1993, *Why Happiness is Good For You: A Commentary on Fredrickson*, Author: Laura King, Prevention & Treatment, Volume 3, Article 4, March 2000, American Psychological Association.

Community Resources

Best Buddies –Provides opportunities for one-to-one friendships and integrated employment for people with mental retardation. Programs include the Best Buddies	Best Buddies Headquarters 100 SE Second Street, #1900 Miami, FL 33131
--	---

<p>Middle Schools, Best Buddies High Schools, Best Buddies Colleges, and e-buddies. Not all programs are available in every state.</p>	<p>(305) 374-2233 (voice) (305) 374-5305 (fax) Lavelnel@BestBuddies.org www.bestbuddies.org/about/index.asp</p>
<p>YWCA – Local chapters at hundreds of locations across the country offer programs to young women. Services offered will vary by location, but may include sports and physical fitness programs, employment training and placement services, child care services and health education services.</p>	<p>YMCA – There are more than 2,400 YMCAs located in the U.S., all with different programs and events. www.ymca.net/find_your_y/findy.htm</p> <p>YMCA (888) 333-9622 (voice)</p> <p>YWCA of the U.S.A. Empire State Building 350 Fifth Avenue, Suite 301 New York, NY 10118 (212) 273-7800 (voice) (212) 465-2281 (fax) www.ywca.org</p>

Romantic Relationships

People with disabilities, like all people, are sexual beings. While topics such as birth control, avoiding sexually transmitted diseases (such as HIV or syphilis) and genetic testing may be somewhat sensitive and difficult to discuss, providing reliable and accurate information about issues related to sexuality is very important so your child with a disability can make an informed decision. The resources listed on the next page provide additional information in the areas of maintaining sexual health, reproduction and family planning.

The Importance of Genetic Counseling and Testing for TSC

Families of young adults with TSC who currently are, or plan on becoming, sexually active need to be aware there is a **50 percent** chance they may pass on their genetic disorder to their offspring. It is strongly recommended that prior to having a family, an individual with TSC consult with a genetic counselor.

Genetic Counseling

Genetic counselors are health professionals with specialized graduate degrees and experience in the areas of medical genetics and counseling. Genetic counselors work as members of a health care team, providing information to families who have members with genetic disorders and to families who may be at risk for a variety of inherited conditions. Counselors identify families at risk, investigate the problem present in the family, interpret information about the disorder, analyze inheritance patterns, and risks of recurrence, and review available options with the family. Genetic counselors also provide supportive counseling to families, serve as patient advocates, and refer individuals and families to community or state support services. Ask your physician for a referral to a genetic counselor, or contact the National Society of Genetic Counselors (listed in the chart below) to find a genetic counselor in your area.

Genetic Testing

Genetic testing is just one of the tools used by doctors and genetic counselors. Molecular genetic testing is available for many inherited diseases. There are three primary uses for this DNA testing: 1)

confirmation of diagnosis made on clinical grounds, 2) ease of testing for other at-risk family members, and 3) prenatal diagnosis.

For additional information about the genetic test for TSC, please contact Athena Diagnostics at (800) 394-4493 or visit www.athenadiagnostics.com. Complete contact information for Athena Diagnostics is listed in the resource chart below.

Sexuality, Family Planning, Genetic Counseling Resources

<p>Sexual Health Network – This Web site deals with all types of sexuality-related topics. Click on the <i>Disabilities or Illness Section</i>.</p>	<p>www.sexualhealth.com</p>
<p>Materials on the Subject of Sexuality, published by The ARC of Minnesota – This 8-page bibliography lists publications and videos that deal with sexual education and related issues for adults with disabilities and their families. Minnesota residents can borrow materials for free. Others must order materials directly from the source.</p>	<p>www.arcminnesota.com/res-sexuality.htm</p>
<p>Genetic Counseling Referral Service – For basic information about genetic counseling and to find a genetic counselor in your area.</p>	<p>National Society of Genetic Counselors, Inc. 233 Canterbury Dr. Wallingford, PA 19086-6617 (610) 872-7608 (voice) www.nsgc.org nsgc@nsgc.org</p>
<p>Genetic Testing – Consult first with your physician and/or genetic counselor. Genetic Test for tuberous sclerosis is available through Athena Diagnostics.</p>	<p>Athena Diagnostics, Inc. Four Biotech Park 377 Plantation Street Worcester, MA 01605 (800) 394-4493 (Ext. 2) (voice) (508) 756-2886 (voice) (508) 753-5601 (fax) www.athenadiagnostics.com</p>
<p>Sexuality Education for Children & Youth with Disabilities – NICHCY News Digest #ND17, 1992 – This 43-page digest addresses the concerns related to informing children with disabilities in their social-sexual development and in preparing them to make healthy, decisions about adult relationships. Includes a list of books and videos on human sexuality.</p>	<p>NICHCY P.O. Box 1492 Washington, DC 20013 (800) 695-0285 (voice/TTY) nichcy@aed.org www.nichcy.org</p>

Recreation, Sports, Leisure and Travel

Recreation and leisure time are important to a healthy life. Although participating in sports, traveling and other leisure activities may be somewhat more challenging for individuals with disabilities, it can be done. Many organizations and resources are available to facilitate the participation of people with disabilities in sports, recreation, travel, and other leisure activities. Below is a partial list of organizations that can provide additional information to young adults who may want to participate in these types of activities.

Recreation, Sports and Leisure Resources

<p>Disabled Sports is the nation's largest organization providing year-round sports and activities to adults and children with disabilities. Chapters serve all 50 states and offer activities such as skiing, bicycling, camping, sailing and more.</p>	<p>Disabled Sports USA 451 Hungerford Dr., #100 Rockville, MD 20850 (301) 217-9840 (voice) information@dsusa.org www.dsusa.org</p>
<p>Special Olympics is an international organization dedicated to empowering individuals with mental retardation become physically fit, productive and respected members of society through sports training and competition. Offers people with MR year-round training and competition in Olympic-type summer and winter sports.</p>	<p>Special Olympics North America 1325 G Street, NW, #770 Washington, DC 20005 (202) 824-0327 (voice) info@specialolympics.org www.specialolympics.org</p>
<p>Wheelchair Sports USA is a volunteer organization that has been developed by wheelchair athletes and wheelchair sports enthusiasts.</p>	<p>Wheelchair Sports, USA 3595 E. Fountain Blvd., #L-1 Colorado Springs, CO 80910 (719) 574-1150 (voice) (719) 574-9840 (fax) wsusa@aol.com www.wsusa.org</p>
<p>MIUSA is a nonprofit organization that provides opportunities for persons with disabilities to participate in international educational exchange programs and travel. MIUSA provides information services in the areas of travel and placement in international work camps and educational exchange programs.</p>	<p>Mobility International USA (MIUSA) P.O. Box 10767 Eugene, OR 97440 (541) 343-1284 (voice) info@miusa.org www.miusa.org</p>
<p>NIAD operates a creative visual arts center for adults with disabilities. It has published "The Creative Spirit", a collection of works by NIAD artists and a directory of art centers for people with disabilities. NIAD responds to requests for information and provides referrals to local programs.</p>	<p>National Institute of Art & Disabilities (NIAD) 551 23rd Street Richmond, CA 94804 (510) 620-0290 (voice) E-mail: redot@niad.art.org www.niadart.org</p>

<p>Lifelong Leisure Skills & Lifestyles for Persons with Developmental Disabilities. Authors: Schleien, Meyer, Heyne, 1995.</p>	<p>Paul H. Brooke Publishing P.O. Box 10624 Baltimore, MD (800) 638-3775 (voice) www.brookespublishing.com</p>
--	---

Travel

Whether a family wants to travel around the corner or around the world, laws and regulations exist to ensure people with disabilities are treated without discrimination in a way consistent with safe passage of all passengers.

Air Travel

In the area of air travel rights, the Air Carrier Access Rules are designed to minimize the special problems travelers with disabilities face as they negotiate their way through the nation’s complex air travel system to and from their destination. The Federal Aviation Administration (FAA) has developed a very helpful Web site that provides a brief, but authoritative source of information about the Air Carrier Access rules: the accommodations, facilities and services that are now available. To obtain a copy of this guide entitled, “New Horizons—Information for the Air Traveler with Disabilities,” see the contact information listed in the travel resource chart below.

Most major airlines have a section on their Web site devoted to travelers with disabilities. Some sites are better than others, but most cover basic areas such as traveling with special equipment, personal-care attendants, and any additional assistance that may be provided to a traveler before, during or after a flight. Airlines may have different policies and procedures for each of these areas; therefore, it is best to contact the airline directly prior to traveling to ensure that your flight goes smoothly.

Air Travel Service Problems

The Aviation Consumer Protection Division (ACPD) operates a complaint system for air travel service problems. If your complaint concerns accessibility problems experienced by a traveler with a disability, there are special forms that can be downloaded from airconsumer.ost.dot.gov/.

Please note that the ACPD does not mediate individual consumer complaints, but all complaints are entered into Department of Transportation’s (DOT) aviation industry monitoring system and are charged to the company in question in the monthly *Air Travel Consumer Report*. The ACPD also publishes a number of booklets and fact sheets (also available from their Web site) that address air travel consumer protection issues.

Airport Complaints

Airports that receive federal financial assistance are subject to Section 504 of the Rehabilitation Act of 1973, as amended and the DOT’s implementing regulation 49 CFR Part 27. Airports owned by a public entity such as a local government are subject to the Department of Justice regulation 28 CFR Part 3 implementing Title II of the Americans with Disabilities Act. This regulation applies whether or not an airport receives federal financial assistance. Specifically, 49 CFR Part 37 including Sections 37.33 (a) and (b) also apply to an airport if it is a designated or fixed route system. 49 CFR Parts 37 and 38 are the DOT regulations implementing Title II of the ADA. If you believe that there has been a violation of one of these regulations, file a complaint with the office listed below:

Federal Aviation Administration
 Office of Civil Rights (ACR-4)
 800 Independence Avenue, SW
 Washington, DC 20591
 (202) 267-3270

Bus and Rail Travel

Other transportation providers, in compliance with the Americans With Disabilities Act and other laws, must also provide certain types of assistance, information, and services for travelers with disabilities. Contact Amtrak and Greyhound (listed in the Travel Resources Chart below) about the services and assistance provided.

Regardless of the mode of transportation you choose, it is strongly recommended you make your travel arrangements well in advance to ensure availability of the accommodations that will best suit your needs. Contact transportation providers and hotels in advance if you have any questions about the services or assistance provided.

Travel Resources

<p>New Horizons – Information for the Air Traveler with a Disability, published by the FAA. This 13-pg. guide provides information about planning your trip, what to expect at the airport, getting on and off the plane, assistive devices, and compliance procedures.</p>	<p>U.S. Department of Transportation Aviation Consumer Protection Division, C-75 400 Seventh Street, SW Washington, DC 20590 www.faa.gov/acr/dat.htm</p>
<p>Amtrak – Their Web site provides information about the accessible services provided to passengers, including boarding with wheelchairs, medications, special dietary requirements, accessible coaches and more. There are a limited number of accessible spaces available on each train, therefore, Amtrak strongly recommends that travelers make their reservations as early as possible.</p>	<p>Amtrak (800) 872-7245 (voice) www.amtrak.com/plan/accessibility.html service@sales.amtrak.com</p>
<p>The National Park Service has more than 350 national parks, activities, and programs. Information on accessibility of park programs and facilities is best acquired directly from the park you plan to visit. The Web site provides specific accessibility information about each park. The Golden Access Passport is a lifetime entrance pass to national parks that charge an entrance fee and is offered to U.S. citizens with a permanent disability. Pass holders are also eligible for discounts on some facility fees such as swimming, camping, etc. This can be obtained by showing proof of medically determined disability or eligibility for receiving benefits under federal law.</p>	<p>Department of the Interior Office of Accessibility National Park Service (NPS) 1849 C St., NW, Room 7253 Washington, DC 20240 (202) 565-1244 (voice) www.nps.gov/parkshtm</p> <p>For more information about the Golden Access Passport: www.nps.gov/fees_passes.htm</p>

<p>Easy Access to National Parks: The Sierra Club Guide for Persons with Disabilities. This book is available from the Sierra Club.</p>	<p>Sierra Club Books 85 Second Street, 2nd Floor San Francisco, CA 94105 (800) 935-1056 (voice) www.sierraclub.org/books/</p>
<p>Guided Tour, Inc. – Professionally supervised travel and vacation program for people with cognitive and physical disabilities. Travelers are people with developmental disabilities ages 17 and up from all over the country. Contact Guided Tour for rates, dates and program information.</p>	<p>The Guided Tour, Inc. 7900 Old York Rd., Suite 114-B Elkins Park, PA 19027-2339 (800) 783-5841(voice) (215) 782-1370 (voice) (215) 635-2637 (fax) gtour400@aol.com www.guidedtour.com</p>
<p>Toll Free Numbers of Accessible Transportation Providers – This handy list provides the toll-free numbers for all major airlines, bus and train providers as well as car rental companies and most major hotel chains. The list may be useful when contacting many different companies to obtain travel information.</p>	<p>www.projectaction.org/paweb/800num.htm</p>

Section Eight: End of Life Issues

Many individuals with TSC live long and relatively healthy lives. Unfortunately, some people with TSC may see their health problems increase and worsen as they age. Complications resulting from TSC may ultimately lead to a premature death. This section of the guide provides resource information about some of the most difficult decisions a family may have to make as their loved one becomes very ill and approaches the end of his or her life. The section contains the following information:

- Hospice Care
- Grief and Bereavement
- Other End of Life Information and Resources

Hospice Care

What is hospice?

Hospice care involves a core interdisciplinary team of professionals and volunteers who provide medical, psychological, and spiritual support to the terminally ill, as well as support for the patient's family. The care is primarily based in the home, enabling families to remain together in peace, comfort and dignity.

How Does Hospice Care Work?

Hospice care follows a team-oriented approach to medical care, pain management, and emotional and spiritual support tailored to the patient's needs and wishes. The team is usually comprised of the patient, family, the personal physician, a hospice physician, nurses, home health aides, social workers, clergy and trained volunteers. Hospice staff members are on-call 24 hours a day, 7 days a week.

How Do I Find Hospice Care?

Finding a program that meets your needs may take some research, but it will be time well spent. Ask your physician or discharge planner to for help in locating hospice organizations in your area. Or, contact the National Hospice and Palliative Care Organization (see contact information on next page) help line or visit www.nhpc.org to find a hospice program close to you.

Listed below are some of the questions you should ask when comparing and selecting hospice programs:

- Is the agency accredited by a nationally recognized, accrediting body (this usually means they meet high standards and provide quality care)?
- Is the program Medicaid-certified (these programs have to meet federal standards for patient care)?
- How many years has the agency been serving the community? Can it provide references from physicians, social workers or families who have used the services?
- What services does the hospice provide (these may include nursing care, continuous care in the home, spiritual support and counseling, physician services, 24-hour on-call availability, and other support services)? Be aware that not every program provides every service. It's best to know what services are provided before making your final selection.

- How flexible is the organization? Is it willing to provide the services and assistance you want and need (for example is it staffed to provide home care vs. facility care)?

Who Pays for Hospice Care?

Hospice services are covered under Medicare, and most states offer hospice care as an option under their Medicaid programs. Many private health insurance companies, HMOs and other managed care organizations cover hospice care for patients who meet the eligibility requirements. There may be co-pays, deductibles and other out-of-pocket expenses depending on the program and the services the patient needs. Military personnel and their dependents are covered for hospice under CHAMPUS. Hospices rely heavily on grants and community support to fund un-reimbursed care and hospice services for patients with little or no insurance. Most hospice services are based upon need, rather than ability to pay. However, it is important for families to find out what the costs will be and what will and will not be covered before services begin.

The Medicare Hospice Benefit is designed to meet the needs of those who have a terminal illness, providing them and their loved ones with the special support and services not otherwise covered by Medicare. Contact Medicare at (800) 633-4227 for more information about this benefit.

Hospice Resources

<p>Books, videos, brochures and a newsletter about hospice and living with grief.</p>	<p>Hospice Foundation of America (800) 854-3402 www.hospicefoundation.org</p>
<p>Hospice Patients Alliance Family Guide to Hospice (What No Hospice Will Tell You)! This nonprofit organization serves hospice patients, families and caregivers.</p>	<p>Hospice Patients Alliance, Inc. (616) 866-9127 www.hospicepatients.org</p>
<p>Consumer Guide to Selecting a Hospice Program, information about hospice care and the Medicare Hospice Benefit and communicating end of life wishes. Many of sections of the Web site are written in Spanish.</p>	<p>National Hospital and Palliative Care Organization (800) 243-5900 www.nhpo.org</p>
<p>How to Choose a Home Care Provider: A Consumer’s Guide. Full text of the guide is available on their Web site. The NAHC represents home care agencies, hospices and home care aide organizations.</p>	<p>National Association for Home Care (202) 547-7424 www.nahc.org</p>

Grief and Bereavement

When dealing with the death of someone as a result of tuberous sclerosis complex (TSC) and its complications, you may wonder how you will carry on. How can you perform your job and manage other family or personal responsibilities? Coping with this traumatic event and its aftermath will be one of the most difficult things you will ever have to do in your life. The finality of death brings to those left behind a tremendous amount of emotional pain. Grief is not something abnormal; rather, it is a normal and inevitable step in our journey through life.

Grieving is difficult because it involves many intense feelings—love, sadness, anger, relief, compassion, regret, hate or happiness, to name a few. Not everyone experiences all of these feelings, but some people may experience many of them at the same time.

Bereavement and grief can feel like an inescapable journey that has to be endured. Some people prefer to travel this path alone in dealing with their feelings. Others prefer to deal with their loss by talking with friends and family. The support of a counselor, social worker or other professional can be very helpful in working through the grieving process. Discussing your grief with a mental health professional provides an opportunity to talk to a third party, who, unlike friends and relatives (who are likely dealing with their own grief), is not emotionally involved. It helps to remember that in time your grief will heal. Grieving the loss of a loved one is a process.

Common Stages of Grief

1. **Shock** – Immediately following the death of a loved one, it is difficult to accept the loss, even if the individual had been ill for sometime and their death was expected. A feeling of unreality occurs. During those first few days, there is a feeling of being out-of-touch.
2. **Denial** – You may deny that a loss has occurred. You may feel numb. Denial may last a few moments or indefinitely.
3. **Anger** – When you can no longer deny that a loss has taken place, you may become very angry. Your anger may be at the TSC that caused the loss of your loved one. Your anger may be turned toward the world, yourself or your family members.
4. **Bargaining** – You may feel that somehow you can make up for the loss if you had done something differently. At this stage you may also feel guilty about failures to do enough for the person who died, guilt about what happened or didn't happen.
5. **Depression** – A feeling of hopelessness may set in as you realize that the loss is final and nothing you can do will change it. The ability to concentrate on day-to-day activities may be severely limited.
6. **Acceptance/Reconciliation of Grief** – In this final stage, balance in your life returns little by little. There are no set time frames for healing. Each individual is different.
7. **Hope** – The sharp, ever-present pain of grief will lessen and hope for a different life emerges. Plans are made for the future and the individual is able to move forward with good feelings knowing they will always remember and have memories of their loved one.

How long each stage lasts depends on the nature of the loss and your reaction to it, but the odds are that some point you will reach acceptance. Be aware that in addition to intense emotional feelings, you may also exhibit physical symptoms such as hollowness in the stomach, tightness in the throat and chest, dry mouth and a lack of energy. Grieving is difficult and takes time. Recognize that you will have good days and bad days. Listed below are some things to consider as you work through the process:

Dos and Don'ts

Do:

- Take the time you need to grieve. Don't let others rush you into "getting over" your feelings.
- Take the time to sleep, rest, think and spend time with people who are supportive.

- Take good care of yourself. Eat nutritiously and regularly.
- Express your feelings. Cry. Tears are the healthiest expression of grief. Don't try to hold back crying for the sake of others.
- Remember the loved one as often as you need to do so.
- Drive more carefully.
- Express your needs clearly.
- Ask for professional help if needed (see resources listed below).
- Remember there is hope.

Don't:

- Make major decisions. The time of grief is a time of instability.
- Bottle up feelings.
- Expect the memories to go away—feelings will stay with you for a long time and will reappear throughout your life.
- Avoid talking about what happened.
- Forget that siblings and other family members will experience similar feelings.
- Use alcohol or drugs to numb the painful feelings.

Be sure to seek out grief counseling if needed. Grief counseling is available through many sources. Ask your physician for a referral or contact your local health agency. They will be able to refer you to a licensed therapist. You may also want to join a local or Internet support group.

Grief and Bereavement Resources

<p>The Grief Recovery Handbook: The Action Program for Moving Forward Beyond Death, Divorce, and Other Losses, Authors: John W. James & Russell Friedman.</p>	<p>Check local bookstores or www.amazon.com.</p>
<p>Awakening from Grief: Finding the Road Back to Joy, Author: John E. Welshons.</p>	<p>Check local bookstores or www.amazon.com.</p>
<p>On Death and Dying, Author: Elisabeth Kubler-Ross.</p>	<p>Check local bookstores or www.amazon.com.</p>
<p>The Grieving Child: A Parents Guide, Authors: Helen Fitzgerald, Elisabeth Kubler-Ross.</p>	<p>Check local bookstores or www.amazon.com.</p>

<p>GriefNet.Org – an Internet community of persons dealing with grief. They host 47 e-mail support groups and two Web sites. KIDSAID provides a safe environment for kids and their parents to find information and answer questions. They also publish a newsletter and sell grief-related books and videos through their online bookstore.</p>	<p>www.griefnet.org www.kidsaid.com</p>
--	---

Other End of Life Issues and Resources

An advance directive tells your doctor what kind of care you would like to have if you become unable to make or communicate such decisions for yourself. Advance directive forms vary from state to state. The most commonly prepared advanced directives are living wills and medical powers of attorney (refer to the Life and Financial Planning section of this guide). **Consult with a lawyer for specific information and counsel about your situation and the laws in your state!** Additional resources for issues related to end of life issues and health care ethics are also listed in the chart below.

End of Life Resources

<p>National Guardianship Association - their mission is to establish and promote a nationally recognized standard of excellence in guardianship. Membership provides access to the NGA newsletter, use of the ethics hotline and extensive links for guardianship management.</p>	<p>National Guardianship Association 1604 N. Country Club Rd. Tucson, AZ 85716-3102 (520) 881-6561 (phone) (520) 325-7925 (fax) www.guardianship.org</p>
<p>Consumer’s Tool Kit for Health Care Advance Planning, published by the American Bar Association, this kit contains 10 ‘tools’ including self-help worksheets, suggestions and resources. The kit does not provide formal legal advice, however it helps the user to discover, clarify and convey what is important in the face of serious illness.</p>	<p>American Bar Association 740 15th Street, NW Washington, DC 20005 (202) 662-1000 E-mail: orders@abanet.org www.abanet.org/aging/toolkit/home.html</p>

Section Nine: National Nonprofit Organizations

The national organizations listed below provide a variety of assistance and services to people with disabilities and their families. Due to the large numbers of these programs, it is impossible for the TS Alliance to track each of these programs individually. The resources and programs available from these organizations and agencies *may* include the following:

- Education and Resource Information
- Publications, Books, Videos
- Newsletters (both print and electronic)
- Recreation/Sports Events
- Respite Care
- Discussion/Support Groups
- Life Skills/Independent Living Skills Training
- Adult Day Services
- Employment, Vocational Training, Job Placement
- Advocacy Services
- Referral Services to Community Resources
- Lobbying and Legislative Advocacy

Please note that not every organization will provide every type of service. However, while an organization may focus on one type of disability, it may offer support to individuals with any type or combination of disabilities.

While some of the resources these groups provide are described in previous sections of the guide, we strongly suggest that you contact the appropriate groups directly to learn more about what is available in your community. Services and support will *vary greatly* by organization and location. For example, the national office of The ARC provides a wide range of publications dealing with issues surrounding mental retardation, while a local chapter of The ARC may provide job training and placement services or day activities for adults with disabilities in your community.

Many of the organizations have chapter locators on their Web sites that enable users to find the chapter(s) located in their state. If you don't have Internet access, contact the national office and ask them to refer you to the chapter nearest you. If the chapter or affiliate in your community does not provide the type of assistance you are looking for, they may know of another organization in your area that does.

Disclaimer: The contact information included in this guide was correct at the time of printing. However, locations and phone numbers of these groups may change from time to time. If an address or phone number is no longer working, please contact the TS Alliance so that we can update our information for future versions of The Young Adult Guide of the Life Stages Program.

National Nonprofit Disability Organizations

Tuberous Sclerosis Alliance	801 Roeder Road, Suite 750 Silver Spring, MD 20910 (800) 225-6872 or (301) 562-9890 (voice) (301) 562-9870 (fax) www.tsalliance.org info@tsalliance.org
The Arc (formerly The Association for Retarded Citizens) of the U.S.	1010 Wayne Avenue, Suite 650 Silver Spring, MD 20910 (301) 565-3842 (voice) (301) 565-3843 (fax) www.thearc.org info@thearc.org
Autism Society of America	7910 Woodmont Avenue, Suite 300 Bethesda, MD 20814-3067 (301) 657-0881 or (800) 328-8476 (voice) (301) 657-0869(fax) www.autism.org info@autism-society.org
Autism Speaks	1 East 33 rd Street, 4 th Floor New York, NY 10016 (888) 288-4762 (voice) contactus@autismspeaks.org www.autismspeaks.org
Epilepsy Foundation of America	4351 Garden City Drive Landover, MD 20785-7223 (800) 332-1000 (voice) www.efa.org
Children & Adults with Attention-Deficit/Hyperactivity Disorder (CHADD)	8181 Professional Place, Suite 201 Landover, MD 20785 (301) 306-7070 or (800) 233-4050 (voice) (301) 306-7090 (fax) www.chadd.org national@chadd.org
Attention Deficit Disorder Association (ADDA)	1788 Second Street, Suite 200 Highland Park, IL 60035 (847) 432-2332 (voice) (847) 432-5874 (fax) www.add.org mail@add.org

The Attention Deficit Information Network, Inc	58 Prince St. Needham, MA 02492 (781) 455-9895 www.addinfonetwork.com adin@gis.net
UCP (United Cerebral Palsy)	1660 L Street, NW, Suite 700 Washington, DC 20036 (800) 872-5827 (voice) (202) 776-0406 (TTY) (202) 776-0414 (fax) www.ucp.org webmaster@ucp.org
American Association of People with Disabilities	1819 H Street, NW, Suite 330 Washington, DC (800) 840-8844 or (202) 457-0046 (voice) (202) 457-0473 (fax) www.aapd.com
Genetic Alliance	4301 Connecticut Ave., NW, Suite 404 Washington, DC 20008-2304 (202) 966-5557 (voice) (202) 966-8553 (fax) www.geneticalliance.org info@geneticalliance.org
Goodwill Industries International	9200 Rockville Pike Bethesda, MD 20814 (240) 333-5200 (voice) www.goodwill.org contactus@goodwill.org
International Association of Jewish Vocational Services	1845 Walnut Street, Suite 640 Philadelphia, PA 19103 (215) 854-0233 (voice) (215) 854-0212 (fax) www.iajvs.org
Learning Disabilities Association of America	4156 Library Road Pittsburgh, PA 15234-1349 (412) 341-1515 (voice) (412) 344-0224 (fax) www.ldanatl.org info@ldaamerica.org

National Family Caregivers Association (NFCA)	1040 Connecticut Avenue, #1500 Kensington, MD 20895-3944 (800) 896-3650 (voice) (301) 942-2302 (fax) www.nfcacares.org info@nfcacares.org
National Alliance for the Mentally Ill (NAMI) Colonial	Place Three, 2107 Wilson Blvd. Arlington, VA 22201 (703) 524-7600 (voice) (800) 950-6264 NAMI Helpline (voice) www.nami.org
National Center for Learning Disabilities	381 Park Avenue South, Suite 1401 New York, NY 10016 (888) 575-7373 (voice) (212) 545-7510 (voice) (212) 545-9665 (fax) www.ld.org
National Organization for Rare Disorders	P.O. Box 1968 Danbury, CT 06813 (800) 999-6673 (voice) www.rarediseases.org
Special Needs Advocate for Parents (SNAP)	1801 Avenue of the Stars, #401 Century City, CA 90067 (888) 310-9889 or (310) 201-9614 (voice) (310) 201-9889 (fax) www.snapinfo.org info@snapinfo.org

Appendix 1: Sample Telephone and Contact Log

This telephone log can help you keep track of the organizations and agencies you contact for information or assistance and the results of those conversations. It may be easy to keep track of whom you spoke to when first searching for information. However, the more time passes and the more people you talk with, remembering whom you spoke to and what they said can become more difficult. This log sheet may help to keep track of the information you received.

Agency Contacted: _____

Person to Whom You Spoke: _____

Phone: _____ **Web Site:** _____ **Date Called:** _____

Topic or Concern: _____

Results of Conversation:

Actions Taken (if any): _____

Follow Up (if any): _____

Additional Topics this Person/Organization May be Helpful With:

Appendix 2: Constituent Satisfaction Survey

The content of this guide reflects the types of questions received most often by the Tuberous Sclerosis Alliance. We hope it has been helpful in answering your questions. Please take a few minutes to give us your feedback about the Young Adult Guide of the Life Stages Program. Please return this form to:

Tuberous Sclerosis Alliance
801 Roeder Road, Suite 750, Silver Spring, MD 20910
Attention: Dena Hook

If you'd like to speak to someone about this guide, contact Dena Hook at (800) 225-6872.

Thanks for taking the time to share your thoughts with us!

1. How did you hear about the *Young Adult Guide of the Life Stages Program*?

Perspective Newsletter Article TS Alliance Web Site TS Alliance Staff Person
 Online Discussion Group Social Media (i.e., Facebook) Community Alliance
 Other (please indicate): _____

2. What Section(s) Did You Find the Most Helpful? Please check all that apply.

Section One – Legal Rights Under Disability Law
 Section Two – Transition Planning
 Section Three – Life and Financial Planning
 Section Four – Assistive Technology
 Section Five – Education, Vocational Programs and Employment
 Section Six – Housing and Independent Living
 Section Seven – Community Integration, Relationships and Recreation
 Section Eight – End of Life Issues
 Section Nine – National Nonprofit Organizations
 Appendix 1 – Telephone Log Sheet

3. What Section(s) Did You Find Least Helpful? (Please check all that apply)

Section One – Legal Rights Under Disability Law
 Section Two – Transition Planning
 Section Three – Life and Financial Planning
 Section Four – Assistive Technology
 Section Five – Education, Vocational Programs & Employment
 Section Six – Housing and Independent Living
 Section Seven – Community Integration, Relationships and Recreation
 Section Eight – End of Life Issues
 Section Nine – National Nonprofit Organizations
 Appendix 1 – Telephone Log Sheet

4. What other types of information would you like to see included in the guide (please be specific)?

5. Overall, did you think the Young Adult Guide of the Life Stages Program was helpful?

Yes No

If not, how can it be improved? _____

6. Would you recommend this guide to other families of individuals with TS? Yes No

7. Please share any other comments or suggestions that you have for future editions of the guide.

Thank you for completing this survey! Your input will help us to improve future versions of this guide.