

# CONSIDERATIONS FOR PEOPLE WITH DISABILITIES AND THEIR FAMILIES



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**American Health Lawyers Association**

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— from a declaration of the American Bar Association*

*Considerations for Persons with Disabilities and Their Families (Considerations)* is a publication of the American Health Lawyers Association's (AHLA) Public Information Series (Series), a growing collection of informational guidebooks that addresses a variety of topics affecting the public. The Series first published in 2004 and is an important aspect of AHLA's public interest commitment as a tax-exempt educational association. As with all of the Series publications, AHLA calls on its members with expertise in the field to help the public navigate difficult legal and healthcare issues that daily affect their lives.

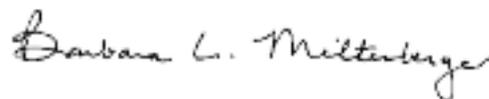
The authors of *Considerations* are well-versed in the day-to-day obstacles confronted by persons with disabilities, including children with disabilities and their parents. They understand the myriad difficult issues that can arise in dealing with school districts and with federal, state, and local agencies. The authors have developed a series of questions parents and families should ask at various stages of the child's life, from infancy to adulthood. This publication will not give all the answers, but the authors have focused on issue spotting to help individuals with disabilities and their families through the legal and practical issues they will face, especially for those with severe disabilities that require some degree of ongoing medical, human and technological services and supports.

As children with disabilities age, their legal issues will change. Parents of all toddlers, including children with disabilities, are trying to provide the most appropriate supports and services so that each child develops to her greatest extent possible. As their child with a disability reaches the age at which she should be entering pre-school, grade school, junior and senior high, school may present unique challenges of integrating the child into the classroom for some or all of each school day. Finally, as both the parents and child age, their focus may well shift to finding suitable employment, transportation, healthcare and housing while laying out a financial plan that will meet the child's needs when the parents are no longer able to do so.

*Considerations* includes a glossary of the key terms (Appendix A) to help the reader navigate the complicated alphabet soup of laws, programs and agencies relevant to the disabled. Appendix B includes many helpful websites that the authors found comprehensive yet easy for the public to use and understand. These online resources provide helpful information on social support services and community resources; they also do a good job explaining how the law can protect the individual with disabilities.

The 10,000+ members of American Health Lawyers Association are committed to advancing its mission to "serve as a public resource on selected healthcare legal issues." Through its Public Interest Committee and volunteer lawyers, the Association's Public Information Series has written on subjects as diverse as emergency planning following the devastation of Hurricane Katrina in New Orleans to preparing advance healthcare directives after the Terry Schiavo case brought the need for advance planning to the public's attention. AHLA provides briefings on healthcare issues of national importance and sponsors public interest dialogue sessions and teleconferences on health law policy. Both the public and the Association's members benefit greatly from the members' generosity and expertise contributed on behalf of their commitment to AHLA's mission.

*Considerations* would not have been possible without the generous contribution of time and knowledge of the following authors: Kathleen M. Boozang, Kelly K. Dineen, Alene V. Haskell, Elizabeth A. Mushill, and Robert L. Schwartz. AHLA and I are indebted to them for their dedication and commitment. I would also like to thank Linda Pritzel for her hard work in the preparation and formatting of this document.



**Barbara L. Miltenberger**  
Task Force Leader, *Considerations for People with Disabilities and Their Families*

In my work as Chairman of Special Olympics International, I have the privilege of meeting many people with disabilities and their families; these disabilities include intellectual, developmental, visual, auditory, sensory, physical, and mental disabilities worldwide. The more I talk with them and learn about their lives, the more I understand the enormous craving they have for information and support. *Considerations for People with Disabilities and Their Families (Considerations)* marks a great stride toward filling that need. It is a practical and comprehensive resource written by legal experts to help educate individuals and families touched by disabilities.

*Considerations* covers many relevant issues and inquiries for individuals with disabilities and their families. It is a valuable and easy-to-navigate tool that lists web resources and services in the areas of social support, community resources, and state and Federal protections. Family members can also find avenues of support and opportunities to share their challenges and accomplishments with others. They can discover community-specific resources for information, assistance and other services.

And, *Considerations* does something of great importance that goes beyond the purely practical; it encourages its readers to realize the potential in individuals with intellectual, developmental, visual, auditory, sensory, physical, and mental health disabilities once the barriers to their participation are removed. This belief is at the very core of our mission in Special Olympics.

I am so pleased that the American Health Lawyers Association has created this disability guide. Based on my years of experience with Special Olympics athletes and their families, I firmly believe that it will prove to be a vitally important and well-used source of knowledge, support and inspiration for individuals with disabilities and their families. Above all, the wealth of information contained in this guidebook will serve as a tool to encourage more inclusive communities and promote the inclusion of individuals with disabilities into society.



**Timothy Shriver**  
Chairman, Special Olympics International

**Considerations for People With Disabilities and Their Families**

<b>I. Introduction</b> .....	5	<b>D. Government Vocational Assistance</b> .....	18
<b>II. Purpose of the Individual with Disabilities Education Act (IDEA)</b> .....	6	<b>VIII. Public Accommodations</b> .....	20
<b>III. Infants and Toddlers (Part C of the IDEA – Newborn to 3 Years)</b> .....	7	A. Access to Transportation.....	20
A. Assistance for Infants and Toddlers with Disabilities .....	7	B. Access to Rental Housing .....	21
B. Transitioning from Infant/Toddler to Pre-School and School Aged Children .....	7	C. Testing Accommodations .....	21
<b>IV. Educational Assistance for Pre-School and School Aged Children with Disabilities (Part B of the IDEA – Ages 3 to 21)</b> .....	8	<b>IX. Government Benefits</b> .....	22
A. Programs Required Under the IDEA .....	8	A. Benefits for Adults .....	22
B. Evaluations and Eligibility .....	8	B. Benefits for Children .....	23
C. Individualized Education Program.....	10	C. Applying for Benefits and Appeals .....	23
D. Procedural Safeguards .....	11	<b>X. Estate Planning</b> .....	24
E. Discipline for Behavior Problems in School .....	11	A. Special Needs Trust.....	24
F. Transition of Services to Post-Secondary Education, Vocational Training, and Independent Living .....	12	B. State-Based Trust Programs (Pooled Trusts).....	24
G. Other Applicable Federal Laws Regarding School Children with Disabilities .....	12	C. Caretaker Planning .....	25
<b>V. Health and Life Insurance</b> .....	13	<b>XI. Complementary and Alternative Medicine</b> .....	26
A. Private Health Insurance Coverage.....	13	<b>XII. Family Law Issues</b> .....	27
B. Exclusion from Benefits and Denial of Coverage for Health Insurance .....	13	A. Custody Determinations .....	27
C. Life Insurance .....	14	B. Disability of the Parent in Child Custody Determinations .....	27
<b>VI. Emergency Preparedness</b> .....	15	C. Disability of the Child in Child Custody Determinations .....	27
<b>VII. Employment</b> .....	16	D. Disability of Parent or Child in Determining Child Support .....	28
A. The Americans with Disabilities Act (ADA) .....	16	<b>XIII. Healthcare Decision Making</b> .....	29
B. Veterans with Service-Connected Disabilities – The Uniformed Services Employment and Reemployment Rights Act (USERRA).....	17	A. Determining Capacity to Make Healthcare Decisions.....	29
C. The Family Medical Leave Act (FMLA).....	17	B. Decision Making for Children .....	29
		C. Decision Making for Adults .....	29
		D. Guardians and Conservators.....	30
		E. Decision Making Policies at Healthcare Institutions.....	31
		<b>XIV. Conclusion</b> .....	32
		<b>Appendix A – Glossary</b> .....	33
		<b>Appendix B – Online Resources</b> .....	35
		<b>Appendix C – Author Profiles</b> .....	37



# Considerations For People With Disabilities and Their Families

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## I. Introduction

“Once I knew only darkness and stillness... my life was without past or future... but a little word from the fingers of another fell into my hand that clutched at emptiness, and my heart leaped to the rapture of living.”<sup>1</sup>

It is difficult to think about how some people live with very severe disabilities without remembering Helen Keller and her incredible accomplishments. We have come a long way from the days of *The Miracle Worker*<sup>2</sup> when little was expected from a person with disabilities. Thankfully we have learned that all persons given appropriate support, training and opportunity can contribute meaningfully to society. Today, even television shows<sup>3</sup> remind us that persons with disabilities have much to offer. Although it has not come easily, change has occurred with the enactment of a number of laws requiring assistance in school, with public accommodations, and with housing and transportation for people with disabilities.

Laws also allow parents time away from work to address the myriad issues presented by a child with a disability. However, the laws can also be unclear and services can be fragmented as they are sometimes provided by government agencies that do not communicate with each other. Caring for an individual with a disability can be physically and emotionally draining at times, especially when having to navigate complex rules and regulations without having adequate information. The authors have applied their expertise in this area to prepare a series of questions and some practical tips that the caregiver, parent or family member should consider to secure the necessary services and to prepare them for future issues.

This guidebook is not comprehensive and does not provide legal advice. Everyone’s situation is different. However it is a good starting point and it will hopefully raise the important questions that should be asked by people with disabilities and their families as they face the many challenges created for them by today’s complex society.

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1 Helen Keller, [http://www.brainyquote.com/quotes/authors/h/helen\\_keller.html](http://www.brainyquote.com/quotes/authors/h/helen_keller.html)

2 *The Miracle Worker, A Play in Three Acts* by William Gibson (1959)

3 [http://www.craegmoor.co.uk/news/industry/18263225/downs\\_syndrome\\_explored\\_in\\_tv\\_drama.aspx](http://www.craegmoor.co.uk/news/industry/18263225/downs_syndrome_explored_in_tv_drama.aspx)

## II. Purpose of the Individual with Disabilities Education Act (IDEA)

Society today places much greater emphasis on abilities, opportunities and achievement for persons with disabilities. While there is still much more that can be done, we have come a long way. Many resources now exist to help families secure services for their disabled child. Federal and state government programs are possible sources of early intervention and care for young children. In addition, numerous healthcare and disability-related support groups or advocacy organizations are usually a wonderful source of support and information.

Families should ask their child's healthcare providers for information about support organizations and government agencies that may be able to help. Many of the legal protections concerning education are found in the *Individual with Disabilities Education Act (IDEA)*<sup>4</sup>, a federal law that is implemented by the individual states. Although all states must meet the requirements of the IDEA, each *state educational agency (SEA)* sets its own criteria for carrying out the IDEA. It is important to know what services are available in the state in which the disabled person resides.

The IDEA is a federal law enacted to ensure a *free and appropriate public education (FAPE)* in the *least restrictive environment (LRE)* for children with disabilities. Part C of the IDEA applies to infants and toddlers while Part B applies to school age children. FAPE is carried out, in part, through the development of the child's *individualized education plan (IEP)* for special education and related services tailored to the child's unique needs. Those requirements are found under Part B of the IDEA.

In 2004, Congress reauthorized the IDEA and emphasized the following concepts:

- Disability is a natural part of the human experience and in no way diminishes the right of individuals to participate in or contribute to society; and
- Improving educational results for children with disabilities is an essential element of our national policy of ensuring equality of opportunity, full participation, independent living, and economic self-sufficiency for individuals with disabilities.

In light of the reauthorization, the parent should determine whether the child's SEA reflects the Act's purposes as identified by Congress. Through state law, regulation, and education policies, the parent also needs to determine whether the SEA requires the following to be provided by *local educational agencies (LEA)*, often school districts:

- Access to a FAPE that emphasizes special education and related services designed to meet the child's unique needs and which prepares her for further education, employment and independent living;
- Protection of the child's and parents' rights with procedures in place to ensure due process;
- The necessary tools for educators and parents to improve educational results for the child; and
- Mechanisms to ensure and measure effective efforts to educate the child.

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4 20 USC § 1400 et. seq.

### III. Infants and Toddlers (Part C of the IDEA – Newborn to 3 Years)

#### A. Assistance for Infants and Toddlers with Disabilities

Part C of the IDEA provides federal grants to states so that they can provide early intervention assistance to infants and toddlers with disabilities and developmental delays. The IDEA requires states to include physical therapy, speech or occupational therapy, vision services, psychological services, medical screenings and family training. To determine whether early intervention and related services might be available for the child, ask the following questions:

1. As a recipient of grant money under Part C of the IDEA, does the state where the child resides offer early intervention services and programs targeted to infants and toddlers? If so, who is eligible?
2. Does the state provide Part C programs to children until the age of kindergarten? If so, who is eligible?
3. Does the state follow Part C of the IDEA in providing evaluations and services to assist in all areas of the infant or toddler’s development?
4. Does the state provide services to all children under the age of 3 with medical disabilities, developmental delays and, in some cases, children considered “at-risk” under Part C? What conditions of “at-risk” children are covered by the state?
5. What is the state’s required system for identifying and evaluating children under the program?
6. Does the state’s program provide service coordination to each eligible child and family, including the development of an *individualized family service plan (IFSP)* with the consent and input of the parent and family?
7. Does the IFSP include the required components of the child’s strengths and weaknesses, the goals

of the plan, how the goals will be measured and the services to be provided? (The IDEA requires that the IFSP be reviewed and updated on a regular basis).

8. Does the state require the parent or family to pay for a portion of the cost of some of the services provided?
9. What rights and remedies are available to a parent when the state may not be complying with federal and state requirements, such as those listed in 1–8 above?

#### B. Transitioning from Infant/Toddler (Part C of the IDEA) to Pre-School and School Age Children (Part B of the IDEA)

As the infant or toddler grows up, new issues will arise as the child enters her pre-school, grade school and junior/senior high school years. Points to consider and questions to ask during this transitional period include the following:

1. Does the SEA begin coverage of children at age 3 under Part B of the IDEA?
2. What are the SEA’s policies and procedures to locate, evaluate and provide appropriate services to all children with disabilities, whether or not the child attends public school?
3. Are children who experience developmental delays between the ages of three and nine (or subset of the age range as determined by the SEA) eligible in the state for special education and related services under Part B of the IDEA?
4. Does the SEA, through the LEA, perform the required evaluations for Part B eligibility at age three (or during the school year when the child will turn three) for those who are receiving services under Part C of the IDEA?
5. What rights and remedies exist for a parent who feels the state has failed in its duty to their child with a disability?

## IV. Educational Assistance for Pre-School and School Age Children with Disabilities (Part B of the IDEA – Ages 3 to 21)

### A. Programs Required Under the IDEA

As mentioned earlier, the IDEA is a federal law that governs how states address the educational needs of children with disabilities. While Part C dealt with infants and toddlers, Part B of the IDEA deals with school-age children from age three to twenty-one. While all states must meet the requirements of IDEA, the child's respective SEA will also have its own set of criteria for carrying out the requirements of the IDEA. Keep in mind that members of the Part C service team are required by the IDEA to be included in the development of the IEP for children transitioning from Part C to Part B services. In addition, the Part B IEP team is required to take the IFSP into consideration when evaluating a child previously served under Part C. Under some circumstances, the IFSP may be used as the IEP. Listed below are some questions that should be asked about the child's SEA when transitioning into Part B:

1. Does the SEA ensure that eligible children receive a FAPE through special education and related services tailored to their unique needs?
2. Does the SEA guarantee access to public school for all children?
3. Does the SEA provide effective education in the least restrictive environment (LRE) for children with disabilities?
4. Does the SEA provide for the delivery of services under the IDEA for children from infancy to age 21?
5. Does the SEA have programs in place to find, evaluate and provide appropriate services (commonly called **Child Find**)?
6. Does the state's Child Find program include children not enrolled in the public school system, such as children in private schools or homeless children?
7. Does the SEA provide a mechanism for the delivery of special education and related services in a manner consistent with Part B of the IDEA, including for children in correctional facilities, those served through mental health departments, or placed in a private school by a public agency?

8. Do all state public agencies involved in education provide the services covered under Part B of the IDEA to children with disabilities from the ages of three to twenty-one?

### B. Evaluations and Eligibility

Having a disability does not automatically qualify the child for educational assistance under the IDEA. To determine if one qualifies for special education and related services, consider the following:

1. How does the state determine eligibility for special education and related services under the IDEA?
  - a. How does the SEA ensure that the LEA has conducted the required evaluation for eligibility under the IDEA?
  - b. To qualify under the IDEA, a doctor's diagnosis is not enough. The LEA must evaluate the child and answer yes to the following questions based on the evaluation:
    - Does the child have a disability as defined by the IDEA and SEA?
    - Does the child's disability impact her educational performance?
    - Does the child require special education and related services because of her disability?
2. How does the SEA allow the parent or a public agency, with appropriate consent, request an initial evaluation?
3. Once consent for evaluation is obtained, under what circumstances can the school district take more than 60 days or longer than the timeline set by the SEA to conduct the evaluation?
4. Note that if the LEA refuses to evaluate the child, the parent is required by law to be informed in writing of the refusal and the reasons for the refusal.
  - a. Does the SEA classify disability for special education and related services under the IDEA categories only? What criteria does the SEA set for each category?
  - b. How are the SEA's criteria for educational diagnoses different for the same or similar medical diagnoses?

- c. If the LEA’s evaluator determines that the child with a medically diagnosed disability does not meet the criteria for special education and related services, how did the evaluator come to that conclusion?
- The child is not a “child with a disability” as defined by the IDEA and the SEA.
  - If the child is a “child with a disability,” her disability does not impact her educational performance.
  - The child’s disability impacts performance but not to the extent that she needs special education.
5. If the parent or family member does not agree with the findings of the school evaluators, the parent has the right to request an independent educational evaluation in writing.
  6. In some cases, the independent evaluation must be performed at the school district’s expense. Find out the circumstances in which the school district would have to pay for the independent evaluation.
  7. Find out what process is in place to ensure that children who receive special education and related services are reevaluated at least every three years.
  8. A child who does not qualify for special education but does have a medical condition, impairment or disorder may be able to receive education and related services under *Section 504 of the Rehabilitation Act (Section 504)*.

### Tips Regarding Evaluations and Eligibility:

- Start and attempt to keep every interaction and relationship with the school district positive, professional and moving forward toward achievement of the evaluation process(es) and mutually agreed upon goals in the IEP and the IFSP—but document everything, always.
- Document all your communications with the school—put every significant discussion and/or decision in writing. For example, a request for an evaluation should be in writing, dated and either hand-delivered or sent by certified mail, return receipt requested. Be sure to keep the signature card showing receipt. If hand-delivered, take an additional copy to have date stamped and signed as received.
- Keep a log or diary of all communication with the school district, including conversations with teachers and administrative personnel at the child’s school. Document dates, times, names of persons and their positions or titles.
- If the school district refuses your request for evaluation, request a written notice of refusal (this is often called a **Notice of Action Refused**). This is required by law.
- Provide evaluators with copies of any medical records or evaluations that may be helpful in obtaining special education and related services for the child. Keep a copy of everything provided to evaluators.
- Ask the child’s healthcare provider(s) to write a letter explaining the child’s medical diagnosis and recommendations for assistance at school. Keep in mind that the school is not required to provide the best or most ideal options for the child; the school is only required to provide education and services designed to provide some educational benefit. Therefore, the healthcare provider should avoid statements of “ideal recommendations” or the “best options” for the child. Finally, ask healthcare providers to consider the school environment in writing the letter. Some providers will charge for this service.
- If you do not agree with the school’s evaluation, request an independent educational evaluation.
- Become familiar with the IDEA and applicable state laws.

### C. Individualized Education Program

Under the IDEA, public schools are required to develop an individualized education program (IEP) for the student who is found eligible under both the federal IDEA and the SEA's requirements. The IEP team (which must include the parents) must be created and tailored to meet the unique needs of the individual child. In creating an IEP that will be tailored to meet the child's specific needs, ask the following questions:

1. Once the child is determined to be eligible for special education and related services, does the LEA follow the IDEA and SEA mandates to assemble the required team of people within 30 days so that a uniquely tailored IEP can be developed?
2. Does the IEP contain the information required under the IDEA and by the SEA?
3. Is the IEP developed, reviewed, and revised periodically in meetings with the appropriate team members?
4. Does the IEP team include the required persons: the parent(s); at least one regular education teacher; at least one special education teacher; a representative of the LEA; an individual who can interpret the evaluation results; the child (if appropriate); and other individuals who have knowledge or special expertise regarding the child? The parent is free to invite anyone to the IEP meeting, including other family members and the child's healthcare providers who may have knowledge or expertise regarding the child.
5. When developing the IEP, does the entire team consider, as required, the results of recent evaluations; the child's strengths; the parent's specific concerns for her child's education; and the academic, developmental, assistive technology, and functional needs of the child?
6. In 2004, the IDEA was changed to remove the requirement that the IEP team consider the results of the child's performance on state or district assessment programs.

#### **Tips Regarding Individualized Education Programs:**

- Feel free to invite family members and healthcare providers to the IEP meeting who can provide information about the child, take notes, or offer support.
- Ask questions. Don't be intimidated. You are your child's best advocate, so speak up.
- Bring along a note taker or notify/ask the school about tape recording the meeting for your reference later.
- Bring along records or documentation that may be helpful.
- Do not feel obligated to sign the IEP if you still have questions or do not agree with everything in the IEP.
- If the school does not agree to something you think is necessary for your child, ask for a notice of action refused.
- Make sure you have a copy of all documents used or referenced during the meeting.

## D. Procedural Safeguards

The IDEA includes procedural safeguards that will protect both the parents' and child's rights and, in addition, children with disabilities and their parents may have additional civil rights protections under Section 504, the *Americans with Disabilities Act (ADA)* and its 2008 Amendments. Those safeguards will also ensure that the child receives a FAPE. Become familiar with these safeguards and understand the rules and guarantees. As the child progresses along the educational continuum, keep in mind the following considerations and ask the following questions:

The IDEA's procedural safeguards, from the parent's initial request for an evaluation to proper implementation of the IEP, include the parent's right to the following:

1. Be informed and participate in all special education decisions about the child.
  - Receive written notice of actions taken or refused.
  - Be informed of the findings made in the child's evaluations.
  - Receive access to the child's education records.
  - Consent in writing to evaluation and placement decisions.
2. Obtain a copy of the procedural safeguards under the IDEA at least once per year and more often in certain circumstances, as required under the IDEA.
3. The IDEA requires that the state's procedural safeguards include a description of opportunities available to the parent and child to present and resolve complaints through the SEA's due process and complaint procedures.
4. Determine whether the state's procedural safeguards include provisions to work out disputes with the school district without a formal hearing or court proceedings. For example, the reauthorized IDEA of 2004 includes processes for informal meetings to discuss disputes as well as procedures for mediation.
5. Once a complaint is filed with the SEA, it is essential that the parent or child's caregiver/legal guardian become familiar with the detailed rules that apply, both from the IDEA and relevant state laws.
6. The IDEA requires that information about the due process complaint and appeals process be available from the SEA through its website and by phone.
7. Find out if there are educational consultants or special education attorneys who can provide assistance, depending on the seriousness of the disputes.

## E. Discipline for Behavior Problems in School

If the child exhibits behavioral problems in school, the situation must be assessed with the child's disability in mind. To ensure that the child's behavioral problem is handled appropriately, ask the following questions:

1. If the child is already identified as having a disability under the IDEA and has an IEP, determine if the behavior resulting in disciplinary action was related to her disability (manifestation of the disability).
2. What discipline may schools impose on children with disabilities?
3. The IEP team is required to consider the use of positive behavioral interventions and supports as well as other strategies to address the child's behavior when she is identified as having behavioral problems that impede her learning or the learning of other students.
4. If behavior problems are anticipated, the parent or family member should specifically ask the IEP team to conduct a functional behavioral assessment and develop a plan to prevent problems in school.
5. Find out if there are special rules that may apply to children with disabilities who are disciplined by their schools.
6. Has a meeting (sometimes called a **Manifestation Hearing**) been held to determine whether the child's behavior was a manifestation of the disability?
7. Was the mandatory manifestation hearing conducted within ten days of a disciplinary decision to remove the child from the current educational placement?
8. If the child's behavior is determined not to be a manifestation of her disability, then she will be subject to the same disciplinary procedures as children without disabilities; however, special education and related services must continue to be provided.
9. Students who are disciplined for possession of a weapon at school, knowingly possessing or soliciting the use or sale of illegal drugs, or inflicting serious bodily injury upon another may be removed from the current setting for up to 45 days, even if the behavior was a manifestation of the disability.

10. The parent and family members should become familiar with the IDEA provisions surrounding behavioral assessments and discipline if the child does have behavior problems.
11. If the child is not already identified as a child with a disability, find out if her behavioral problems are symptoms of an underlying disability.
12. Does the behavior or pattern of behavior indicate that the school should have suspected a disability?
13. Is the failure to evaluate the child with behavior problems a violation of the IDEA and/or the Child Find obligations of the *No Child Left Behind Act* (NCLB)?
14. Parents and family members should request an expedited evaluation for the child so that services may be provided more quickly, if appropriate.

#### **F. Transition of Services to Post-Secondary Education, Vocational Training, and Independent Living**

A post-secondary education, vocational school and/or independent living arrangements will be options that a young adult with a disability may want to consider or pursue. To help make this transition as smooth as possible, keep in mind the following facts and consider the following questions, especially keeping in mind that post-secondary institutions are not covered by the IDEA but rather by the ADA, the *ADA Amendments Act of 2008* (ADAAA) and Section 504.

1. The IDEA of 2004 placed greater emphasis on the needs of high school students to receive transition services that better prepare them for a vocation, post-secondary education and/or independent living.
2. At or before the child's sixteenth birthday, the IDEA requires that specific transition plans and goals be included in her IEP.
3. As required by the IDEA, the child is invited and should be strongly encouraged to attend any IEP meeting in which transition goals are discussed.
4. If the child plans to attend a post-secondary institution, consider whether she is or will be prepared for

the changes she will experience regarding services, supports, and accommodations.

5. Because post-secondary institutions are not covered by the IDEA, the ADA and Section 504 usually apply to prevent discrimination against students on the basis of a disability.
6. In post-secondary school, there is no obligation for the institution to identify students with disabilities in need of assistance; instead, students are responsible for notifying the institution about their need for program accessibility and reasonable accommodations needs, if any.

#### **G. Other Applicable Federal Laws Regarding School Children with Disabilities**

For students who are not eligible under the IDEA or for whom the IDEA does not apply, Section 504 and/or the ADA may allow the child to receive reasonable accommodations to ensure equal access to educational opportunities.

1. Section 504 prohibits discrimination against children with disabilities by public or private agencies or entities that receive federal funding, including private schools that receive federal assistance (such as a private school that participates in the federal lunch program).
2. Section 504 ensures a student's access to education through an institution's reasonable program modifications that do not disrupt the educational goals of their programs.
3. Title II of the ADA prohibits discrimination against children with disabilities by public entities, such as a public school.
4. Title III of the ADA applies to places of public accommodation which includes certain private institutions such as private schools or child care centers.
5. Children who are eligible and receive services under the IDEA are also covered under the ADA, its Amendments of 2008 and Section 504.

## V. Health and Life Insurance

Health and life insurance plans help alleviate the financial burden of medical care and other life expenses for a disabled person. These plans can be purchased through employers or private insurance plans, though the latter option can be somewhat expensive. There are a number of issues that should be considered when searching for an individual plan or when comparing the health and life insurance benefits offered by a potential employer.

### A. Private Health Insurance Coverage

1. Health Insurance in General
  - a. Many health plans are offered as part of employee benefits.
  - b. Insurance plans that cover a large number of employees usually do not require individual health information to determine if coverage will be provided.
  - c. People who do not have access to health insurance through an employer often must seek individual plans, which are sold to individuals or families rather than through an employer.
  - d. It is more difficult and often impossible to obtain health insurance through individual plans for persons with disabilities because coverage is based on the health history of the person to be covered.
2. Employer Provided Health Insurance
  - a. What insurance benefits has the employer set up?
  - b. What state and federal insurance laws apply to the type of insurance being offered by the employer?
  - c. Does the employer provide health insurance that falls under the *Employee Retirement Income Security Act (ERISA)*?
  - d. Does the plan include a waiting period for coverage of pre-existing conditions?
  - e. Does the plan cover therapies and procedures related to the individual's disability?
3. Individual Health Insurance
  - a. Does the individual plan require health information, as most usually do?

- b. Does the individual plan deny coverage to people with pre-existing health problems, as many often do?
  - c. What process is in place to appeal a decision that denied coverage to an individual with a disability?
4. If a disabled individual is ineligible for government plans or has been denied coverage by private insurers through the use of high risk pools, find out if the state offers another way to obtain basic health insurance coverage.
5. What laws and regulations are in place that determine when and how health insurance plans cover claims for individuals?
6. What insurance laws apply to the type of insurance plan under consideration?
7. There are several laws that also protect some consumers when they must change health plans because of a change in life situation.

### B. Exclusion from Benefits and Denial of Coverage for Health Insurance

1. What illnesses or disorders (usually referred to as diagnosis), procedures and services are covered under the health insurance plan?
2. Is the covered diagnosis known before services are provided by a healthcare provider (either when enrolling in an insurance plan or when someone covered under the policy is diagnosed with a condition)?
3. Did the insurance company provide a copy of its plan's summary benefits during the time of enrollment or when one was looking into coverage issues?
4. The plan summary may be helpful to the patient, the patient's family and the healthcare provider in helping obtain coverage or finding cost effective alternatives to care and treatment.
5. What is the insurance plan's process to handle disputes?
6. If a claim is denied, contact the insurance company and ask for a detailed explanation of the reasons for the denial:
  - a. What was the reason for the initial denial?

- b. Was the denial because of inaccurate or insufficient information?
  - c. Would additional information from the health-care provider resolve the problem?
7. Is a formal appeal necessary if the dispute is not resolved with additional information?
  8. Is the information about filing an appeal explained in the plan's benefits or is it available on request from the insurance company?
  9. Are there any time limits in which individuals can appeal and in which the insurance company must respond?
  10. Are the time limits governed by the policy or state law?
  11. Does the state have laws that require outside review of the insurance company's decision?

### **C. Life Insurance**

1. Is life insurance for the person with a disability reasonably priced or too expensive to obtain?
2. Does the individual life insurance policy require medical information on the person to be covered?
3. Does a history of any chronic condition result in a denial to provide coverage?
4. Can parents or other family members use life insurance to fund a special needs trust for the individual with a disability? (The topic of special needs trusts is discussed in greater detail later in this guidebook.)

### **Tips Regarding Insurance Coverage:**

- Keep a log of all conversations with the insurance company and record the name(s) of the person(s) with whom you discussed issues as well as the date and time of the conversation.
- Keep a written record of medical information with dates of service.
- Ask for explanations in writing.
- Ask healthcare providers to help you with an appeal.
- Don't accept a denial without seeking further information and/or appealing the decision.
- Provide medical information including information from medical literature to the insurance company if it helps explain the services and treatment provided or proposed.
- Carefully read the billing statements from the healthcare provider and the explanation of benefits from the insurance company. Pay special attention to the following important details: the dates, procedures and times; the billing reflects the contract rate between your provider and your health plan; and all payments from you and the plan are properly credited.

## VI. Emergency Preparedness

All individuals and families should take basic steps to prepare for emergencies and disasters. For persons with disabilities, some additional preparations are essential to protect their health and safety during an emergency:

1. Identify safe and accessible locations and inform the appropriate persons of those locations.
2. Create a list of emergency contacts, including individuals who live out-of-town (emergency situations may impact one geographic area, making in-town contacts difficult to reach).
3. Create a list of the disabled person's healthcare providers with contact information; medical history; medical conditions; current medications and treatments; allergies or unusual reactions to foods, substances or medications; adaptive equipment and assistive technology; and any important information about cognitive or communicative difficulties and limitations. Distribute this list to all emergency contacts.
4. Prepare a disaster kit in case of an emergency and/or if home evacuation is necessary. This kit should include a week's supply of medication, an extra copy of prescriptions (if possible), and essential adaptive and medical equipment such as wheelchair supplies, Braille clocks or communication technology.
5. Create a plan for care for service animals in case of evacuation.

## VII. Employment

### A. The Americans with Disabilities Act (ADA)

The American with Disabilities Act, its Amendments of 2008 and other federal laws<sup>5</sup> prohibit employers from discriminating against qualified individuals on the basis of disability with respect to hiring, firing, training, and all other job privileges. Signed into law in 1990, the ADA underwent some major changes when the ADAAA took effect on January 1, 2009. The ADAAA broadened the definition of “disability” so that more individuals will be considered disabled and entitled to accommodations, and disabled plaintiffs will receive more favorable treatment in the courts. The ADAAA also increased the accommodations schools will have to make for students with a learning disability. The House of Representatives Committee Report noted that it “expects that individuals with specific learning disabilities that substantially limit a major life activity will be better protected under the amended Act.”<sup>6</sup> When seeking employment or assisting an individual with a disability with her employment issues, ask the following questions to determine whether the ADA would be applicable:

1. Does the ADA apply in my situation?
  - a. Does the employer employ fifteen or more employees? The ADA applies to employers who employ fifteen or more individuals.
  - b. Is the individual qualified for the job? Would she be able to meet the essential job functions, skill and education requirements with or without reasonable accommodation (a reasonable alteration of the job) from the employer?
  - c. Does the individual seeking a job have a disability as defined by the ADA:
    - The person has a physical, mental or emotional impairment that substantially limits one or more major life activities. Note that the ADAAA which took effect on January 1, 2009, now applies a standard that is broader and more expansive than the standard used in the ADA when determining whether an individual is considered disabled.
    - The person has a record of such an impairment;

- The person is regarded as having an impairment that substantially limits one or more major life activities.

2. Some examples of when the ADA would be applicable:
  - a. The employer terminated or refused to hire or promote a qualified person because of her disability.
  - b. The employer asked questions about a non-obvious disability during the hiring process.
  - c. The employer refused to train or train differently a qualified person because of her disability.
  - d. The employer treated a qualified person differently with regard to work privileges because of her disability.
  - e. The employer failed to offer or provide reasonable accommodation for the application process.
  - f. The employer refused to discuss the need for reasonable accommodations for an applicant or employee or the employer refused to put those reasonable accommodations into place.
3. Reasonable Accommodations

To determine if the employer must grant the employee a particular accommodation, ask the following questions:

- a. Has the employee requested an accommodation?
- b. Have possible accommodations been suggested and refused?
- c. Would a proposed accommodation impose undue hardship on the employer’s business?
  - Would the implementation of an accommodation result in the employer having to spend large sums of money?
  - Would the accommodation be a danger to or disrupt business processes that involve other employees or violate other federal laws such as the regulations of the *Occupational Safety and Health Administration (OSHA)*?

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5 42 USC § 12101 et. seq.

6 H.R. 110-730, p 11 (June 23, 2008)

d. If applicable, has the employer offered the following accommodations:

- Modifying work facilities and/or office equipment to make them accessible;
- Restructuring a job;
- Providing effective communication, such as qualified readers, interpreters, or video relay services;
- Modifying examinations, training, or other programs;
- Reassignment to a vacant position;
- Relocation of employee break rooms or other rooms to places accessible to the employee;
- Flexibility in scheduling or parking.

e. With the accommodation, is the employee able to perform essential job requirements?

## B. Veterans With Service-Connected Disabilities – The Uniformed Services Employment and Reemployment Rights Act (USERRA)

The *Uniformed Services Employment and Reemployment Rights Act*<sup>7</sup> (USERRA) provides additional rights to those provided by the ADA for disabled veterans returning to work. Under USERRA, employers are prohibited from discriminating against an individual because of her service in any of the uniformed services. To determine eligibility and compliance by the employer, consider the following questions:

1. Is the person a disabled veteran who is entitled to the rights granted by the USERRA?
  - a. Has the person served on active duty in the armed forces, been honorably discharged, and have a service-connected disability or receive compensation, disability retirement benefits, or a pension under a public statute administered by the Department of Veteran's Affairs?
2. If the person is a disabled veteran, has her employer complied with the USERRA?
  - a. Did the employer re-employ the disabled veteran when she returned from active duty?

b. Did the employer make reasonable efforts to assist the disabled veteran to become qualified for the job, including providing any necessary training or accommodations?

c. Did the employer provide any other reasonable accommodations necessary for the person to perform all job functions, even if the person's disability does not fall under the ADA's definition of "disability"?

## C. The Family Medical Leave Act (FMLA)

The *Family Medical Leave Act*<sup>8</sup> (FMLA) requires employers to provide eligible employees up to twelve weeks of unpaid leave to care for their own serious health condition or that of an immediate family member, and the employer must attempt to allow the employee to return to the same or an equivalent job position. Recent amendments provide longer leaves of absence for families of returning veterans who require care. To determine eligibility and the rights and obligations of both the employee and employer, ask the following questions:

1. Does the employee qualify for FMLA benefits under the following criteria?
  - a. The employer has fifty or more employees within a seventy-five mile radius.
  - b. The employee has worked a minimum of 1,250 hours in the twelve-month period preceding her leave and has been employed for at least one year.
  - c. The employee has a qualifying reason for requesting leave:
    - To care for a child after birth, adoption, or placement in one's home for foster care.
    - To care for a child, parent, spouse, or domestic partner with a serious healthcare condition. The FMLA defines a "serious healthcare condition" as an illness, injury, impairment, or physical or mental condition that involves inpatient care or continuing treatment by a healthcare provider.

7 38 U.S.C. § 4301, et. seq.

8 29 U.S.C. 2601, et. seq.

d. The employee gave her employer the proper amount of notice regarding her plans to use FMLA leave time:

- At least thirty (30) days notice; or
- As soon as was possible or practicable.

e. The employee complied with any of her employer's special procedures for requesting leave time (e.g., in writing), if any.

2. What rights are granted under the FMLA?

a. What is the employer's medical leave policy? Does it provide for greater rights (for example, paid leave) under any circumstances?

b. Does the employer allow (or require) the employee to use paid vacation or sick time? Did the employer grant up to twelve weeks unpaid leave, or twenty-six weeks for families of disabled veterans?

c. Was the employee's serious health condition caused by a work-related incident? Are worker's compensation benefits applicable?

d. Did the employer return an eligible employee to the same or to a substantially similar position after leave?

3. Did the employee submit the necessary medical certification on time?

4. Did the employer inform the employee of her FMLA rights?

5. Did the employer violate the FMLA?

a. Did the employer deny leave to an eligible employee who followed all of the Act's requirements?

b. Did the employer treat one's FMLA leave as a negative factor in any employment decision or otherwise discriminate against the employee for exercising FMLA rights?

c. Did the employer refuse to reinstate an employee who returned to work before using twelve weeks of leave time? (An employer may be able to deny reinstatement to certain highly-paid, salaried, "key" employees.)

d. Did the employer treat FMLA leave as absences and terminate the employee for excessive absenteeism?

#### D. Government Vocational Assistance

Federal and state governments have developed a wide-range of programs aimed at encouraging and assisting persons with disabilities in obtaining employment. The federal Social Security Administration provides several incentives to people receiving federal benefits to return to work, such as not considering a person's income from a trial work period when making income eligibility determinations. Individuals and their families should carefully consider the impact of wages on the government benefits being received by asking the following questions:

1. Can a person with a disability use the **Ticket to Work Program** (an employment program for people with disabilities who are interested in going to work)?

a. Does the person have a documented disability for Social Security purposes?

b. Does the person receive government benefits related to her disability?

c. Is there an employment network in the area that participates in Ticket to Work?

d. If the person had a bad experience with one employer is there another in the area? What are the employment goals and what training is required to reach those goals?

e. Does the employment network provide all the services required?

f. Once an employment network has been chosen, what should be included in the employment plan created by the network and person?

g. If the employment network or plan is not satisfactory, should the person take the ticket back and work with a different network?

2. Are state vocational rehabilitation programs available?

a. Is a person with a disability eligible for state vocational rehabilitation assistance?

- Is the disability a substantial barrier to employment?

- Is there a realistic possibility that the person will benefit by a vocational program and find employment?
- b. If the state agency determines that the person is not eligible for services, can the person appeal the decision?
- c. If the person is eligible, what should be included in the person's *Individualized Written Rehabilitation Plan (IWRP)*? The IWRP is generally a document that lists the disabled person's vocational goal and the services she will receive to obtain that goal.
- What are the person's long-term employment goals?
  - What services does the person require to meet those goals?
- Does the person need vocational guidance, counseling, on-the-job training, funding for education (college or vocational school), vehicle modification, and job development and placement?
- d. Will the person have to pay for the costs of any of the services?
- Is the person financially able to pay for the services?
  - Is federal financial aid available?
  - Should an employer or school have to bear the cost?

## VIII. Public Accommodations

Several statutes protect the rights of disabled individuals to access public accommodations such as housing, government properties, businesses, and air and local transportation. These laws set accessibility standards for public areas and public transportation and prevent discrimination by landlords and businesses. Familiarity with these laws can help the disabled person enjoy equal access to basic services.

### A. Access to Transportation

Under the ADA, all new fixed-route public transit buses must be accessible to persons with disabilities within specified time periods. Furthermore, public transit companies must have a paratransit service for the transportation of individuals who cannot use fixed-route services. While airlines must be accessible as well, each air carrier may have different rules or offer different services, so make sure to check with the respective airline regarding assistance, logistics and requirements.

#### 1. Accessibility of Public Transportation

- a. Can the person with a disability travel on a fixed bus route?
  - Is the entire route accessible (getting to the stop, leaving the stop, transferring to different buses or trains)?
  - Can the person navigate the trip with training?
  - Are there reasonable modifications of the non-paratransit bus service that would permit the person to navigate the route (for example, allowing the person to eat on a bus even though there is a no-food policy)?
- b. If the person cannot navigate the fixed route, is a local paratransit service available?
  - Does the individual's situation meet one of the following eligibility requirements?
    - Is the person unable to navigate travel because of an inability to know or understand when to get on/off the bus?
    - Are any of the fixed route vehicles not accessible?
    - Does the person have a disability that prevents him from traveling to a boarding/disembarking location at certain

times (i.e., bad weather, disabilities with periodic impairments, construction sites blocking travel)?

- Has a personal application been filed with the paratransit service?

#### 2. Air Travel

The air carrier or airline needs to receive advance notice of a disability if the traveler wishes to receive special accommodations from the airline.

- a. Are the airports and airplanes accessible?
- b. Does the airline provide storage space for a wheelchair or allow a service animal to accompany the person?
- c. Is assistance required for getting on or off the plane? (Keep in mind that airline personnel are not required to carry a person by hand.)
- d. Does the airline require that the person travel with an attendant?
- e. Does the person with the disability require any special accommodations to receive passenger information about ticketing and change-of-gate assignments?
- f. Does the person with the disability require an individual safety briefing from airline personnel?
- g. An airline can refuse transport under certain circumstances:
  - The person is unable to sit in the plane without violating Federal Aviation Administration (FAA) seating rules.
  - The person has a communicable disease that has been deemed by a federal public health authority to be transmittable during the normal course of flight.
- h. Under limited circumstances, the airline can require a medical certification stating that the person is capable of completing the flight safely. Circumstances that might require medical certification include:
  - The person requires a stretcher or incubator. Find out if the airline offers this service.

- The person requires medical oxygen during the flight. Find out if the airline offers this service.
- The person has a medical condition that causes the carrier to have reasonable doubt that she can complete the flight safely.
- The person has a communicable disease that generally can be transmitted during flight.

## B. Access to Rental Housing

The *Fair Housing Act (FHA)* was passed by the federal government to prohibit discrimination against persons with disabilities in the sale or rental of housing. The law also requires that landlords make reasonable policy adjustments and access-related modifications so people with disabilities can live on the property. New construction should be fully accessible and older buildings must be modified to the extent modification is possible. Consider the following questions when leasing or renting property:

1. Can the person with a disability live safely and comfortably in the rental housing, with or without reasonable modifications?
2. Is the tenant eligible for FHA protection? A person is eligible if she has a mental or physical impairment that substantially limits one or more major life activities.
3. Has the landlord violated the FHA?
  - a. Did the landlord refuse to rent to a person with a disability or create different rental conditions because of the disability?
  - b. Did the landlord refuse a request to make reasonable accommodations to living or common-use space at the tenant's expense?
  - c. Did the landlord refuse to make reasonable accommodations in the rules or policies to permit a person with a disability to use the housing on an equal basis with non-disabled tenants?
4. If the landlord has violated the FHA, a complaint can be filed through the Office of Fair Housing and Equal Opportunity of the U.S. Department of Housing and Urban Development.

## C. Testing Accommodations

When applying for special accommodations at a test or exam site, each testing service has specific requirements. Make sure the requirements are followed closely.

1. Each test site has its own requirements, but most consider the following issues:
  - a. Does the person have a disability, defined as a physical or mental impairment that substantially limits a major life activity?
  - b. Was the required documentation supporting the existence of the disability and the need for the accommodation submitted within the specified period of time?
2. What type of reasonable accommodation(s) will aid the person with a disability to take the exam on a basis equal to that of non-disabled test-takers?
  - a. Does the person require the test to be presented in a certain manner, such as with large print, Braille, colored paper, or with auditory amplification?
  - b. Does the person require a certain manner of responding to the test questions, such as with a tape recorder, computer, or a scribe?
  - c. Does the person require a modified test schedule, such as the allowance of additional time or frequent breaks?
  - d. Does the person require a specific setting to take the test, such as in a private room, with special lighting, or certain seating?

## IX. Government Benefits

There are several types of disability benefits paid for by the government and eligibility is different for each. Adults and children have different eligibility requirements as well. Applying for benefits is a difficult process, and one may have to navigate several levels of appeals. An attorney is not required for this process but having one may make the experience easier.

### A. Benefits for Adults

1. Is the person with a disability eligible for *Social Security Disability Insurance (SSDI)*?<sup>9</sup>
  - a. Has the adult been unable to work because of a medical condition expected to last at least one year?
  - b. How long did the person spend in the workforce?
  - c. How recently was the person in the workforce?
  - d. What are the person's average lifetime earnings?
  - e. Has the person contacted the Social Security Administration to investigate eligibility?
    - Has the person spent the required amount of time in the workforce? Does the disability prevent the person from doing any type of work?
    - Does the individual want to work?
    - Is the person's spouse eligible to receive benefits as well? How will SSDI payments affect other government benefits, such as worker's compensation payments?
    - Should the person file for SSDI even if one is financially secure? (Income is not a factor in SSDI eligibility, so there is no reason not to file even if one does not have financial concerns.)
2. Is the person with a disability eligible for *Supplemental Security Income (SSI)*?
  - a. Is the person eighteen or over with a disability? Do her income and assets fall below a certain level? (Previous time in the workforce is not considered.)
  - b. Have federal or state Social Security agencies examined the person's income (including both earned and unearned income but excluding other governmental benefits, such as food stamps) and her resources, not including her home or primary automobile, to see if she meets the eligibility financial limits?
  - c. Does the state benefit include additional monies above the set SSI amount paid all persons by the federal government?
  - d. Will a gift from a family member or friend be considered income or resources, so as to make a person ineligible?
  - e. Can the person still work? (Unlike SSDI, there is no requirement that one cannot work, but income from working could force one out of the income eligibility requirement.)
3. Is Medicare or Medicaid available to the person with a disability?
  - a. Medicare
    - Is the person with a disability eligible for Medicare, a federal health plan for people sixty-five and older and some individuals under sixty-five with disabilities?
    - Has the person applied for Medicare after receiving SSDI for two years, as allowed?
    - What hospital insurance is paid for by Medicare to eligible persons with disabilities?
    - What additional medical insurance and prescription drug coverage must the eligible person pay for even if covered by Medicare?
    - Has the person with a disability applying for additional Medicare coverage considered the following:
      - Does the person have medical insurance currently through work or another private provider?

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9 42 U.S.C. §402 et seq. (2004).

- Does the other medical insurance cover nursing home care? (Medicare does not cover nursing home care except in very limited circumstances.)
- Are family members covered by the other medical insurance and will switching to Medicare affect them?

## b. Medicaid

- Is the person eligible for Medicaid, a joint federal/state health coverage system that provides health coverage for some low-income individuals and families? If the individual is receiving SSI benefits, she will still be allowed to apply for Medicaid.
- What does the Medicaid program cover in the state where the person resides?
- How is eligibility for benefits determined under the Medicaid program in the state where the person lives?

## B. Benefits for Children

### 1. When are SSDI benefits available to children?

- a. Is the person with a disability an adult child who was disabled before turning 22 and;
- b. Has the parent worked the required amount of time to be eligible for SSDI or does the parent currently receive SSDI? (The amount of SSDI payment is based on the parent's average lifetime earnings.)

### 2. When are SSI benefits available to children?

- a. Is the child under eighteen and have a medical condition that is expected to last at least one year resulting in marked and severe functional limitations?

- b. Has the Social Security Agency determined that the child meets the income level necessary to receive SSI, including the child's income and resources as well as those of family members living with the child?

- c. If the child has turned 18, has the Social Security Agency re-examined the child's income and resources without considering the income and resources of family members? If so, has the agency also applied the definition of "disability" used for adults, which is a lesser standard than that used for children?

## C. Applying for Benefits and Appeals

An individual may apply for benefits online, over the phone, or at her local Social Security office. Agencies deny almost 75% of first-time applications but there are four levels of appeal: reconsideration, hearing, review by the Appeals Council, and federal court review. The following issues should be considered when filing an appeal:

- Should an attorney be hired to handle the appeal?
- Was the request for appeal filed in a timely manner (i.e., after denial, did the person request an appeal in writing within 60 days of receiving the denial letter)?
- Will the payment of benefits continue while the decision to discontinue benefits is being appealed?
- Is it worthwhile to continue the appeal to the federal courts, where legal fees may be substantial?

## X. Estate Planning

Because Social Security agencies consider simple gifts in wills to be income when calculating benefit eligibility, family members should consider alternative means of estate planning to ensure that the disabled person can continue to receive government benefits while also being able to enjoy additional comforts provided by the parent's or caretaker's estate. In addition to estate planning, the parent or caretaker should make plans regarding who will take care of the loved one with a disability.

### A. Special Needs Trust

Sometimes called a supplemental needs trust, a special needs trust is a vehicle that provides support to people with disabilities without that support being considered income or property owned by the disabled individual. These trusts allow a disabled beneficiary to receive gifts and other funds without losing her eligibility for certain government assistance programs. Special needs trusts are generally designed to pay for items or services that go beyond the simple necessities of life, such as over-the-counter medicine, treatment by specialists, vacations, specialized clothing or equipment, legal representation, recreation, counseling, education, and spending money. An improperly created trust can result in the funds being seized by the government to pay for back benefits; therefore, one should always work with an attorney experienced in this area. To make sure a special needs trust is set up properly, ask the following questions:

1. Is there an attorney experienced with special needs trusts in the area?
2. Should a financial planner be consulted in addition to an attorney?
3. What funds will the person with a disability have to live on when the caretaker is deceased?
4. Will the individual rely primarily on SSI benefits to pay for necessities or will she have other sources of income?
5. Will the individual be able to work to supplement her income?
6. Is there a reliable person who can serve as the trustee of the trust?
  - a. Will the trustee be able to monitor the beneficiary's interest and spend the trust funds appropriately?

b. Should an institutional trustee be considered?

7. How much additional income will the individual require?
8. Are there extraordinary medical expenses?
9. Will the individual be living on her own, in a group setting, or with family?
10. Rather than create a special needs trust, is it better to disinherit the individual and give a large gift to someone else with instructions to use the gift for the individual's benefit?
  - a. Is the beneficiary of the gift certain to spend the gift on the disabled individual?
  - b. Is it certain that the beneficiary will not get into a situation where creditors will be able to seize the gift?
11. Who should receive the remainder of the trust funds if the individual dies before the trust funds are exhausted?

### B. State-Based Trust Programs (Pooled Trusts)

State-based trust programs or pooled trusts allow families of disabled children to establish a relatively inexpensive and effective way to provide supplemental funds for individuals with disabilities without forfeiting important government benefits. Generally speaking, the resources of many beneficiaries are "pooled" and that pool of resources is managed by a nonprofit association. The association acts as the trustee and the trust funds are used for the benefit of all the beneficiaries. Once funds are placed in the pooled trust, the caretaker cannot direct how the funds are used. A pooled trust may be a good option for families who have limited funds or who have no access to a trustworthy and competent trustee. To determine if this financial arrangement might be ideal for one's situation, ask the following questions:

1. What specific laws does the state have for pooled trusts?
2. Does the state in which the disabled individual resides consider the income from a special needs trust or a pooled trust when calculating eligibility for government benefits?
3. Have any pooled trusts in the state where the disabled individual resides failed in past years due to mismanagement?

4. What precautions have been taken when selecting a pooled trust to make sure the organization is a well-run and knowledgeable organization?
  - How will the professional caregiver be chosen? Should one select an agency and allow the agency to choose?
5. How long has the trust been in existence and does it have a good record of caring for individual beneficiaries?
6. Does the individual have specific needs and will the trustee provide enough attention to care for those needs?
7. How much control does the parent or family member want to have over how the trust funds will be spent?
8. If the pooled trust fails, are there other resources that the individual can turn to for support?
  - b. Have written instructions been created for the successor caretaker?
  - c. Has the successor caretaker spent time caring for the individual on a daily basis in order to understand what will be required of her?
  - d. If the disabled individual will be moving to a new home, does the new home have the specific devices that the individual requires?

### C. Caretaker Planning

The parent or caretaker of an individual with a disability may want to plan for the individual's care in the event the parent or caretaker can no longer care or provide for the disabled individual. Consider these questions when planning for the individual's future:

1. Where will the disabled individual live?
2. Does the individual require live-in care? Who will provide that care?
  - a. Should the successor caretaker be a family member or a professional caregiver?
    - How will the cost of a professional caregiver be paid and by whom?
    - Is there a family member who can observe and oversee the care the professional caregiver provides?
3. If the individual does not require live-in care, who will ensure that she is adequately caring for herself?
4. Is there a plan in case the successor caregiver predeceases the current caregiver?
5. As for children, who will be making all medical decisions for the child?
  - a. Is the child able to make these decisions herself?
  - b. If the child is unable to make decisions, does the person making the decision have the legal authority to do so?
  - c. What legal steps should be taken to give that person authority?
  - d. Who will be playing the role in making all other major life decisions for the child (for example, educational, employment, and financial decisions)?

## XI. Complementary and Alternative Medicine

Many disabled and chronically ill individuals use what is commonly referred to as *Complementary and Alternative Medicine (CAM)*. Integrative medicine is another term that is used by practitioners who use both conventional treatments and promising, high quality CAM therapies. Once a CAM therapy is proven to work through clinical trials and becomes part of mainstream medicine, it is no longer referred to as CAM.

Consequently, some interventions that were once considered to be CAM are now used by both CAM practitioners as well as conventional medical practitioners (medical doctors and nurses). Acupuncture is such an example. Individuals contemplating CAM for their disabled loved one should keep in mind the following considerations:

1. CAM refers to any modality that might help people with their symptoms or even their underlying conditions but which have not yet been proven through scientific studies to be safe or effective.
2. CAM can be used to treat chronic pain, which is where the therapies appear to have achieved the greatest success.
3. It is important to research the CAM that will be used to determine its likelihood of effectiveness, its side effects, and safety level.
4. If the CAM is being self-prescribed, it is generally safer to use the CAM *with* the conventional treatment recommended by the medical doctor, rather than in lieu of the doctor's recommendation. Using complementary modalities in conjunction with conventional treatments recommended by your primary physician is a common practice in the United States.
5. CAM products can sometimes adversely interact with medicines prescribed by the medical doctor, especially before and after surgery. Therefore, be sure to inform the primary physician and specialists of any CAM products being taken.
6. Some CAM products are imported from countries that do not have the same manufacturing standards and safety protections enforced in the United States and as a result, may contain unsafe elements such as arsenic or lead.
7. It can be particularly risky to allow a child to use a CAM without consulting with the child's pediatrician. Using a CAM instead of having the child vaccinated, for example, may not be healthy for the child or her playmates.
8. Many CAM practitioners are unlicensed and unregulated depending on the laws of the state in which the CAM is being used.
9. While many CAM practitioners charge less per visit than a medical doctor, CAM providers may recommend more frequent visits, which can result in costing more in the end.

### Tips for Persons Considering or Using CAM:

- Always tell your physician what CAM products or services you are using. Inform your personal physician, specialists, dentist, and emergency care providers.
- If you are an inpatient at a hospital, inform those taking care of you that you have brought CAM products to the hospital. Some hospitals will allow you to continue taking CAM remedies but will supply them through the hospital's own pharmacy.
- Keep a journal of all of your CAM products and practices so that your medical doctor has accurate information.
- Many people learn about CAM options on the internet. The quality of information on the internet varies greatly. Generally, the most reliable sources are the National Institutes of Health's National Center on Complementary and Alternative Medicine and national organizations related to your particular condition.
- If you have a bad experience with a practitioner who provides CAM, call your state's department of consumer affairs or medical board.
- Check with your health insurance provider to see if the CAM practitioner, services, or products used are covered.

## XII. Family Law Issues

While all of the general legal principles of family law apply to those with disabilities, courts have sometimes considered the disabilities of parents, children and other relatives in determining questions related to child custody, child support, the propriety of a guardianship or conservatorship, and spousal support following a divorce. Courts attempt to carefully limit their consideration of disabilities to those issues on which the disability has an actual consequence in real life. The mere fact that one person has a disability is irrelevant by itself to most family law determinations. Still, disabilities are at times relevant when judges are required to establish and adjust family relationships.

### A. Custody Determinations

The general principles that apply to all child custody determinations apply to determinations with regard to disabled children as well. The court seeks to serve the best interests of the child when assigning custody to parents who are capable of providing for the physical, emotional, educational, financial and other needs of the disabled child. In preparing for a child custody case, parents should ask and remember the following:

1. Is the disability of a child or a parent relevant when a court makes custody determinations?
2. As a general matter, both parents are considered equally appropriate as custodians. While neither parent has priority over the other, both parents have priority over others who seek custody as long as the parents are capable of taking care of the child. In most states, however, the court will find it not in the child's best interest to be placed in the custody of a parent who is incapable of taking care of a child with a disability.
3. Most states presume that it is in the child's best interest to spend a relatively equal amount of time with both parents, although this time allocation may change during different periods in a child's life. Does the state in which the custody determination will be made start with this assumption?

### B. Disability of the Parent in Child Custody Determinations

The mere presence of a parent's physical or mental disability is not a disqualifying factor in custody determinations. In some cases, the richness that a child will experience in the home of a disabled parent or guardian may even be a factor favoring that parent in a custody proceeding.

1. If one of the parents (or someone else seeking custody of a child) has a physical or mental disability, the court will decide whether it is relevant to the determination of the best interest of the child.
2. The court might determine that neither parent has the capacity to take care of the child and attempt to find someone else to be assigned custody of the child. Who will the court consider in this case?
3. Will claims by one parent that the other is psychologically, emotionally or mentally disabled be relied upon by the court, without more evidence, to prevent a parent from obtaining custody rights?
  - a. Due to the emotionally fraught atmosphere that so often surrounds child custody disputes, the judge should require that such allegations be evaluated thoroughly.
  - b. Even if such a claim were true, it should, in most cases, be insufficient grounds to deny a parent custody unless the psychological, emotional or mental disability would affect the parent's ability to provide for the child.
4. Some courts have faced custody determination cases where one parent's history includes a suicide attempt. The custody outcome will depend on the facts, such as:
  - a. Whether the parent failed to seek any help following a very recent attempt. This information might be relevant in determining what placement would be in the child's best interest.
  - b. On the other hand, a suicide attempt made years ago – or a more recent attempt that was followed by appropriate mental health therapy – is less likely to be relevant in making this best interest determination.

### C. Disability of the Child in Child Custody Determinations

Disability of the child by itself is not enough to dictate which parent should have custody of a child. A variety of factors are weighed.

1. It is in the child's best interest to be in the custody of a parent or guardian who has the time, energy and financial resources to address the child's disability.

2. There is normally no assumption that the spouse with the higher income should (or should not) have custody of a child with disabilities. The measuring stick, as always, is what is best for the child. In fact, the court can often provide for sufficient child support to overcome the financial strain of taking care of a disabled child.
3. A parent who has dedicated a lifetime to addressing her child's disability will be in a particularly strong position when a custody determination is made, but a parent who is now willing to do whatever is necessary to learn to provide proper care for that child will be in a strong position as well.
4. Since disabilities may give rise to large medical expenses, does the divorce or separation agreement provide for the source of health insurance coverage?
  - a. Does the parent with the health insurance that is most likely to cover the child's medical expenses have responsibility for including the child on that plan?
  - b. Is there a back-up plan under the divorce or separation agreement in case that coverage is not available sometime in the future?
  - c. What, if any, expensive aspects of care are also covered by the state's Medicaid program or its *State Children's Health Insurance Program (SCHIP)*?
  - d. Was the availability of healthcare coverage by state Medicaid or SCHIP programs investigated prior to or during the divorce proceedings and factored into the divorce agreement?

#### **D. Disability of Parent or Child in Determining Child Support**

The disability of a parent seeking or paying child support is not generally relevant to the amount of child support. Most states have fill-in-the-blank worksheets that are used to determine the amount of child support due in any particular case. These forms are designed to transfer financial resources to the parent who would need the support to properly care for the couple's child. In most states when a parent is not working, the court will attribute an income to that parent for child support purposes unless there is good reason not to do that. A disability may provide such a reason, but only if the parent's disability makes it impossible for her to work and contribute any resources to the cost of raising the child. Just as a disabled parent is not eliminated as a custodian because of the existence of the disability, the disabled parent has the same support obligations as any other parent. When determining support, consider the following:

1. Does the extent of the child's disability affect the amount of child care awarded in the state where the custody determination is being made?
2. Does the state where the child resides take into consideration special expenses related to the disability, such as high medical bills or exceptional counseling expenses when determining the financial support obligation of each parent?
3. How are the special medical (and legal, if necessary) expenses and accommodations of the custodial parent factored into the child support rate by the state in which the child resides?
5. In most states, parents' support obligations end when their children reach the age of majority (now 18 in all states for most purposes). Is this the case in the state where the child resides or does the parent's obligation continue past the age of majority?
6. Can one's obligation of parental support be revived or renewed if the child becomes disabled as an adult, even if the child lived independently as an adult before developing/sustaining the disability?
7. Are parental obligations likely to depend on the needs of the adult child and the financial ability of the parents to provide their disabled adult child with appropriate care?
8. Is there also a legal obligation on children to support their disabled parents in the state where the disabled parent resides? If so, how consistently is this obligation enforced?
9. Is the state in which the disabled person resides one of the few states where other relatives are also obligated to support their disabled family members? If so, how effectively are those laws enforced?

### XIII. Healthcare Decision Making

Disabled people do not lose any authority to make healthcare decisions. The essential principle underlying all healthcare decision-making is that every adult with decisional capacity is entitled to make all of her own healthcare decisions; therefore, a disabled person is fully entitled to make any healthcare decision that anyone else could make as long as she has decisional capacity.

#### A. Determining Capacity to Make Healthcare Decisions

Different states have different standards for determining a person's capacity to make healthcare decisions. Strict standards are often applied before a person is ruled to be decisionally incapacitated as such a finding would limit a person's fundamental right to make healthcare decisions.

1. What are the legal standards for decision-making capacity in the state where the disabled person resides?
  - a. Is the presence of a physical or mental disability sufficient to make a person decisionally incapacitated or does the state, like in most other states, consider the following standards:
    - One's ability to understand basic information about the medical condition, proposed treatment, and alternatives;
    - One's ability to process information rationally; and
    - One's ability to communicate a decision.
2. When discussing the decision-making capacity of a disabled person, the law usually does not ask whether the person understands the relevant facts or is thinking rationally; rather, the law generally only asks whether the person has the present capacity to make a decision. The fact that a decision may seem foolish or irrational to her family or society does not render that decision to be the result of incapacity.
3. Does the state allow its courts to consider additional attributes, including mental illness, mental retardation, developmental disability, alcohol or drug abuse, extreme age, dementia, and grave disabilities in determining whether the patient has decisional capacity?

4. Every person is presumed to have decisional capacity until it is proven otherwise. The burden of proof is always on the person who wants to show that the disabled individual is decisionally incapacitated.

#### B. Decision Making for Children

The general principles that apply to all parental decision making power for minor children apply to determinations involving disabled children as well. In general, authority to make healthcare decisions is given to the child's parents or legal guardian(s) who are thought to be most likely to act in the best interest of the child and most likely to understand the child and her values and wishes.

1. Does the state in which the child resides permit a minor (under 18) to make her own healthcare decisions?
2. Does the state where the child resides allow teenagers to make some healthcare decisions as they mature and as they approach the age of 18?
3. As a matter of Constitutional law, teenagers have the right to make some decisions regarding their reproductive healthcare; however, a court will also consider the decision making capacity of the teenager if her capacity is at issue.
4. Even when parents have the clear legal authority to make decisions for their children, healthcare providers (and courts) are likely to seek consensus among the child and parents before any significant treatment is rendered.

#### C. Decision Making for Adults

When an adult lacks the capacity to make healthcare decisions, someone else will be required to make those decisions. Ask the following questions to determine if, and to what degree, an adult with a disability will need assistance in making healthcare decisions:

1. Did the adult provide instructions ahead of time on the kind of care she desires in the event she becomes incapacitated?
2. Did the individual complete a state approved form (a "living will" or now sometimes called "individual instructions") for making these decisions?
3. What are the conditions and limitations on the use of these forms? Each state may have different requirements on how these forms are completed and executed.

4. Alternatively, the adult, as the “principal” can appoint someone else to make healthcare decisions for her if she becomes incapacitated. This can be done through a “durable power of attorney for healthcare.” The person who is appointed is called the “agent” or the “attorney in fact” for the incapacitated adult.
5. The agent, appointed by the principal, does not have to be an attorney.
6. Different states impose different limitations on the use of durable powers and individual instructions. For example, some states in which the principal resides require that the agent or decision maker be appointed in writing in accord with formal legal requirements while other states may merely require just a word from the principal to her doctor to appoint someone to make healthcare decisions on the principal’s behalf.
7. If no agent is appointed in a durable power of attorney or an individual instruction, how can another person make healthcare decisions for a patient without capacity?
8. Does the principal’s state law provide a list of family members who can act to make those decisions? If yes, although there is variation from state to state, many states will list the following individuals as potentially able to make decisions on behalf of the incapacitated person:
  - a. The spouse and, in some states, someone other than the spouse who is in the position of a spouse;
  - b. If there is no spouse or spouse-like person, the obligation falls to the next level of the family, usually the patient’s adult children;
  - c. If no adult children are available, the authority may go to a parent and then to an adult sibling under the state’s law.
9. Who makes decisions if the incapacitated individual provided instructions but there is no family alternative to act as the attorney-in-fact? Does the state law provide for a residuary decision maker?
  - a. Is this person the public guardian (a state official) or someone who knows the patient’s values and has a special care and concern for the patient such as a good friend?

- b. Is the residuary decision maker the physician, the clergyman, or even the patient’s lawyer?
- c. Does the state have a surrogate law that provides a decision maker who is not directly appointed by the patient in writing?

#### **D. Guardians and Conservators**

Sometimes a court will appoint a decision maker for an incapacitated person. Usually, the person who is appointed is called a guardian or a conservator who may have plenary authority (the authority to make any decision that the incapacitated individual could make), or the guardian/conservator may have limited authority (the authority to make decisions in limited areas such as handling financial matters or selecting a long term care facility). In many states, the term conservator is used to describe one making financial decisions, and the term guardian is used to describe one making personal decisions; however, the terms may be used differently in different states.

1. Who should seek the appointment of a guardian or a conservator for a person with a disability? Courts take guardianship/conservator petitions very seriously because the actions and decisions can have tremendous impact and consequences for the incapacitated person.
2. The person seeking to become a conservator for or guardian of someone with a disability should be aware of the following:
  - a. As a part of the guardianship process, a court may appoint a guardian *ad litem* who is unrelated to any potential guardian and who acts as an attorney for the allegedly incapacitated person.
  - b. As a part of the guardianship process, a court may also appoint a “visitor” to write a report on the necessity of appointing a guardian or conservator.
  - c. Courts view a guardianships and conservatorships as a last resort to help those whose life, financial resources, or personal safety will be threatened without a competent decision maker.
  - d. Courts require a high level of proof to order a guardianship or conservatorship, and courts are increasingly reluctant to establish guardianships because of the limitations they impose on the person’s freedom.

- e. In determining whether or not to grant a guardianship or conservatorship, the court usually must determine whether it is impossible for the incapacitated person to function in society and to protect herself and her resources.
  - f. In choosing a guardian, the court will usually ask who will best be able to serve the interests of the incapacitated person.
  - g. In many states, public guardians can serve as the guardians for those who have no one else who can serve in that capacity.
3. Does the state allow an incapacitated person to consent to the appointment of a conservator over financial matters?
  4. Does the state allow the incapacitated person to consent to the guardianship? (This is generally done by way of an advance directive that is completed while the person has capacity.)
  5. Does the state tend to avoid plenary or total guardianships and instead create narrowly limited guardianships where the appointed guardian has only the power to make particular kinds of decisions that are specifically listed in the judge's order?
  6. Do the courts apply the principle of "least restrictive alternative" to assure that any restrictions placed on the person are the most limited possible restrictions and that they are absolutely necessary to protect that person?
  7. The appointment of a guardian or conservator for the incapacitated person does not limit any of that person's civil liberties except as explicitly provided in the court's order.

## E. Decision-Making Policies at Healthcare Institutions

1. Hospitals, nursing homes, clinics and even individual providers sometimes have policies or practices that describe their decision-making processes.
2. Prior to placing a person with a disability in an institution, consider the following:
  - a. Individual institutions may have different views about who constitutes a family member entitled to make a decision; and
  - b. Some institutions also have ethical or religiously based policies that limit the choices available to their patients.
3. Before a person is hospitalized or institutionalized, family members and the person with the disability should determine what, if any, limitations might be applied to decisions made on behalf of that person.
  - a. Are there limitations on the kinds of decisions family members or others can make for the person with a disability?
  - b. Are there limitations on the family members or others who can make those decisions?

## XIV. Conclusion

Caring for a child or adult with a disability presents challenging questions and issues that can become overwhelming for both the individual with a disability and the parent or caretaker if not addressed appropriately. Knowing what questions to ask, whom to ask, understanding what the applicable laws provide, and where to look for information is half the battle in ensuring that the rights of the disabled individual are protected and that her opportunities are not curtailed. The laws for individuals with disabilities may seem intimidating and confusing at times but remember, the parent, caretaker, or family member will be the best at advocating on behalf of the child or adult with a disability.

We hope this reference guide provided a starting point by outlining the primary legal considerations that may apply throughout the disabled individual's lifetime. States differ significantly in their laws and regulations, so it is important to research and answer the questions based on the information specific to the location where the child or adult resides. Revisit this guide often and use the resources outlined in the following appendices as the child or adult reaches her greatest potential.

## GLOSSARY

**ADA** – Americans with Disabilities Act. A federal civil rights law that prohibits discrimination based on disability.

**ADAAA** – ADA Amendments Act of 2008. A federal law that broadens the definition of “disability” so that more individuals will be considered disabled and entitled to accommodations, and disabled plaintiffs will receive more favorable treatment in the courts.

**CAM** – Complementary and Alternative Medicine. Medical treatment or therapy that does not fall within the realm of conventional medicine, or a treatment or therapy that is used in conjunction with mainstream techniques.

**Child Find** – A state program to find, evaluate and provide appropriate services to children with disabilities.

**ERISA** – Employee Retirement Income Security Act. A federal statute that protects employee plan benefit participants and their beneficiaries.

**FAPE** – Free and Appropriate Public Education. Under Part B of the Individuals with Disabilities Act, school districts must provide special education and related services at no cost to the child or his/her parents.

**FHA** – Fair Housing Act. A federal law that prohibits discrimination on the basis of race, color, religion, national origin, sex, disability and familial status by landlords and home sellers.

**FMLA** – Family Medical Leave Act. A federal law that allows an eligible employee to take unpaid leave due to her own serious health condition, in order to take care of a sick family member or to care for a new child.

**IDEA** – Individuals with Disabilities Education Act. A federal law that addresses the educational needs of children with disabilities from birth to age 21.

**IEP** – Individualized Education Program or Plan. Required under the Individuals with Disabilities Education Act, public schools must develop a special education plan or program uniquely tailored for the eligible student.

**IFSP** – Individualized Family Service Plan. Under Part C of the Individuals with Disabilities Education Act, states may provide early intervention services to families and to their infants or toddlers (birth to age 3) who have disabilities.

**IWRP** – Individualized Written Rehabilitation Plan. State vocational rehabilitation programs must develop a plan for each eligible handicapped individual that includes a statement of the rehabilitation goal and the vocational rehabilitation services to be provided.

**LEA** – Local Education Agency. A local school system within a state with a board of education that maintains administrative control over the schools in that city or county.

**LRE** – Least Restrictive Environment. One of the major principles that governs the education of students with disabilities under the Individuals with Disabilities Education Act.

**Manifestation Hearing** – A hearing to determine if a child’s behavior was a manifestation of the child’s disability.

**NCLB** – No Child Left Behind Act. A federal law that sets standards of accountability for states and schools, including specific standards for education of students with disabilities.

**Notice of Action Refused** – A written notice required by law to be given by a school district that refuses a request for an evaluation or action on behalf of the child.

**OSHA** – The Occupational Safety and Health Administration. An agency of the U.S. Department of Labor created by the Occupational Safety and Health Act. The purpose of the Act is to prevent work-related injuries, illnesses, and deaths.

**SCHIP** – State Children’s Health Insurance Program. A federal program that funds states so that families with children who do not qualify for Medicaid may still have health insurance.

**SEA** – State Education Agency. Also known as a state department of education, the agency in each state that oversees educational funding and policies.

**Section 504** – Section 504 of the Rehabilitation Act. A civil rights law that prohibits discrimination against individuals with disabilities. Unlike the Individuals with Disabilities Education Act, however, Section 504 provides fewer procedural safeguards than under the IDEA.

**SSDI** – Social Security Disability Income or Insurance. A federal insurance program that provides income to those who are unable to work due to a disability.

**SSI** – Supplemental Security Income. A federal program that provides income to the aged, blind or disabled based on need.

**Ticket to Work Program** – A federal employment program that increases the vocational opportunities available to Social Security disability program beneficiaries. Participants receive a ticket to present to a qualified public or private employer which then receives federal funding for providing certain vocational rehabilitation services.

**USERRA** – The Uniformed Services Employment and Reemployment Rights Act. A federal law that prohibits discrimination against persons of the uniformed services (e.g., the Armed Forces Reserve, the National Guard).

## ONLINE RESOURCES

### Educational Assistance

#### *IDEA and Special Education Law*

- IDEA – U.S. Department of Education: [idea.ed.gov/](http://idea.ed.gov/)
- National Dissemination Center for Children with Disabilities (NICHCY): [www.nichcy.org/](http://www.nichcy.org/)
- Wrightslaw: [www.wrightslaw.com/](http://www.wrightslaw.com/)
- State educational agencies listing with contact information – U.S. Department of Education: [wdcrobcolp01.ed.gov/Programs/EROD/org\\_list.cfm?category\\_ID=SEA](http://wdcrobcolp01.ed.gov/Programs/EROD/org_list.cfm?category_ID=SEA)

#### *Early Intervention Services*

- Early Intervention (Part C) – Wrightslaw: [www.wrightslaw.com/info/ei.index.htm](http://www.wrightslaw.com/info/ei.index.htm)
- Early Intervention Service for Infants and Toddlers with Disabilities (Part C of IDEA) – National Early Childhood Technical Assistance Center: [www.nectac.org/partc/partc.asp](http://www.nectac.org/partc/partc.asp)
- Finding Help for Young Children with Disabilities – National Dissemination Center for Children with Disabilities: [www.nichcy.org/pubs/parent/pa2.pdf](http://www.nichcy.org/pubs/parent/pa2.pdf)
- Early Intervention Program for Infants and Toddlers with Disabilities – U.S. Department of Education, Office of Special Education and Rehabilitative Services: [www.ed.gov/programs/osepeip/index.html](http://www.ed.gov/programs/osepeip/index.html)

#### *Evaluations and Eligibility for Pre-School and School Aged Children with Disabilities (Part B of the IDEA – Ages 3 to 21)*

- Disability Rights Education & Defense Fund: [www.dredf.org/programs/PTI.shtml](http://www.dredf.org/programs/PTI.shtml)
- Building the Legacy, Training Curriculum on IDEA 2004: Handouts for Theme A (an overview of the IDEA and additional state and federal resources) – National Dissemination Center for Children with Disabilities (NICHCY): [www.nichcy.org/training/a-handouts.doc](http://www.nichcy.org/training/a-handouts.doc)

- Building the Legacy, Training Curriculum on IDEA 2004: Handouts for Theme C (evaluation and reevaluation specific information) – National Dissemination Center for Children with Disabilities (NICHCY): [www.nichcy.org/training/C-handouts.doc](http://www.nichcy.org/training/C-handouts.doc)
- Your Rights Under Section 504 of the Rehabilitation Act – U.S. Department of Health and Human Services, Office for Civil Rights: [www.hhs.gov/ocr/504.html](http://www.hhs.gov/ocr/504.html)

#### *Individualized Education Program*

- IEP Meetings, Content, Review & Revision, Placements, Transition & Transfers – Wrightslaw: [www.wrightslaw.com/idea/art/iep.roadmap.htm](http://www.wrightslaw.com/idea/art/iep.roadmap.htm)
- Guide to the Individualized Education Program – U.S. Department of Education: [www.ed.gov/parents/needs/speced/iepguide/index.html](http://www.ed.gov/parents/needs/speced/iepguide/index.html)

#### *Discipline for Behavior Problems in School*

- Discipline and IDEA 2004 – U.S. Department of Education, Office of Special Education Programs: [idea.ed.gov/explore/view/p/%2Croot%2Cdynamic%2CTopicalBrief%2C6%2C](http://idea.ed.gov/explore/view/p/%2Croot%2Cdynamic%2CTopicalBrief%2C6%2C)
- Questions and Answers on Discipline Procedures – U.S. Department of Education: [idea.ed.gov/explore/view/p/%2Croot%2Cdynamic%2CQaCorner%2C7%2C](http://idea.ed.gov/explore/view/p/%2Croot%2Cdynamic%2CQaCorner%2C7%2C)
- What You Need to Know about IDEA 2004: IEPs for Children with Behavior Problems – Wrightslaw: [www.wrightslaw.com/howey/iep.special.factors.htm](http://www.wrightslaw.com/howey/iep.special.factors.htm)
- Discipline of Special Education Students Under IDEA 2004 (flowchart) – Massachusetts Department of Education: [www.doe.mass.edu/sped/IDEA2004/spr\\_meetings/disc\\_chart.pdf](http://www.doe.mass.edu/sped/IDEA2004/spr_meetings/disc_chart.pdf)

#### *Transition of Services to Post-Secondary Education, Vocational School and Independent Living*

- Connections to Transition Resources for Students – National Dissemination Center for Children with Disabilities (NICHCY): [www.nichcy.org/resources/transition\\_students.asp](http://www.nichcy.org/resources/transition_students.asp)
- Transition, Transition Services, Transition Planning – Wrightslaw: [www.wrightslaw.com/info/trans.index.htm](http://www.wrightslaw.com/info/trans.index.htm)

## Health and Life Insurance

### *Health Insurance*

- U.S. Department of Labor Consumer Health Plan: [www.dol.gov/ebsa/consumer\\_info\\_health.html](http://www.dol.gov/ebsa/consumer_info_health.html)
- Kaiser Insurance Law –Family Foundation: [www.kff.org/consumerguide/7350.cfm](http://www.kff.org/consumerguide/7350.cfm)
- The Health Insurance Resource Center: [www.healthinsurance.org/risk\\_pools/](http://www.healthinsurance.org/risk_pools/)

### *Life Insurance*

- What You Should Know About Buying Life Insurance – The American Council of Life Insurers (ACLI): [www.pueblo.gsa.gov/acli/#faq](http://www.pueblo.gsa.gov/acli/#faq)

## Emergency Preparedness

- Ready America – U.S. Department of Homeland Security: [www.ready.gov/america/makeaplan/index.html](http://www.ready.gov/america/makeaplan/index.html)
- Disaster Preparedness for People with Disabilities – Red Cross: [www.redcross.org/services/disaster/beprepared/disability.pdf](http://www.redcross.org/services/disaster/beprepared/disability.pdf)

## Employment

- ADA – Equal Employment Opportunity Commission: [www.eeoc.gov/ada/adadocs.html](http://www.eeoc.gov/ada/adadocs.html)
- ADA – Department of Justice: [www.esdoj.gov](http://www.esdoj.gov)
- USERRA and FMLA –Department of Labor: [www.dol.gov/vets](http://www.dol.gov/vets)
- Accommodations – Job Accommodation Network: [www.jan.wvu.edu](http://www.jan.wvu.edu)
- Ticket to Work Program – Social Security Administration: [www.socialsecurity.gov/pubs](http://www.socialsecurity.gov/pubs)
- Veteran’s Rehabilitations Programs – Department of Veteran’s Affairs: [www.vba.va.gov](http://www.vba.va.gov)
- Individual states also have websites for their own vocational rehabilitation programs.

## Public Accommodations

- ADA – Department of Justice: [www.usdoj.gov](http://www.usdoj.gov)
- Public Transportation – Easter Seals Project Action: [projectaction.easterseals.com](http://projectaction.easterseals.com)
- Air Carrier Access Act – Department of Transportation: [airconsumer.ost.dot.gov/publications/horizons.htm](http://airconsumer.ost.dot.gov/publications/horizons.htm)
- Fair Housing Act – Department of Housing and Urban Development: [www.hud.gov/fairhousing](http://www.hud.gov/fairhousing)
- The federal government’s disability information site: [www.disabilityinfo.gov](http://www.disabilityinfo.gov)
- Each test or licensing examination center also has a link on its website regarding accommodations.

## Government Benefits

- Social Security Administration: [www.socialsecurity.gov/pubs](http://www.socialsecurity.gov/pubs)
- National Organization of Social Security Claimants’ Representatives: [www.nosscr.org/hallfaq.html](http://www.nosscr.org/hallfaq.html)

## Estate Planning

- Planning for Your Child’s Future – Special Child: [www.specialchild.com/archives/ia-001.html](http://www.specialchild.com/archives/ia-001.html)
- Preparing for the Future with a Special Needs Trust – The National Fragile X Foundation: [www.fragilex.org/html/trust.htm](http://www.fragilex.org/html/trust.htm)
- Supplemental Needs Trusts: Some Frequently Asked Questions – National Special Needs Network: [www.nsnm.com/frequently.htm](http://www.nsnm.com/frequently.htm)
- The Special Needs Trust – KidSource: [www.kidsource.com/kidsource/content4/estate.dis.all.3.3.html](http://www.kidsource.com/kidsource/content4/estate.dis.all.3.3.html)

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Ms. Boozang is Associate Dean for Academic Advancement at Seton Hall University School of Law where she co-founded the School's nationally ranked Health Law and Policy Program and the Health Law, Science and Technology Graduate Programs. Before arriving at Seton Hall, Ms. Boozang practiced in the health law field, primarily representing a multi-state Catholic healthcare system. Ms. Boozang writes and speaks extensively on nonprofit corporate issues, alternative medicine, medical futility, end-of-life care and sectarian providers. She is currently a member of the AHLA Board of Directors, the Journal of Health Law Editorial Board and the New York State Task Force on Life and the Law. Ms. Boozang completed her undergraduate education at Boston College where she studied theology and business administration. She also has a J.D. from Washington University School of Law and an LL.M. from Yale Law School.

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Mr. Schwartz has been a professor with the University of New Mexico Schools of Law and of Medicine since 1976. During his tenure, he has focused his research on health law and has become a nationally recognized scholar in the area of bioethics. Before coming into academia, Mr. Schwartz worked for the Albuquerque firm of Rodey, Dickason, Sloan, Akin & Robb. Mr. Schwartz is a well-known author and helped to write *Health Law: Cases, Materials and Problems*, which is now the leading health law textbook in the country. Recently, he has written on the topics of end-of-life care, death and dying, managed care, and the application of civil liberties principles to the healthcare enterprise. Mr. Schwartz has also consulted on health legislation for Cambodia, Tonga and Vietnam through the World Health Organization. Mr. Schwartz received his undergraduate degree in 1970 from Stanford University and his J.D. in 1975 from Harvard University.



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