

The School-Aged Guide of the Life Stages Program
A Resource Guide for Parents of School-Aged Children with
Tuberous Sclerosis

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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 for 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 that 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 that are commonly experienced in each age range:

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

The School-Aged Guide of the Life Stages Program focuses on those areas that are often of greatest concern from the age of 6-13 (e.g., legal rights, obtaining special education services, assistive technology, financial planning, 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.

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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.

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The Tuberous Sclerosis Alliance is dedicated to finding a cure for tuberous sclerosis while improving the lives of those affected.

Introduction

Who is the School-Aged Guide of the Life Stages Program designed for?

- Parents of school-aged children (between the ages of 6-13) with TSC
- Other family members or caregivers who may be involved with or responsible for the care of a school-aged child with TSC

What is the purpose of the School-Aged Guide?

The purpose of the School-Aged Guide of the Life Stages Program is to provide helpful resource information for parents and families of school-aged children with TSC. For easy reference, the information contained in this guide is organized into seven 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 (including the *Americans with Disabilities Act (ADA)* and the *Individuals with Disabilities Education Act (IDEA)*), how to find legal assistance, and general disability law resources.
- ***Section Two: Education***—Describes the educational rights of children with disabilities. Explains how to obtain special education for your child under the *IDEA*, developing an Individual Education Program (IEP) and special education resources.
- ***Section Three: Life & Financial Planning***—Describes how to provide for a child with disabilities after the death of his or her parents. Includes information about financial and estate planning such as guardianships, trusts and wills, public disability benefit programs such as Social Security and Medicaid and ensuring eligibility for those programs, and private insurance considerations (pre-existing conditions, factors to consider when selecting insurance, etc.).
- ***Section Four: Assistive Technology***—Defines assistive technology. Describes assistive technology projects and products and includes assistive technology resources.
- ***Section Five: Staying Healthy & Family Support***—Discusses the importance of staying healthy, how to communicate with your child and his siblings about the disability, and coping strategies that can be used by all family members to deal with the challenges that result from TS. This section also includes leisure, recreation and travel information. Family support and general disability resources are also included as well as where to find adaptive clothing and equipment, and cosmetic products.

Section Six: Looking to the Future—This section briefly addresses those areas that become more important as your child matures, including transition planning, housing and employment.

Section Seven: Contact Information for National Disability and Related Organizations

Includes headquarter office contact information (address, phone, Web site and e-mail) 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 & Contact Log-- This form may be helpful in keeping track of the information you receive when contacting different organizations.

Appendix 2: Constituent 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.

A note about contact information

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 Internet and E-mail addresses are provided.

DISCLAIMER: Please note that 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 that this guide is not intended to provide specific financial, legal, medical or other professional 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 caregivers identify the types of programs that may be available in their area.

Section One - Legal Rights Under Disability Law

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

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:

- A physical or mental impairment that substantially limits one or major life activities of the individual.
- A record of such impairment
- 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.

What is the IDEA?

Under the Individuals with Disabilities Education Act (IDEA), public schools are required to make available to all eligible children with disabilities a free appropriate education (FAPE) in the least restrictive environment appropriate to their individual needs. IDEA requires public school systems to develop appropriate Individualized Education Programs (IEP's) 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, special education representative and other individuals as requested by the parent or other agencies involved). The IEP must be reviewed at least annually.

IDEA and Transition Services

Transition services are defined in the *1997 Reauthorization of the IDEA* as a coordinated set of activities for a student, designed with an outcome-oriented process and based upon the individual student's needs, that promotes movement from school to post-school activities. The post-school activities include post-secondary education, vocational training, integrated

employment (including supported employment), continuing and adult education, adult services, independent living, and community participation. Transition planning involves planning for and coordinating services such as those provided by the Department of Mental Retardation, Department of Vocational Rehabilitation, etc., to enable a young adult to live as independently as possible as an adult. This transition plan is a required part of the IEP after the age of 14. By age 16, the IEP should contain a statement of needed transition services. For more information about transition planning, you may want to request a copy of the *Young Adult Guide of the Life Stages Program* from the Tuberous Sclerosis Alliance.

Related Laws

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.

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 this 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.

Disability Law Resources

For More Information About:	Contact:
<i>General Disability Rights Information</i>	ADA Information Line (800) 514-0301 (voice) (800) 514-0308 (TTY) www.usdoj.gov/crt/ada/adahoml.htm
<i>ADA – Title II</i> , Questions and complaints about	Office of Civil Rights,

Public Transportation Services (city buses, subways, para transit services, etc.)	Federal Transit Administration Dept. of Transportation 400 Seventh St., SW Washington, DC 20590 (888) 446-4511 (voice) www.fta.dot.gov/office/civ.htm
ADA Title II - Accessing state and local government programs, services, and activities (public education, employment, transportation, recreation, health care, social services, etc.). ADA – Title III Public Accommodations provided by businesses and nonprofit service providers (movie theaters, zoos, day care centers, recreation centers, etc.)	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)
Wrightslaw – Provides parents, advocates, educators and attorneys with information about effective advocacy for children with disabilities.	Pete and Pam Wright P.O. Box 1008 Deltaville, VA 23043 www.wrightslaw.com
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.	www.specialedlaw.net/index.my
Air Carrier Access Act – Prohibits discrimination in air transportation. Applies only to air carriers that provide regularly scheduled services for hire to the public.	Aviation Consumer Protection Division U.S. Department of Transportation 400 Seventh Street, SW, Rm. 4107, C-75 Washington, DC 20590 (202) 366-2220 (202) 755-7687 (TTY) www.dot.gov/airconsumer
Family and Medical Leave Act – Fact Sheet #028 provides detailed information about the act and can be printed from the Web site (5 pages when printed).	Contact nearest office of Wage and Hour Division, listed in most telephone directories under U.S. Government, Department of Labor. www.dol.gov/dol/esa/fmla.htm
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.	U.S. Department of Justice ADA Information Line (800) 514-0301 (voice) (800) 514-0383 (TTY) www.usdoj.gov/crt/ada/adatacel.htm
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 not provided to individuals. But it is a good starting point for basic legal information. The site links to a nationwide directory of programs that provide pro bono services by state and a state-by-state listing of legal aid programs.	ABA Service Center 541 N. Fairbanks Ct. Chicago, IL 60611 (312) 988-5000 E-mail: service@abanet.org <i>Consumer’s Guide to Legal Help on the Internet</i> , www.abanet.org/legalservice/publicfree.html Pro Bono Program Links www.abanet.org/legalservices/probonodirectory/home
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,	DREDF—Main Office 2212 Sixth Street Berkeley, CA 94710 (510) 644-2555 (voice/TTY)

<p>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>(510) 841-8645 (fax) E-mail: dredf@dredf.org</p> <p>DREDF—Government Affairs 1629 K Street, NW, Suite 802 Washington, DC 20006 (202) 986-0375 (voice) (202) 775-7465 (fax)</p>
<p><i>The Council of Parent Attorneys and Advocates (COPAA)</i> – 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 (202) 544-2210 (voice) E-mail: copaa@copaa.net www.copaa.net/</p>
<p><i>The Paper Chase: Managing Your Child's Documents Under the IDEA</i>, written by a lawyer specializing in special education and disability law, this 7 pg. 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 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>	<p>Robert K. Crabtree Kotin, Crabtree & Strong, LLP One Bowdoin Square Boston, MA 02114-2925 (617) 227-7031 (voice) (617) 367-2988 (fax) www.fetaweb.com/03/paperchase.crabtree.htm</p>

Section Two - Education

This section of the *School-Aged Guide of the Life Stages Program* provides a brief overview of your child's educational rights, how to obtain special education services during the elementary and middle school years and educational resources. For easy reference, this section is organized into the following subsections:

- Obtaining Services Under the *IDEA*
- Developing an IEP
- Transition Planning
- Preparing for the IEP Meeting and the Importance of Documentation
- Special Education, *IDEA*, and IEP Resources

Obtaining Services Under the *IDEA*

As discussed in Section One of this guide, the *Individuals with Disabilities Education Act (IDEA)* 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 mental retardation, 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 or not 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.

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.

However, the school does not have to evaluate your child just because you have asked. The school may not think that your child has a disability or needs special education. In this case, the school may refuse to evaluate your child. The school must let you know of their decision in writing, as well as why it has refused. If the school refuses to evaluate your child, there are two things you can do immediately:

- Ask the school for information about its special education policies, and the rights and procedures for parents who disagree with decisions made by the school system. These materials should describe the steps parents can take to challenge a school system's decision.
- Contact your state's Parent Training and Information (PTI) Center. A nationwide list of PTI centers can be found at www.taalliance.org/pti_list_20000629.pdf (complete contact information is listed in the Special Education, IDEA and IEP Resource chart). The PTI is an excellent resource for parents to learn more about special education, their rights and responsibilities and the law. The PTI can recommend the next steps to take to find help for your child.

If it is determined that your child is not eligible for special education services, the school system must tell you this in writing and explain why your child has been found "not eligible." Under the *IDEA*, you must also be given information about what you can do if you disagree with this decision. Your local PTI may also be able to provide assistance in appealing the school system's decision and/or make recommendations as to other steps to take in obtaining services for your child.

You may also want to consider having your child evaluated by your pediatrician or other professionals as appropriate, who are not affiliated with the public school system. You will have to pay for this evaluation, however, it may be helpful to as you advocate for the special education services that your child needs. An evaluation conducted outside of the school system gives you the added benefit of determining what needs to be done to strengthen your child in every area, not just those in the school setting. Parents need to remember that the school is only required to minimally meet your child's requirements by providing him or her a "free and appropriate" education. Depending on your child's limitations, you may need to obtain services and support for him or her in addition to what the school provides.

Developing an Individual Education Program (IEP)

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).

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 14 and be complete 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.

Note: Some information for this section of the guide was excerpted from the Individuals with Disabilities Education Act Amendments of 1997, 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.

Preparing for the IEP Meeting & The Importance of Documentation*

There are a number of steps that parents can take to prepare themselves for their child’s first IEP meeting. Taking these steps prior to the meeting may assist you in advocating for the services your child needs.

- Do your homework—Determine what it is you want for your child. Make a list with specific examples. Be able to communicate that to the team members at the meeting. Remember, the school is only required to provide a “free and appropriate education” under the IDEA, not the best education. However, while the school may not provide every service that you request, the old adage, “you’ll never know unless you ask” definitely holds true in developing IEPs.
- Come prepared—Bring any notes from previous meetings or discussions with teachers, counselors or other school professionals. Bring reports from any evaluations or assessments that have been conducted outside of the school system.
- Be objective—Use objective measurements that illustrate your child’s weaknesses. For example, “it takes my child 3 hours to complete a reading assignment, whereas most children his age finish it in a half hour.”
- Bring support—Bring your spouse, significant other, a friend, or family member who can provide support and/or help take notes during the meeting. It is easy to become emotional and overwhelmed in a meeting that may include your child’s teacher, counselor, therapists and other administrators. Parents new to the IEP process may feel intimidated and outnumbered by the school representatives who are present at a meeting.
- Take good notes—Keep track of the discussion that takes place during the meeting. Make sure to note any action items, the person they were assigned to and any follow up actions. By noting whether a proposed idea is accepted or rejected, you will know where you stand and what to advocate for at future meetings. Using the chart** below may help with your note-taking, and if attached to the school’s copy of the record of the meeting, can help ensure that everyone leaves the meeting with the same understanding of the actions to take place following the meeting.

Proposal	Accepted/Rejected	Reason	Start Date	Person Responsible	Follow Up Actions

Whether you are attending an IEP meeting or advocating for your child with TSC in another manner, the importance of proper documentation cannot be overemphasized. For example, writing letters and maintaining a written record of requests made and actions taken are also very important. You may want to write letters to:

- Request information
- Request action
- Provide information or describe an event
- Decline a request
- Express appreciation

Letters can help build relationships, identify and solve problems, clarify decisions, and motivate people to take action. Be sure to make your requests in writing. Be sure to write polite follow-up letters to document events, discussions and meetings. Train yourself to write things down!

It may also be helpful to keep logs, calendars and journals to help plan future and document past events. By writing letters and documenting events, discussions, and meetings, you can often resolve problems before your relationship with the school becomes strained and polarized.

Sources: **The Importance of Documentation* portion of the guide was excerpted from Wrightslaw, Special Ed Advocate Newsletter, September 3, 2002, Issue 177. For more information about this topic, read: “Letters, Documents and Paper Trails” on their Web site at: www.wrightslaw.com/advoc/articles/advo.create.trails.htm.

**How to Use a Parent IEP Attachment, by Judy Bonnell, Parent Advocate, Wrightslaw, www.wrightslaw.com/advoc/tips/bonnell.iep.attach.htm.

Transition Planning

As your child enters his or her teen years, you will learn more about the phrase “transition services.” 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 in the school setting. Providing transition planning is also mandated by the IDEA.

An effective transition plan has the following components:

- Is designed with 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 14,
- By the age of 16, includes a statement of needed transition services for the student.

For more information about transition planning, you may want to request a copy of the *Young Adult Guide of the Life Stages Program*. Copies can be obtained by contacting the TS Alliance at (800) 225-6872, or download a copy from the Web Site at: www.tsalliance.org.

Special Education, *IDEA* and IEP Resources

Resource	Contact Information
<i>Individuals with Disabilities Education Act (IDEA) Amendments of 1997.</i>	www.ideapractices.org
<i>Guide to the Individual Education Program –</i>	ED Pubs

<p>published by the Office of Special Education and Rehabilitation Services, U.S. Department of Education, this guide (51 pages when printed) assists parents and educators in implementing the IDEA with regard to IEP programs for children with disabilities. Sections of the Guide include: Contents of the IEP, IEP Team Members, Deciding Placement, Implementing the IEP, What if Parents Don't Agree with the IEP, Reviewing and Revising the IEP and more.</p>	<p>Editorial Publications Center U.S. Department of Education P.O. Box 1398 Jessup, MD 20794-1398 (877) 433-7827 (voice) (877) 576-7734 (TTY) (301) 470-1244 (Fax) www.ed.gov/gov/pubs/edpubs.html www.ed.gov/offices/OSERS Document is also available in alternate formats (Braille, large print, audio cassette or disk)</p>
<p><i>A Guide to Disability Rights Laws</i> – This guide (15 pages when printed from the Internet) 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><i>NICHCY Briefing Paper #LG1 – “Questions Often Asked by Parents About Special Education.”</i> (16 pgs.) Helps parents learn about the IDEA and how students with disabilities access special education and related services. <i>NICHCY News Digest #16 – “Related Services for School-aged Children with Disabilities.”</i> (30 pgs.) Looks at the related services as identified by the IDEA including occupational and physical therapy, speech therapy, transportation and special health services. <i>Sexuality Education for Children & Youth with Disabilities—NICHCY News Digest #ND17, 1992.</i> (43 pgs.) addresses concerns regarding the social-sexual development of children and how to prepare them to make healthy decisions. It presents an overview of points to consider when providing sexual education and offers a list of materials families can use to inform themselves more fully.</p>	<p>NICHCY P.O. Box 1492 Washington, DC 20013 (800) 695-0285 (voice) E-mail: nichcy@aed.org www.nichcy.org</p>
<p><i>Basics for Parents: Your Child’s Evaluation(BP1)</i> This 8 pg. article discusses what is involved when a child is evaluated by the school system to determine whether or not he or she is eligible for special education services.</p>	<p>See contact information for NICHCY above www.nichcy.org/pubs/basicpar/bp1tst.htm.</p>
<p><i>“What Makes a Good IEP for Your Child.”</i> While based on Minnesota’s special education laws, much of the information is applicable to all IEP plans. Includes information about what the plan should define, how to prepare for IEP conferences and parental rights throughout the IEP process.</p>	<p>Parent Advocacy Coalition for Educational Rights 8161 Normandale Blvd. Minneapolis, MN 55437 (952) 838-9000 (voice) (952) 838-0190 (TTY) (952) 838-0199 (fax) www.pacer.org E-mail: pacer@pacer.org</p>
<p><i>Developing Legally Correct and Educationally Appropriate IEPs</i>, Authors: Drasgow, Yell & Robinson, “Remedial & Special Education,” Vol. 22, No 6, Nov/Dec. 2001, pgs 359-373. Can be</p>	<p>www.ldonline.org/ld_indepth/iep/legallycorrect_ieps.html</p>

downloaded online from LD Online Web Site.	
The Parent as Advocate —This 5 pg. fact sheet, written by the law firm of Spain, Spain & Varnet, P.C. provides information to parents to be a more effective advocate for the student with special needs.	Spain, Spain & Varnet, P.C. 33 North Dearborn Street, Suite 2220 Chicago, IL 60602 (312) 220-9112 (voice) (312) 220-9261 (fax) www.altonwe.com/cs/downsyndrome/spainadvocate.html
The Transition to Middle School , ERIC Digest # ED422119, publication date 1998. This 5 pg. digest discusses the concerns involved in transitioning from elementary school to middle school, including social factors, motivational factors, transition programs and activities, school community and where to find additional information. Sex Education and Students with Disabilities This ERIC FAQ provides a bibliography of sexual education materials, including links to Internet Resources and Discussion Groups. Legal Aspects of Inclusion – this 6 pg. article links to ERIC Digests, mini-bibliographies, internet resources that address the topics of inclusion and IDEA.	ERIC EC The Council for Exceptional Children 1110 N. Glebe Rd. Arlington, VA 22201-5704 (800) 328-0272 (voice) E-mail: ericec@cec.sped.org www.ed.gov/databases/ERIC_Digests/ed42119.html http://ericec.org/faq/i-idea.html (Legal Aspects of Inclusion)
Attention Deficit Disorder: What Teachers Should Know —Describes instructional practices in the area of classroom accommodations, behavior management, and academic instruction. While aimed at activities teachers can use, it may also be helpful to parents.	www.dped.org/articles/101tips.html
Educational Rights for Children with AD/HD Part of CHADD's Information and Resource Guide, pgs 95-98 summarize the various legal issues affecting the education of children with AD/HD. The Web Site also has information about IDEA, Section 504 and ADA.	CHADD 8181 Professional Place, Suite 201 Landover, MD 20785 (800) 233-4050 or (301) 306-7070 (voice) (301) 306-7090 (fax) E-mail: national@chadd.org www.chadd.org
School Psychology Resources Online – this Web site provides resource information about various learning disabilities including: Autism, mental retardation, ADD, etc.	www.schoolpsychology.net
Wrightslaw – The Special Ed Advocate Newsletter – this online newsletter provides information needed to best advocate for your child. Web site 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, and others with a need for information about special Education law.	www.specialedlaw.net
Special Education News – provides in-depth, timely news related to educating students with disabilities. The Web site offers resources to special education professionals in one place. The site also includes sections for families and addresses	Special Education News 141 12 th St., Suite 9, NE Washington, DC 20002 (202) 320-0521 (voice) (202) 320-0521 (fax)

topics such as behavior management, recreation and sports, and specific disabilities.	E-mail: info@specialednews.com www.specialednews.com
KidNeeds.com – provides resources for special needs children and their families for different types of disabilities, growth, development and technology.	KidNeeds.com World Headquarters 29-01 216 th Street Bayside, NY 11360 (866) 543-6333 E-mail: 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) E-mail: webmaster@schwablearning.org www.schwablearning.org
Negotiating the Special Education Maze: A Guide for Parents and Teachers – This guide provides a description of the special education process in easy-to-understand terms. Authors: Anderson, Winifred, Chitwood and Hayden.	Woodbine House 6510 Bells Mills Road Bethesda, MD 20817 (800) 843-7323 (voice) www.woodbinehouse.com
One Child at a Time: A Parent Handbook and Resource Directory for African American Families with Children who Learn Differently , published by the National Association for the Education of African American Children with Learning Disabilities, this free handbook contains information about how African American parents can better advocate for their children. Contact the NAEAACLD for a copy or download from the Web site.	NAEAACLD P.O. Box 09521 Columbus, OH 43209 (614) 237-6021 (voice) E-mail: info@aacl.org www.charityadvantage.com/aacl/articlesandpublications.asp
Steps to Independence: Teaching Everyday Skills to Children with Special Needs – a training guide for parents of children with special needs. Authors: Baker & Brightman. Developing Personal Safety Skills in Children with Disabilities – Addresses self-esteem, dealing with strangers, and sexual abuse. Special Children, Challenged Parents: The Struggles & Rewards of Raising a Child with a Disability , offers support and techniques to help families with the challenges of raising a special needs child. Author: Dr Robert Naseef.	Paul H. Brookes Publishing P.O. Box 10624 Baltimore, MD 21285 (800) 638-3775 (voice) (410) 337-8539 (fax) E-mail: custserv@brookespublishing.com www.p.brookes.com
The Prompt Institute – a nonprofit organization dedicated to investigating and promoting holistic, dynamic, multi-sensory assessment and interventions for individuals with speech production disorders.	The Prompt Institute 4001 Office Court Drive, Suite 305 Santa Fe, NM 87507 (505) 466-7710 (voice) (505) 466-7714 (fax) www.promptinstitute.com
Attention Deficits: What Teachers Should Know Provides recommendations for developing educational programs for students with ADD. While written primarily for teachers, parents may also find the information useful.	Chesapeake Institute Washington, DC www.dbpeds.org

Section Three - Life and Financial Planning

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

- Life Planning
- Financial and Estate Planning—(guardianships, trusts, wills, and resources)
- Financial Planning and Life Planning Resources
- Public Disability Benefits Programs - SSI, SSDI, Medicaid and resources
- Private Insurance Considerations - what to consider when selecting insurance, pre-existing conditions, where to get help in finding insurance, and insurance resources

Please be aware that 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, nonprofit, 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. Parents 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 the person 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 TS 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 which 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 that 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 & Estate Planning

Estate planning is important for determining what resources will be available to a child 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. Families need to be aware that an inheritance may cause a child 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 a child with a disability is *not* eligible for or is not receiving government benefits, families may be able to leave their 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 child with a disability may not responsibly handle an inheritance, then utilizing a trust is likely the best way to plan for the future.

For individuals 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 their assets. When the court determines that a person is incapable of handling either their 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 children with disabilities may not be able to give reasoned and well-informed consent when making decisions as they mature into young adults. In order 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 TS 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?

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

a) 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 that were 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.

b) 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.

c) A **Limited Guardianship** may limit the guardian's decision making to certain areas, such as decisions about medical treatment, in order 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.

d) 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, their current status and what their 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 TS 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 that 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, 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 which requires prior approval for all out of state moves, may sanction the guardian for failing to obtain permission from the court 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 individual's 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) 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) A **Durable Power of Attorney for Property** is useful for individuals with mild or moderate disabilities 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 TS and their families need to be aware that many states have their own statutory form that must be completed when establishing a Power of Attorney. Other states allow individuals to design their own unique Power of Attorney. To learn more about power of attorney requirements in your state, contact the state attorney general’s office and ask about statutory Power of Attorney, 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 Power of Attorney at anytime and can remove the agent verbally or by the physical act of destroying the Power of Attorney. 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) 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 Power of Attorney 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.

- b) An **Appointment of Advocate and Authorization** is a customized power of attorney which allows an individual with a disability to designate an agent to advocate on his/her behalf with administrative agencies such as the Department of Mental Retardation, 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.

- c) 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 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 below. Many of these community agencies have published 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 who is experienced in wills and trusts and is 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, movies, 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 TS needs his or her own will. Prior advance legal planning will ensure that the assets are distributed according to the wishes of the adult with TS 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 child 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.

Financial Management and Life Planning Resources

Resource	Contact Information
<i>Financial Protection for the Disabled: Wills, Estates and Trusts</i> This 90-min. videotape was filmed at the session that addressed this topic at the 2001 TS Alliance	Tuberous Sclerosis Alliance 801 Roeder Road, Suite 750 Silver Spring, MD

National Family Conference (NFC). Order from the TS Alliance. Cost: \$16.00 (Shipping included).	(301) 562-9890 (voice) (800) 225-6872 (fax) www.tsalliance.org
<i>With Open Arms—Embracing a Bright Financial Future for You and Your Child with Disabilities and Other Special Needs</i> Created by the Easter Seals Society and the National Endowment for Financial Education, this excellent guide addresses financial planning, money management, government benefits and insurance options for people with disabilities and their families. Includes worksheets to help families develop a spending plan and prepare a letter of intent. Cost: \$5.00.	<i>With Open Arms</i> Easter Seal Society 230 W. Monroe St., Suite 1800 Chicago, IL 60606 www.easter-seals.org
<i>Future Planning Resources</i> – This free 12-page 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.	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) Note: At the time this guide went to press, The Arc was restructuring its literature distribution system. The publication is available electronically via their Web site. http://thearc.org/misc/futplan.html
<i>Future Planning: Making Financial Arrangements with a Trust</i> (Berkobien & Varnet). This article, written in Q&A format, describes the importance of careful financial planning and the types of trusts available.	See full contact information for The Arc listed above. http://TheArc.org/faqs/trustqa.html
<i>Special Needs Trust Helps Ensure Support, Care</i> —2 pg. fact sheet written by the law firm of Spain, Spain and Varnet.	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
<i>After We're Gone, A Program for the Lifetime Care of Persons with Disabilities</i>	Life Services for the Handicapped, Inc. 352 Park Avenue, South, Suite 703 New York, NY 10010 (212) 532-6740, (800) 995-0066 (voice) E-mail: disabledandalone@aol.com
<i>Estate Planning News Digest</i> - Written by estate planners for those planning for the needs of those with disabilities. This 23–pg. digest provides an overview of the process that can be used to create specialized wills and trusts to provide for their 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.	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” #ND18.
<i>Merrill Lynch</i> 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, Customer Service (800) 637-7455 Contact local office listed in your phone book http://askmerrill.ml.com/product_details/1,2270,20294,0.html
<i>The Life Planning Checklist</i> that appears on their Web site summarizes the recommended steps in life planning for a person with a disability. They provide life-planning	Life Planning Institute of New Jersey, LLC P.O. Box 75 Oakland, NJ 07436

services (for a fee) and also publish an annual newsletter that is available for \$7.50.	(201) 405-0288 (phone/fax) E-mail: lifepan@usa.com http://members.tripod.com/lifepanning/feedback.htm
<i>Metropolitan Life Insurance Company</i> provides financial planning services for people with disabilities and their families.	Metropolitan Life Insurance Company One Madison Avenue New York, NY 10010 (800)-638-3375 (voice) www.metlife.com/desk

Public Disability Benefits Programs

The Three Ways a Child Can Get Benefits from Social Security or SSI*

There are three ways a child might be eligible for benefits from Social Security or SSI. The three kinds of benefits are:

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.

Social Security Dependents Benefits—These are benefits payable to the children under the age of 18 as dependents of a parent who is 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.

Social Security Benefits for Adults Who Have Been Disabled Since Childhood—Dependents benefits normally stop when the child reaches 21 if he or she is a full time student. However, these benefits can 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 2002, “substantial” was considered to be monthly earnings of \$740 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 your child’s name and social security number appear on each page or form you complete. 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. You will be asked to provide copies of your child’s medical records to substantiate your claim. These records should include the 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.) and prescribed medication names and dosage amounts.

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. They 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. Please note, the SSA may also 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 who have knowledge of your child’s condition and or his or her ability to function in determining whether or not 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:

- Reconsideration – a written request to have a decision reviewed
- Hearing by an Administrative Law Judge
- Review by the Appeals Council
- 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, Katie Beckett Waiver, OBRA '93, Medicare)

Medicaid is a federal-state assistance health care program that pays medical bills of people with low-incomes and limited assets. Medicaid comes automatically with SSI eligibility. Some children can get Medicaid coverage even if they don't qualify for SSI. To be eligible to receive Medicaid, an individual cannot have more than \$2000 in cash assets or assets that can be converted to cash. For more information about Medicaid, contact the Health Care Financing Administration (HCFA) at (800) 638-6833 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 a child is covered by a private health insurance (see Subsection C, Private Insurance Considerations), often the coverage in private policies for people

with disabilities is very minimal. And the cost for private medical coverage may be prohibitive in the future. In some cases, 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.

Katie Beckett Waiver (Option)-When determining a child's eligibility for Medicaid, a parent's income and assets are counted. However, if a child has a severe disability and meets specific medical guidelines and standards, the child's income and assets are counted and those of the parents may be waived. If the child is then eligible, Medicaid will pay for the same services it does for other children with Medicaid. To be eligible for the waiver, your child must be:

- 18 years of age or younger
- Disabled for at least one year (the disability must be severe enough that he or she cannot accomplish without assistance the same things as other children of the same age)
- In need of care that is generally provided in a hospital or nursing home. Note, your child does not have to reside in the facility, just be need of care that is normally provided in one.
- Able to live at home (in lieu of a hospital, nursing home or other facility) if he or she can get the care needed.

For children with emotional/behavioral problems, the following standards apply:

Your child's behavior must be life threatening, destructive, or disabling to himself, or herself or others, characterized by:

- Active suicidal/homicidal threats, plans or attempts
- Assault, arson or self-mutilation
- Psychotic Depression
- Gross Dysfunction resulting in inability to care for himself or herself (confusion/disorientation/memory loss)
- Sustained and severe withdrawal from life activities and relationships

In some instances, your child may qualify for the Katie Beckett Option even if he or she is in a residential facility. If your child qualifies, he or she will get full Medicaid coverage which includes hospital care (both inpatient and outpatient), physician care/services, most prescribed medications, eye and dental care and any other service provided in a home that would normally be provided in a hospital or nursing home. There is a limit, however, to psychiatric expenses.

When applying for this program, you will be asked to provide your child's school and medical records. You will also be asked to verify your income (and your child's income, if appropriate) and some verification of the severity of your child's disability. Your Medicaid caseworker can assist you in locating these items if you need assistance.

The Katie Beckett waiver is retroactive, so if you think your child may be eligible, apply as soon as possible. If your child is found eligible, Medicaid will pay covered expenses from the date you applied, not just the date your child was deemed eligible.

Even if you aren't sure if your child is eligible due to income or severity of need, parents are strongly encouraged to apply! The worst thing that can happen is that you are turned down. Even if your child has been denied Medicaid in the past, it is important to apply again. If your application is turned down, start the appeals process. This process may be successful in overturning a denial and eligibility will be retroactive to the date you applied for the waiver. While the Katie Beckett program plays a role in assisting families of children with severe disabilities, it isn't without pitfalls. The waiting list in many states can be months to years long. So it is important to apply early!

To apply for the Katie Beckett waiver/option, contact your local Department of Human Services (check the blue pages in your local phone book).

OBRA'93 & Federal Medicaid Rules—The Omnibus Budget Reconciliation Act of 1993 (OBRA '93) changed 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. This law also contains another exception which 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 OBRA '93, 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 child with disabilities if all of their money had to be spent on their own nursing home care. There may be additional advantages and disadvantages related to OBRA '93 when considering your own financial situation. For more information about this law and whether or not it applies to you, consult with a special needs attorney and or financial planner.

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.

Other Benefit Programs

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 qualify, contact your local Veterans Administration Office or their headquarters office at (800) 827-1000 or visit their Web site at: www.va.gov/

Private Insurance Considerations

Finding health insurance with a serious medical condition can be difficult. Prior to exploring insurance options, determine what your child's health needs and medical costs are now and what they will likely be in the future. Meet with the appropriate medical professionals who may help you know what to expect. This information will help you make an educated choice when selecting an insurance policy.

Be sure to look at the nonprofit medical providers in your area, including health maintenance organizations (HMOs) or your state Blue Cross/Blue Shield. Early in the process you may discover that TS is considered a "pre-existing condition," which may mean that insurance will not cover the costs related to TS symptoms. Nonprofit insurers are more likely to accept you than traditional for-profit insurers, and there may even be "open enrollment" periods when an individual or family can join a health plan regardless of health status.

In looking to your child's later teenage years, many parents are not aware that they can continue their group plan health coverage for their dependent adult child after their child graduates or leaves school. Check with your employer's human resources department to see if your company health insurance plan has this option available. Most insurance companies require that they be notified within 3 months of the child's 19th birthday that he or she has a disability and is dependent on you for care. **If you do not notify your health insurance carrier of your child's special needs, they may drop your child from coverage when they reach the age of 19 or age out of school.**

If you are a parent of a child with TS and you own your own business, you may be eligible for group insurance which is easier to get than individual insurance. If this is not an option to you, make a list of all the business, professional, trade, and fraternal organizations and associations to which you belong. Call each one to see if they offer some kind of medical health plan. It is technically group insurance, and you will have to be evaluated based on your family's medical situation. However, the terms of the policy are likely to be more advantageous than if you get coverage on your own.

For those people who are not eligible for any type of group health insurance and have been denied health insurance coverage once or twice, it does not necessarily mean that you cannot obtain any health insurance at all. Shop around. Do some searching. You may find an insurance company that is willing to provide coverage for your child's specific needs. But keep in mind that even if a company offers individual coverage, it may require a higher premium. If so, you must weigh the cost of the insurance against the potential benefits.

If you are lucky enough to find several different insurance options, be sure to compare the following factors in choosing the policy that is right for your child:

What is the Deductible?

With an individual policy, there may be a deductible of \$3,000 a year or more. But remember, insurance should cover the most catastrophic needs first. The deductible should be considered in your decision-making process, but it should not be the deciding factor.

What is the Lifetime Cap?

How much coverage will this policy provide? Does it stop paying after a certain amount (\$1 million, \$2 million)? Does it have an unlimited lifetime benefit? Depending on how long a person may be relying on this policy, the lifetime cap becomes much more important than the deductible.

Does the Coverage Exclude Pre-existing Conditions?

All medical insurance and health care plan companies have written a list of standard exclusions within their plan document. These are called “pre-existing conditions.” Simply put, this means that certain medical conditions that exist at the time the insurance is purchased will not be covered by insurance. Sometimes, coverage will be granted for certain medical conditions, but at an additional cost to the insured. Different companies have different definitions for pre-existing conditions, but most are along the lines of the following:

“Any condition which one is diagnosed to have, aware of, any reasonable person should be aware of, has been treated for within the past two years, currently being treated, has been recommended for treatment or providing symptoms of within the past two years.”

Coverage of pre-existing conditions generally fall into four general categories:

- Conditions existing now or recently before applying for a new plan are excluded automatically
- Coverage is possible, if fully described in detail and accepted by the company
- Coverage may be offered, combined with an increase in premium, limited coverage or special terms on coverage
- Coverage may be offered on a pre-existing condition, but only if the insured waits a year or more to collect the benefits

Bear in mind that coverage under group accounts is generally more liberal and individual accounts may allow for annual review of a person’s situation.

To fully evaluate the best plans available and to ensure complete coverage of future claims, fully and accurately disclose (in some detail) all pre-existing conditions when completing an application for coverage. Future claims may be rejected if an applicant knowingly omits material facts when originally applying for coverage. Coverage may even be cancelled if it is determined that an individual omitted or falsified information during the application process.

If, while exploring the options described above, you find that you or your child is uninsurable for medical reasons, contact your state department of insurance. Many states have

special programs to provide medical coverage for adults and children who cannot obtain insurance due to their medical history. The premiums are subsidized, reducing the cost of the insurance substantially. Ask your state insurance department (contact information for state insurance departments is included in the resource chart at the end of the section) for a list of all health care providers in your area that allow individuals with pre-existing conditions to join, and for a list of all state programs which might be available to you.

Where to Get Help

The Title XXI of the Social Security Act, known as the State Children’s Health Insurance Program (SCHIP) enables states to insure children from working families with incomes too high to qualify for Medicaid, but too low to afford private health insurance. The program provides protection for prescription drugs, vision, hearing, and mental health services and is available in all 50 states and the District of Columbia. Your state Medicaid agency can provide more information about SCHIP. Or visit the Centers for Medicare and Medicaid Services Web Site at: www.hcfa.gov/init/children (contact information is listed in the Resource Chart at the end of this section).

In addition, state insurance departments are responsible for licensing and regulating insurance companies in each state. These departments regulate the insurance industry within each state and protect consumers by ensuring that insurance companies and health plans act in accordance with insurance laws. These departments are also responsible for investigating and resolving consumer complaints and questions concerning insurance companies operating in their state. Some offices may also provide a list of companies that provide supplemental insurance. The National Association of Insurance Commissioners (NAIC) Web site at: <http://www.naic.org/1regulator/usamap.htm> provides a link to all State Insurance Departments.

***Sources:** Some of the information included in the Life and Financial Planning portion of the guide was taken from various financial planning fact sheets developed by Spain, Spain and Varnet, a law firm located in Chicago, Illinois, and from the Web sites of the SSA, Centers for Medicare and Medicaid Services (CMS) and SSA Publication No. 05-10026, entitled: *Benefits For Children With Disabilities*. This material is intended to offer general information and should not be treated as specific legal advice. Families should consult with an attorney who is experienced and knowledgeable in both estate planning and in the special problems, laws and government benefits concerning people with disabilities.

Benefits & Insurance Resources

Resource	Contact Information
Social Security Administration (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.	Consult the blue pages in your phone book under “Health and Human Services“ in the U.S. Government Section. www.ssa.gov (800) 772-1213 (voice) (800) 325-0778 (TTY)
Benefits for Children with Disabilities – SSA Publication # 05-10026, August 2001. Written for the parents of children with disabilities and adults disabled	

since childhood. It illustrates the kinds of SSI benefits a child with a disability might be eligible for and explains how the SSA evaluates disability claims for children.	
Centers for Medicare & Medicaid Services (CMS) Web site – For information about the State Children’s Health Insurance Program (CHIP)	CMS 7500 Security Blvd. Baltimore, MD 21244-1850 (410) 786-3000 (voice) www.cms.hhs.gov/schip
Introduction to Social Security Benefits That Are Available to Persons with Disabilities – 3 Pg. Fact Sheet from the law firm of Spain, Spain & Varnet. OBRA ’93: Recent Changes in Federal Medicaid Rules, this one page fact sheet describes the Omnibus Budget Reconciliation Act of 1992 and how it applies to the transfer of assets to people with disabilities and Medicaid eligibility. Government Benefits for Persons Who are Disabled, Fact sheet.	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/spainobra.html
<i>State Health Insurance Assistance Program</i> – to locate the program in your state visit the Web site.	www.medicare.gov/contacts/Related/Ships.asp
<i>Guide to Disability Income Insurance</i> – Explains the various sources of disability income, what disability income insurance is, and what it covers. It includes a worksheet that can be used 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.	Health Insurance Association of America www.hiaa.org/consumer/disability.cfm .
National Organization of Social Security Claimants’ Representatives (NOSSCR) is an association of attorneys 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.	NOSSCR 6 Prospect St. Midland Park, NJ 07432-1691 E-mail: nossr@worldnet.att.net www.nossr.org/ (800) 431-2804

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 & assistive technology projects
- Additional Sources of Funding & Access to Technology
- 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 & Assistive Technology Projects

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 (IEP). 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 Two of this guide.

Assistive technologies can include mechanical, electronic, and microprocessor-based equipment, non-medical and non-electronic aids, 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:

1. Access to computerized information on the use of assistive technology
2. Develop demonstration centers where people with disabilities may go to try different pieces of equipment
3. Consultants to help individuals make informed decisions about equipment
4. Referral services
5. 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.

Additional Sources of Funding & 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 require 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. In addition, the PEP: Resources for Parents, Educators and Publishers Computer Recycling, Web site hosts an international directory of agencies that facilitate donations of used computer hardware for individuals, schools and community groups. Visit: www.microweb.com/pepsite/Recycle/recycle_index.html for more information.

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 the Tuberous Sclerosis Alliance does not recommend or endorse these companies and organizations, but provides this as a resource for your information. Be sure to thoroughly research any company and their products prior to ordering or sending money.

Sources: Portions of this section of the guide were excerpted from the following publications: News and Notes from the Family Center on Technology and Disability, May/June 2002, 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

Resource	Contact Information
ABLEDATA –a national assistive technology information exchange, serving the nation’s disability, rehabilitation and senior communities. Database has information on thousands of products. Specialists assist with product searches. Site links to many helpful assistive technology and general disability sites.	ABLEDATA 8630 Fenton Street, Suite 930 Silver Spring, MD 20910 (800) 227-0216 (voice) (301) 608-8912 (TTY) (301) 608-8958 (fax) www.abledata.com

<p>State Assistive Technology Projects – To find the assistive technology project in your state (funded under the Tech Act)</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>assistivetech.net – This site is in development with an anticipated completion date of 11/02, although some sections of the site are operational. It will provide 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 (toll free, voice) (404) 894-0240 (voice) (404) 894-9320 (fax) http://www.assistivetech.net</p>
<p>The Alliance for Technology Access (ATA) is dedicated to connecting adults and children with disabilities to disability tools. Callers are referred to the technology resource center nearest them. The site includes many resources, available from ATA and other sources. ATA also publishes <i>Computer and Web Resources for People with Disabilities</i>, which is available in paperback for \$20.95, or can be read online.</p>	<p>Alliance for Technology Access 2175 E. Francisco Blvd. Suite L San Rafael, CA 94901 (415) 455-4575 (voice) (415) 455-0491 (TTY) (415) 455-0654 (fax) E-mail: ATAinfo@ATAccess.org www.ataaccess.org</p>
<p>Ability Hub – 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. 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) E-mail: 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) 767-2775 (voice) www.apple.com/disability E-mail: 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. Users search for products by disability type (such as language or learning).</p>	<p>www.microsoft.com/enable/default.htm</p>
<p>Half the Planet – This organization supports the application of technology to promote the values of the ADA. Includes a Family Resources Section.</p>	<p>Half the Planet 1875 Eye Street, NW, 12th Floor Washington, DC 20006 (202) 429-6810 (voice) (202) 429-6813 (fax) http://www.halftheplanet.com E-mail: suggestions@halftheplanet.com</p>
<p>Tech Connections – Sponsored by the UCP Center for Rehabilitation Technology, this site provides an overview of assistive technology resources,</p>	<p>Tech Connections 490 Tenth St. NW Atlanta, GA 30318</p>

<p>including a list of state projects, disability resources and a newsletter. Specialists are available to answer questions about assistive technology.</p>	<p>(877) 835-7335 (voice) E-mail: techconnections@crt.gatech.edu http://www.techconnections.org</p>
<p><i>Assistive Technology New Digest #ND13</i> Published by NICHCY, this digest (23 pgs.), explores the broad subject of assistive technology. Originally published in 1989, it does not contain the most current information about assistive technology. But it does provide basic information that should be supplemented with information from other sources. The resource information that appears at the end of the article has been updated recently.</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) (202) 884-8441 (fax) E-mail: nichcy@aed.org http://www.nichcy.org To access article: http://www.nichcy.org/pubs/newsdig/nd13txt.htm</p>
<p><i>News & Notes from the Family Center on Technology and Disability newsletter.</i></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><i>Assistive Technology for Individuals with Learning Disabilities Fact Sheet (2 pages)</i></p>	<p>Learning Disabilities Association 4156 Library Road Pittsburgh, PA 15234-1349 (412) 341-1515 (voice) (412) 344-0224 (fax) info@ldaamerica.org www.ldnatl.org/factsheets/assistive.html</p>
<p><i>Disabled Children's Relief Fund (DCRF)</i> provides assistance in obtaining assistive devices (wheelchairs, 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.</p>	<p>DCRF P.O. Box 7420 Freeport, NY 11520 www.dcrf.com</p>

Section Five - Staying Healthy and Family Support

Participating in quality of life activities and interacting with friends may bring added enjoyment to your child's life. In addition, connecting with others who are living with similar challenges may help you cope with the problems and frustrations that may occur as a result of having a child with special needs. This section includes information and resources to assist families in the following areas:

- Staying Healthy
- Respite Care
- Communication and Coping Strategies
- Skin Disorders Associated with TS
- Adaptive Clothing & Equipment
- Family Support and General Disability Resources
- Building Friendships Outside of the Family
- Recreation, Travel, Sports, and Leisure Activities

Staying Healthy

Eating a balanced diet, exercising regularly, and getting regular medical and dental check ups are basic steps to ensure that your child with a disability stays healthy.

Some older children 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. Raising a child with a disability can be overwhelming at times. Parents and caregivers need to be mindful of their own physical and mental health as well and ask for help when needed.

Respite Care

For families of a person with a disability, respite care is a support service that is 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 their Web site at: www.epilepsyfoundation.org/aboutus/lookup.cfm. In addition, the National Respite Locator Service helps individuals, parents and caregivers find respite services in their state and local area.

The information in this guide focuses on non-medical issues confronted by children with TS and their families. Proper medical management of Tuberous Sclerosis is essential. If you need assistance in keeping track of the medical issues associated with your child with TS, you may want to request a copy of the TS Alliance Journal. The purpose of the journal is help families

keep track of doctor visits, medications, and other information related to medical care. To obtain a free copy of the journal, contact the TS Alliance at (800) 225-6872, or download a PDF version from the Web site at www.tsalliance.org.

Communication and Coping Strategies*

In addition to managing the medical aspects of Tuberous Sclerosis, psychological management, or “coping” is also very important for families living with this disorder. Successful coping means considering the situation manageable, even if it is difficult and anxiety producing. This concept is important to understand, because there are many factors that determine how manageable a situation is. Each child with TS and their family is affected differently. Once you identify which factors specifically affect your child and your family, you can learn to change them so that you can all adapt to a better life with TS.

The issues relevant to your child depend largely on his age. To meet the needs of a young child:

- Provide age-appropriate explanations about TSC
- Identify misconceptions
- Be honest, but don't overwhelm your child with information
- Model positive coping by being calm and not overreacting

To meet the needs of an older child, educate them regarding:

- Independent disease management (taking medication on their own)
- Long-term implications of non-adherence to his or her treatment plans
- Reconciling treatment needs with social needs

To facilitate an adaptive coping style in your child:

- Encourage open communication within your family (how are they feeling, what are their concerns?)
- Encourage communication with professionals and participation in treatment planning (teach your child how to ask questions)
- Seek psychological services or support if needed (when verbal or nonverbal signs of distress are present and not lessening)

Your child's coping style is important. The way family members cope with the disease is also very important. Children will model the coping styles they observe from their parents. To maximize parent coping skills and model coping behavior for children:

- Manage your own anxiety, and seek social support (join support groups, speak with friends and adult family members) as needed
- Practice stress management with your child (learn relaxation techniques, teach kids to prioritize their needs so they aren't overwhelmed)

- Model positive coping and help prepare kids for specific situations (e.g., what to do if they are teased)

Brothers and sisters of the child with TSC will also be affected by the disease. To help siblings cope:

- Provide information about the disease from the start
- Include siblings in the learning process
- Encourage communication and expression of their feelings
- Discuss ways they can be helpful and praise them for being helpful and cooperative
- Seek social support (e.g. establish relationships with others who have a sibling with a disability)
- Carve out special time to spend with the child who does not have a disability

Finally, many of the stressors that come with having a disability develop from the need to cope with peer pressure and social situations. To help your child manage social concerns:

- Identify social concerns early
- Encourage your child to use positive coping responses and to be comfortably assertive with peers
- Role-play, coach and problem solve with your child
- Utilize support groups for children with TSC and/or other disabilities as appropriate
- Help your child establish positive relationships with non-disabled peers

Successfully coping with TSC does not mean not experiencing anxiety over it. It means finding effective ways to manage the anxiety.

The General Disability Resources and Family Support Resource Chart below lists many resources that help families living with the challenges of having a child with a disability.

*The Communication and Coping Strategies section was excerpted from the article entitled, "Helping Your Child Cope with Chronic Illness," by Stacie B. Isenberg, [Washington Parent](#), September 2002. Ms. Isenberg is a child and adolescent psychologist with the Ross Center for Anxiety and Related Disorders.

Skin Disorders Associated with TSC

Some individuals with TS experience certain types of skin discoloration or pigmentation as one of their symptoms. These symptoms may appear at the onset of puberty. Although most skin disorders associated with TS 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 TS. There are different companies that sell cosmetics for concealment and de-pigmented skin.

Cosmetic Companies

Covermark Cosmetics 157 Veterans Dr., Suite D Northvale, NJ 07647 (800) 524-1120 (voice) www.covermarkusa.com
Linda Seidel (800) 590-5335 (voice) www.lindaseidel.com
Dermablend Corrective Cosmetics 1135 Pleasant View Terrace West Ridgefield, NJ 07657 (877) 900-6700 (voice) www.dermablend.com
Skin Store Customer Service 2000 Glades Road, #400 Boca Raton, FL 33431 (888) 371-SKIN (voice) www.skinstore.com

Adaptive Clothing, Shoes and Equipment

Finding clothes and equipment that are easy-to-wear, stylish, and affordable may help add to a child’s confidence and better enable him or her to focus on living an active and healthy life. The sources listed in the chart below sell different types of special needs clothing and incontinent supplies.

Adaptive Clothing & Equipment Resources

Vendor/Products	Contact Information
JC Penney’s Special Needs Catalog – health care items, exercise equipment, beds, bedding and bath aids and easy dressing fashions for men and women. Call to request their “special needs” catalog. Cannot order online at this time	(800) 222-6161 (voice)
Sears Home Health Care – Bath and shower seats, grooming and personal care items, disposable and reusable incontinent garments, ramps, etc.	(800) 326-1750 (voice)
Easy Access Clothing –clothing for all ages including cargo pants, dress pants, sweats, jeans, tops, underwear and bathing suits.	(800) 775-5536 (voice)
The Family Village Web site provides an extensive list of adaptive clothing vendors, catalogs, and other resources.	The Family Village Waisman Center University of Wisconsin-Madison 1500 Highland Avenue Madison, WI 53705-2280 E-mail: familyvillage@waisman.wisc.edu www.familyvillage.wisc.edu/index.html

Family Support and Disability Resources

The amount of information generated by and for the greater “disability” community is vast, depending on your area of interest. Hundreds of 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.

Some of the more popular 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 Seven of this guide.

Disability Resources

Resource	Contact Information
<p>Tuberous Sclerosis Alliance – Online Communities. Through its Web site, the TS Alliance provides four online forums to provide an opportunity for people with TSC and their families to connect with others facing similar challenges. Listservs are available for the following groups: parents with a teenager with TSC, adults with TSC, grandparents of children with TSC and parents and caregivers. Brochures and fact sheets that address different aspects of TSC are also available.</p>	<p>Tuberous Sclerosis Alliance 801 Roeder Road, Suite 750 Silver Spring, MD 20910 (800) 225-6872 (voice) E-mail: info@tsalliance.org Visit the TS Alliance Web Site to join: www.tsalliance.org/Online%20Communities/default.asp</p>
<p><i>Federal Disability Information</i> – Provides one-stop access to government disability information and resources including education, employment, transportation, housing, technology, health, income, support and community life.</p>	<p>www.disability.gov/</p>
<p><i>Disability Resources</i> reviews hundreds of resources available to people with disabilities. The newsletter, <i>Disability Resources Monthly</i> (DRM)– \$15.00 subscription --and the “DRM Web Watcher” (an online guide to disability resources on the Internet) provides comprehensive information on a 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><i>Channels of Support – Guidance for Managing Seizure Disorders</i>, this kit provides a means to record seizure information as well as guidance on what to do about seizures depending the age or sex of the individual.</p> <p><i>Respite Care: Time Out for Families</i>, 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.</p>	<p>Epilepsy Foundation 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)</p>

Children with Disabilities Web site—offers families information about advocacy, education, employment, health housing, recreation, and transportation covering a broad array of disabilities.	www.childrenwithdisabilities.ncjrs.org
KidNeeds.com – Sponsored by the St. Mary’s Healthcare System for Children, this site provides information and resources on a broad range of topics relative to emotional and behavior concerns.	St. Mary’s Healthcare System for Children 29-01 216 th Street Bayside, NY 11360 (718) 281-8750 (voice) (718) 631-7874 www.kidneeds.com info@kidneeds.com
Zigawhat! A Web site for young people with disabilities that provides them with the opportunity to learn more about themselves, connect with other kids, tell their story and play games.	www.nichcy.org/kids/index.htm
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.	AACAP 3615 Wisconsin Avenue, NW Washington, DC 20016-3007 (202) 966-7300 (voice) (202) 966-2891 (fax) www.aacap.org/publications/factsfam/index.htm
The Autism Information Center, hosted by the Center for Disease Control (CDC), this site focuses on the activities of federally funded programs and resources related to autism, including information about autism spectrum disorders, state activities funded by the CDC, education, research resources, and activities to help children use the Internet to learn more about autism spectrum disorders.	www.cdc.gov/ncbddd/dd/ddautism.htm
Special Child—This Web site for parents and caregivers of children with special needs provides information, success stories, and advice regarding family issues. Also features an interactive bulletin board and other information.	The Resource Foundation for Children with Challenges P.O. Box 1405 Santa Clarita, CA 91386-1405 (661) 298-2610 (voice) E-mail: RFCC@specialchild.com www.specialchild.com
Band-aids & Blackboards – this site addresses those issues encountered when growing up with a disability. Includes sections for kids, teens, and adults.	www.faculty.fairfield.edu/fleitas/contents.html
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 and provides an overview of government policy.	Family Voices 3411 Candelaria NE, Suite M Albuquerque, NM 87107 (505) 872-4774 or (888) 835-5669 (voice) (505) 872-4780 (fax) 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	www.noeasytask.com

Adult and Teen Issues.	
Children's Disabilities Information—this Web site includes resources for children with special needs. Includes books about seizures, epilepsy, Autism and ADD.	www.childrensdisabilitiesinfo/
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) E-mail: system_manager@ablelink.org www.ablelink.org
Support, Education and Advocacy (SEA) Center Online discussion boards and help on education and advocacy issues for parents and youth with disabilities.	SEA Center 6402 Skyway Paradise, CA 95969 (888) 263-1311 (voice) E-mail: sea@sunset.net www.sea-center.org/letstalk.html
<i>Beyond All Barriers E-Zine</i> – this online magazine written by and for teens with disabilities includes a chat room, message board, advice columns, legislative decisions and conferences.	www.disabilitycentral.com/activteen/magazine/this_issue.htm
<i>BLURT</i> —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.	EFA 4351 Garden City Dr. Landover, MD 20785-7223 (800) 332-1000 (voice) www.efa.org/blurt
<i>Directory of Summer Camps for Children with Disabilities</i> —(4 pgs). includes directories and listings of summer camps for children with disabilities. <i>Children With Disabilities: Understanding Sibling Issues, NICHCY News Digest #ND11.</i> (17 pgs). focuses on how a child's disability can affect siblings in the family with many of the articles written by siblings themselves.	NICHCY P.O. Box 1492 Washington, DC 20013 (800) 695-0285 (voice/TTY) www.nichcy.org/pubs/genresc/camp2000.htm E-mail: nichcy@aed.org
<i>Special Needs Project</i> – provides books about disabilities, that serve individuals, families and professionals with a large collection of disability-related materials, including titles about Autism, 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
<i>The Sibling Support Project</i> – 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.	Don Meyer Director, Sibling Support Project The Arc of the U.S. 6512 23 rd Avenue, NW, Suite 213 Seattle, WA 98117 (206) 297-6368 (voice) www.thearc.org/siblingsupport
<i>Families and Disability News</i> – this newsletter is published by the Beach Center at the University of Kansas.	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) E-mail: beach@dole.lsi.ukans.edu www.beachcenter.org
Our-Kids – this site supports an e-mail list comprised of 800 people representing children of varying diagnosis including rare genetic disorders.	www.our-kids.org
Parents Helping Parents (PHP) – a comprehensive, family resource center run for and by parents of children with special needs.	PHP 3041 Olcott Street Santa Clara, CA 95054 (408) 727-5775 (voice) (408) 727-0182 (fax) E-mail: general@php.com www.php.com
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.	www.everydaywarriors.com
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.	NARIC 4200 Forbes Blvd., Suite 202 Lanham, MD 20706 (800) 346-2742 or (301) 459-5900 (voice) E-mail: naricinfo@heitechservices.com www.naric.com
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.).	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
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.	Eileen Laird Cooking Made Easy P.O. Box 2117 Boone, NC 28607-2117 E-mail: Eileen@cookingmadeeasy.org www.apptechnc.net/~cme/hometx.htm
Mealtime Manual for People with Disabilities by Judith Lannefeld Klinger, Howard Institute of Rehabilitation Medicine, publisher, Slack, Inc., ISBN: 1556423411, 232 pages. \$26.00	Check with your local library, bookstore or at www.amazon.com

Building Friendships Outside of the Family

Friendships foster a sense of belonging and 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, 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 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 that are so important to an individual’s mental health. The organizations and resources listed below are provided as a starting point to help your child 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.

Municipal Departments of Parks and Recreation

There may also be opportunities available through your city or 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. Classes offered by local governments must be offered to children with disabilities by law. In addition, depending on where you live, there may also be special recreational classes offered specifically for children with disabilities.

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.

*Sources: 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, *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

Organization	Contact Information
YMCA – There are more than 2,400 YMCAs located in the U.S., all with different programs and events.	YMCA (888) 333-9622 (voice) www.ymca.net/find_your_y/findy.htm
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,	YWCA of the U.S.A. Empire State Building 350 Fifth Avenue, Suite 301 New York, NY 10118

employment training and placement services, child care services and health education services.	(212) 273-7800 (voice) (212) 465-2281 (fax) www.ywca.org
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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 more challenging for children with disabilities, it can be done. Many 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 for families with children who may want to participate in these types of activities.

Recreation, Sports and Leisure Resources

Resource	Contact Information
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.	Disabled Sports USA 451 Hungerford Dr., #100 Rockville, MD 20850 (301) 217-9840 (voice) E-mail: information@dsusa.org www.dsusa.org
Special Olympics --dedicated to empowering individuals with mental retardation (MR) become physically fit, productive and respected members of society through sports training and competition. Offers year-round training and competition in 26 Olympic-type summer and winter sports.	Special Olympics North America 1325 G Street, NW, #770 Washington, DC 20005 (202) 824-0327 (voice) E-mail: landrews@specialolympics.org www.specialolympics.org

Travel

Whether a family wants to travel around the corner or around the world, laws and regulations exist to ensure that 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 that 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 the Department of Transportation Web site at: www.dot.gov/airconsumer/problems.htm. Or contact them at:

Aviation Consumer Protection Division
U.S. Department of Transportation
Room 4107, C-75
Washington, DC 20590
E-mail: 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 that you make your travel arrangements well in advance to ensure availability of the accommodations that will best suit the needs of your child. Contact transportation providers and hotels in advance if you have any questions about the services or assistance provided.

Travel Resources

Resource	Contact Information
<i>New Horizons – Information for the Air Traveler with a Disability</i> , 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.	U.S. Department of Transportation Aviation Consumer Protection Division, C-75 400 Seventh Street, SW Washington, DC 20590 www.faa.gov/acr/dat.htm
<i>Amtrak</i> – 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.	Amtrak (800) 872-7245 (voice) www.amtrak.com/plan/accessibility.html E-mail: service@sales.amtrak.com
<i>Greyhound-- Customers with Disabilities Assist Line</i> . They recommend that travelers contact them at least 48 hours prior to travel. In some instances, personal care assistants may travel one way with a traveler with a disability for free. Some restrictions apply. Their Web site describes how they are able to meet special needs, including lifts for wheelchairs, rest stop assistance, and priority seating policies.	Greyhound Bus Lines (800) 752-4841 Customers With Disabilities Assist Line (800) 755-2357 Corporate ADA Compliance Office www.greyhound.com/services/ada.shtml
<i>The National Park Service</i> has over 350 national parks, activities, and programs. Information on accessibility of 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 fees.	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 For more information about the Golden Access Passport: www.nps.gov/fees_passes.htm
<i>Easy Access to National Parks: The Sierra Club Guide for Persons with Disabilities</i> . This book is available from the Sierra Club.	Sierra Club Books 85 Second Street, 2 nd Floor San Francisco, CA 94105 (800) 935-1056 (voice) www.sierraclub.org/books/
<i>KidsCamps.com</i> – provides a list of special needs camps.	KidsCamps.com 6421 N. Congress Avenue, Suite 200 Boca Raton, FL 33487 (561)443-2924 (voice) (561) 443-2904 (fax)

<p><i>Camp Lee Mar</i> – special programs and teaching methods are incorporated that emphasize academics, speech and language therapy.</p>	<p>Camp Lee Mar Winter Address: 805 Redgate Road Dresher, PA 18435 (570) 685-7188 (voice) Summer Address: 450 Route 590 Lackawaxen, PA (215) 658-1708 (voice) (215) 658-1710 (fax) E-mail: gtour400@aol.com www.leemar.com</p>
<p><i>Camp Nuhop</i> – “New Hope” for children with learning disabilities, attention deficit and behavior disorders. The camp is not appropriate for children who are severely mentally retarded or physically disabled.</p>	<p>Camp Nuhop 404 Hillcrest Drive Ashland, OH 44805 (419) 289-2227 (voice/fax) E-mail: cnuhop@bright.net www.campnuop.org</p>

Section Six - Looking to the Future

The primary focus of parenting a child with a disability between the ages of 6-13 is ensuring that the child receives the special education and other related services he or she needs to be as successful as possible in school. Knowing your child's legal rights, determining whether or not he or she would benefit from assistive technology, planning for his or her financial future and facilitating his or her participation in extracurricular activities is also important. Previous sections of the guide address each of these areas in greater detail.

As your child matures, you will need to give serious consideration to other areas of his or her adult life, such as: where will he live; what type of education will he need after high school; will he or she be able to work or participate in another vocational activity; etc.

While all parents consider these questions at some point in their child's life, parents of children with disabilities must consider them much earlier than other parents. There are some legal protections for adults with disabilities. However, provision of services (e.g. vocational, residential assistance and support) is not mandated by law as it is when a child receives services through the public school system. Many of these areas will be addressed in your child's transition plan, which is required as part of his Individual Education plan. But while this planning will begin by age 14, it is not too early to start exploring the options available in your community well before he turns 14. Depending on where you live, waiting lists for housing and vocational programs can be very long, requiring families to wait years for an opening for some services. Therefore, it is never too early to place your child's name on a waiting list. Choices may range from situations that provide a high level of support and assistance to options that provide for more independence.

Funding for residential and employment services varies greatly depending on location. Services and programs can be very different, depending on the city, county, and state in which you live. If families learn while their child is still young that there aren't many services (or that those services are inadequate) in their community for teens and young adults with disabilities, they may want to consider moving to an area where there greater opportunities exist for their son or daughter as they grow into young adulthood.

This section of the guide provides some very basic resources in exploring the housing and vocational programs that may be available in your community. For a more detailed description of issues to consider and the types of programs that may be available to your child in the future, please request a copy of the Young Adult or Adult Guide of the Life Stages Program from the TS Alliance at (800) 225-6872 or download from the Web site at www.tsalliance.org.

Getting Started

Listed below are some resources that you may want to explore early in the search for residential and vocational programs. Even if your child is in elementary or middle school, it is not too early to begin to identify the different options in your community. Identifying the available programs and researching the options that will best meet your child’s needs in the future should be included as part of the transition planning process which begins at age 14, as mandated by the IDEA. 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.

To learn 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. The state VR agency will also be able to help determine the services and programs for which your son or daughter may qualify. To find a link to the vocational rehabilitation agency in your state, visit: www.jan.wvu.edu/SBES/VOCREHAB.HTM.

Local chapters of national disability organizations are also excellent resources for disability-related employment and housing programs that exist in your community. In addition to providing early intervention and services for children with disabilities, some of these agencies also provide job training and placement support to young adults and adults with disabilities. 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. Contact information for the national or headquarters office of these organizations can be found in Section Seven of this guide.

Housing & Vocational Resources

Resource	Contact Information
<i>Arclink.org</i> – Provides detailed information on home and community-based services.	www.thearclink.org (800) 433-5255 (voice) E-mail: info@thearc.org
<i>Federal Disability Information</i> – this Web site provides one-stop access to government disability information and resources, including employment, education, transportation, housing, technology, health, income, support and community life.	www.disabilityinfo.gov
<i>How to Choose a Provider—A Guide From CARF</i> , published by the Commission on Accreditation of Rehabilitation Facilities. CARF measures the outcomes of services provided to persons with disabilities. Provides a list of questions to ask providers about their assisted living programs.	CARF 4891 E. Grant Rd. Tucson, AZ 85712 (520) 325-1044 (voice/TTY) (520) 318-1129 (fax) www.carf.org
<i>Developmental Disability (DD) Councils</i> (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.	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

	E-mail: mgray@naddc.org
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. To find the center for your state, contact the Pacer Center or visit their web site.	Pacer Center - Alliance Coordinating Office 8161 Normandale Blvd. Minneapolis, MN 55437 (952) 838-9000 (voice) (952) 838-0190 (TTY) (952) 838-0199 (fax) E-mail: alliance@taalliance.org www.taalliance.org
ResCare – A for profit service provider for people with developmental and other disabilities in 32 states, D.C. and Puerto Rico that enable people with disabilities to live and work in the community.	ResCare 10140 Linn Station Road Louisville, KY 40223 (502) 394-2478 (voice) E-mail: dpdsupportservices@rescare.com www.rescare.com
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.	Epilepsy Foundation 4351 Garden City Drive Landover, MD 20785-7223 (800) 332-1000 (voice) www.efa.org
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: www.jan.wvu.edu/SBES/VOCREHAB.HTM

Section Seven - 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 made up of the patient, family, the personal physician, a hospice physician, nurses, home health aides, social workers, clergy and trained volunteers. Hospice staff 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 listed below) help-line or visit their web site to find a hospice program close to you.

Listed below are some of questions that should be asked when comparing hospice programs. You may also want to read, "All About Hospice: A Consumer's Guide," published by the Hospice Association of America (see contact information listed below) for more detailed information and recommendations for selecting a hospice program. 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 they provide references from physicians, social workers or families who have used their 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. Its best to know what services are provided before making your final selection.
- How flexible is the organization? Are they willing to provide the services and assistance you want and need (for example are they staffed to provide home care vs. facility care)?

Who pays for Hospice care?

Hospice services are covered under Medicare. Currently, 45 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 before services begin, families find out what the costs will be and what will and will not be covered.

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.

Note: Much of the information for this fact sheet was excerpted from, “All About Hospice: A Consumer’s Guide” and the “Hospice Fact Sheet,” (both published by the Hospice Association of America) and the End of Life Issues and Resources section of the Breast Cancer Resource Directory of North Carolina:

<http://cancer.med.unc.edu/bcresources/hospice.htm>

Resource	Contact Information
<i>All About Hospice: A Consumer’s Guide</i> and <i>Hospice Fact Sheet</i> , this organization offers general information about hospice. Call to order or view the full text on their web site.	Hospice Association of America (202) 546-4759 www.hospice-america.org
Books, videos, brochures and a newsletter about hospice and living with grief.	Hospice Foundation of America (800) 854-3402 www.hospicefoundation.org

<i>Hospice Patients Alliance Family Guide to Hospice (What No Hospice Will Tell You)!</i> Cost \$23.00. This nonprofit organization serves hospice patients, families and caregivers.	Hospice Patients Alliance, Inc. (616) 866-9127 www.hospicepatients.org
<i>Consumer Guide to Selecting a Hospice Program</i> , 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.	National Hospital and Palliative Care Organization (800) 243-5900 www.nhpo.org
<i>How to Choose a Home Care Provider: A Consumer's Guide</i> . Full text of the guide is available on their Web site. The NAHC represents home care agencies, hospices and home care aide organizations.	National Association for Home Care (202) 547-7424 www.nahc.org

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:

Grieving 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
- Drive more carefully.
- Express your needs clearly
- Ask for professional help if needed (see resources listed below)
- Remember that 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 can refer you to a licensed therapist. You may also want to join a local or Internet support group.

Grief and Bereavement Resources

Resource	Contact Information
<i>The Grief Recovery Handbook: The Action Program for Moving Forward Beyond Death, Divorce, and Other Losses</i> , Authors: John W. James & Russell Friedman.	Check local bookstores or www.amazon.com
<i>Awakening from Grief: Finding the Road Back to Joy</i> , Author: John E. Welshons.	Check local bookstores or www.amazon.com
<i>On Death and Dying</i> , Author: Elisabeth Kubler-Ross.	Check local bookstores or www.amazon.com
<i>The Grieving Child: A Parents Guide</i> , Authors: Helen Fitzgerald, Elisabeth Kubler-Ross.	Check local bookstores or www.amazon.com
<i>GriefNet.Org</i> – 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.	http://griefnet.org www.kidsaid.org E-mail: webmaster@greifnet.org

Other End of Life Issues and Resources

An advance directive tells your doctor what kind of care you would like your child 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 the Life and Financial Planning section of this guide). For more information on advance directives, visit the Partnership for Caring Web site (listed in the resource chart below). **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:

Resource	Contact Information
Partnership for Caring: America’s Voices for the Dying is a national nonprofit organization that operates the only national crisis and information hotline dealing with end-of-life issues and provides state specific living wills and medical powers of attorney.	Partnership for Caring 1620 Eye Street, NW, Suite 202 Washington, DC 20006 (202) 296-8071 (voice) (202) 296-8353 (fax) (800) 989-9455 (hotline) www.partnershipforcaring.org E-mail: pfc@partnershipforcaring.org
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.	National Guardianship Association 1604 N. Country Club Rd. Tucson, AZ 85716-3102 (520) 881-6561 (phone) (520) 325-7925 (fax) www.guardianship.org

<p>Tool Kit for Health Care Advance Planning, published by the American Bar Association, this kit contains worksheets, suggestions and resources. It 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>
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Section Eight - National Nonprofit Organizations

The national organizations listed below provide various services and support 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 that are 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 & 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 age appropriate activities for school-age children 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 future versions of the *School-Aged Guide of the Life Stages Program*.

National Nonprofit Disability Organizations – Contact Information

Headquarters Address & Phone Numbers	Web Site & E-mail Address
Tuberos Sclerosis Alliance 801 Roeder Road, Suite 750 Silver Spring, MD 20910 (800) 225-6872 or (301) 562-9890 (voice) (301) 562-9870 (fax)	http://www.tsalliance.org E-mail: 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)	http://www.thearc.org E-mail: info@thearc.org
Asperger Syndrome Coalition of the U.S. P.O. Box 2577 Jacksonville, FL 32203-2577 (904) 745-6741 (voice)	www.asperger.com E-mail: aspden@cybermax.net
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)	http://www.autism.org E-mail: info@autism-society.org
Developmental Delay Resources 6701 Fairfax Road Chevy Chase, MD 20815 (301) 652-2263 (voice)	www.devdelay.org
Epilepsy Foundation 4351 Garden City Drive Landover, MD 20785-7223 (800) 332-1000 (voice)	http://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)	http://www.chadd.org E-mail: 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)	http://www.add.org E-mail: mail@add.org
The Attention Deficit Information Network, Inc 58 Prince St. Needham, MA 02492 (781) 455-9895	www.addinforonetwork.com E-mail: adin@gis.net
Easter Seals National Headquarters 230 W. Monroe Street, Suite 1800 Chicago, IL 60606 (312) 726-6200 or (800) 221-6827 (voice) (312) 726-1494 (fax)	http://www.easter-seals.org
UCP (aka United Cerebral Palsy) National	http://ucpa.org/main.cfm/1

1660 L Street, NW, Suite 700 Washington, DC 20036 (800) 872-5827 (voice) (202) 776-0406 (TTY) (202) 776-0414 (fax)	E-mail: webmaster@ucp.org
TASH (formerly The Assoc. of the Severely Handicapped) 29 W. Susquehanna Ave., Suite 210 Baltimore, MD 21204 (410) 828-8274 (voice) (410) 828-6706 (fax)	http://www.tash.org
American Association of People with Disabilities (AAPD) 1819 H Street, NW, Suite 330 Washington, DC (800) 840-8844 or (202) 457-0046 (voice) (202) 457-0473 (fax)	http://www.aapd.org-dc.org E-mail: aapd@aol.com
Genetic Alliance 4301 Connecticut Ave., NW, Suite 404 Washington, DC 20008-2304 (202) 966-5557 (voice) (202) 966-8553 (fax)	http://www.geneticalliance.org E-mail: info@geneticalliance.org
Goodwill Industries International 9200 Rockville Pike Bethesda, MD 20814 (240) 333-5200 (voice)	http://www.goodwill.org E-mail: contactus@goodwill.org
Internat'l Assoc. of Jewish Vocational Services (IAJVS) 1845 Walnut Street, Suite 640 Philadelphia, PA 19103 (215) 854-0233 (voice) (215) 854-0212 (fax)	http://www.iajvs.org
Learning Disabilities Association of America 4156 Library Road Pittsburgh, PA 15234-1349 (412) 341-1515 (voice) (412) 344-0224 (fax)	http://www.ldanatl.org E-mail: info@ldaamerica.org
National Association for the Education of African American Children with Learning Disabilities P.O. Box 09521 Columbus, OH 43209 (614) 237-6021 (voice)	www.charityadvantage.com/aacl/articlesandpublications.asp E-mail: info@aacl.org
National Family Caregivers Association (NFCA) 1040 Connecticut Avenue, #1500 Kensington, MD 20895-3944 (800) 896-3650 (voice) (301) 942-2302 (fax)	http://www.nfcacares.org E-mail: info@nfcacares.org
Federation of Families for Children's Mental Health 1101 King St. Alexandria, VA 22314 (703) 684-7710 (voice) (703) 836-1040 (fax)	www.ffcmh.org ffcmh@ffcmh.org
National Mental Health Association 2001 N. Beauregard St. 12 th Floor	www.nmha.org

<p>Alexandria, VA 22311 (703) 684-7722 or (800) 969-6642 (voice) (800) 433-5959 (TTY) (703) 684-5968 (fax)</p>	
<p>National Alliance for the Mentally Ill (NAMI) Colonial Place Three, 2107 Wilson Blvd. Arlington, VA 22201 (703) 524-7600 (voice) (800) 950-6264 NAMI Help-line (voice)</p>	<p>http://www.nami.org</p>
<p>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)</p>	<p>http://www.ld.org</p>
<p>National Organization for Rare Disorders P.O. Box 8923 New Fairfield, CT 06812-8923 (203) 746-6518 or (800) 999-6673 (voice) (203) 746-6481 (fax)</p>	<p>www.rarediseases.org</p>
<p>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)</p>	<p>http://www.snapinfo.org E-mail: info@snapinfo.org</p>

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. This log sheet may help to keep track of whom you spoke to when searching for information.

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 useful. Please give us your feedback about the *School-Aged Guide of the Life Stages Program*. Please return this form to:

Tuberous Sclerosis Alliance
801 Roeder Road, Suite 750
Silver Spring, MD 20910
(301) 562-9890

If you'd like to speak to a staff person about this guide, please contact us. Thanks for taking the time to share your thoughts with us!

1. How did you hear about the *School-Aged Guide of the Life Stages Program*?

Perspective Newsletter Article TS Alliance Web Site TS Alliance Staff Person

Other (please indicate): _____

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

<input type="checkbox"/> Section One – Legal Rights Under Disability Law	<input type="checkbox"/> Section Five – Staying Healthy and Family Support
<input type="checkbox"/> Section Two – Education	<input type="checkbox"/> Section Six – Looking to the Future
<input type="checkbox"/> Section Three – Life and Financial Planning	<input type="checkbox"/> Section Seven – End of Life Issues
<input type="checkbox"/> Section Four – Assistive Technology	<input type="checkbox"/> Section Eight – National Disability Organizations

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

<input type="checkbox"/> Section One – Legal Rights Under Disability Law	<input type="checkbox"/> Section Five – Staying Healthy & Family Support
<input type="checkbox"/> Section Two – Education	<input type="checkbox"/> Section Six – Looking to the Future
<input type="checkbox"/> Section Three – Life and Financial Planning	<input type="checkbox"/> Section Seven – End of Life Issues
<input type="checkbox"/> Section Four – Assistive Technology	<input type="checkbox"/> Section Eight – National Disability Organizations

4. What other types of information would you like to see included in future versions of the *School-Aged Guide* (please be specific)?

5. Overall, did you think the *School-Aged 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 school-aged children with TS? Yes No

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