



**Guidebook
for People
with
Disabilities**

GUIDEBOOK FOR PEOPLE WITH DISABILITIES

The American Health Lawyers Association is grateful to the following authors for their contributions to this publication.

Karl Dean Hendrick

Dean is an intern at the American Health Lawyers Association, where most of his work involves health care-related public interest issues. Previously, he worked on insurance access for HIV/AIDS patients as part of the Harrison Institute for Public Law. He was also an intern for the Florida Fifth Judicial Circuit. He graduated from Georgetown Law, and received his undergraduate from Duke University.

Lindsay P. Holmes

Lindsay is an Associate at Squire Patton Boggs (US) LLP. She focuses her practice on regulatory and transactional health care matters.

Her experience includes advising health care clients on various data privacy and security matters; assisting insurance companies develop and file health insurance products; and counseling clients on fraud and abuse, telemedicine, and medical tourism issues, and FDA regulatory matters.

Editors

Annie M. Harkins

Julianne P. Story

The *Guidebook for People with Disabilities* owes much of its content and expertise to the original authors of *Considerations for People with Disabilities and Their Families*, which the American Health Lawyers Association published in 2008. This guidebook provides updated information in a reader-friendly format that is intended to provide general guidance regarding the most commonly encountered issues for people with disabilities. AHLA is grateful for the significant contributions of the original authors:

Kathleen M. Boozang

Kelly K. Dineen

Alene V. Haskell

Barbara L. Miltenberger

Elizabeth A. Bozicevic

Robert L. Schwartz

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American Health Lawyers Association
1620 Eye Street, NW, 6th Floor
Washington, DC 20006
(202) 833-1100
www.healthlawyers.org

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—From a declaration of the American Bar Association

TABLE OF CONTENTS

FOREWORD	2	IV. EDUCATION	10
I. INTRODUCTION	3	Individuals with Disabilities Education Act.....	10
II. PROTECTIONS AGAINST DISCRIMINATION IN THE AMERICANS WITH DISABILITIES ACT	3	Infants and Toddlers.....	11
Employment	3	Preschool and School Age Children	12
The Qualified Individual	3	Parents' Rights Under IDEA.....	14
Veterans with Service-connected Disabilities	5	Behavioral Problems and School Discipline.....	14
Family Medical Leave Act	5	College Age Students and Postsecondary Education.....	15
Government Vocational Assistance	6	Accommodations by Testing Entities	15
Public Accommodations.....	6	Financial Aid	15
Housing.....	6	V. FAMILY LAW	16
Transportation.....	6	Custody Determinations.....	16
III. HEALTH CARE	7	When the Parent has a Disability	16
Private Health Insurance	7	When the Child has a Disability	16
Eligibility and Coverage	7	Child Support	16
Obtaining Health Insurance.....	7	When the Parent has a Disability	16
Government Benefits	8	When the Child has a Disability	16
Social Security	8	VI. ESTATE PLANNING	16
Medicare, Medicaid, and Children's Health Insurance Program	9	Special Needs Trusts.....	17
Making Health Care Decisions	10	State-based Trust Programs	17
Determining Capacity	10	Planning for a Successor Caretaker.....	17
		VII. CONCLUSION	17
		GLOSSARY OF COMMON TERMS	18

FOREWORD

Many years ago, I handled the first case in Massachusetts resulting in a written decision under the Americans with Disabilities Act (ADA). The Supreme Judicial Court of Massachusetts ruled in favor of my client, who was merely seeking additional time on his law board exams. I would not call it a great victory. The lawyer representing the board administering the exams simply did not recognize that the law—and the times—had changed.

Happily, since those early days under the ADA, progress has continued and the universe of disability rights has grown dramatically. As disability rights cases have come down from courts and as the regulatory framework has expanded, the legal protections for individuals with disabilities have extended across most of the activities of modern life. Disability rights now extend into education, health care, insurance, government benefits, employment, transportation, access to housing and buildings, as well as into estates and family law.

But with this expanded, more robust set of protections comes complexity. While rights have expanded, the number of cases and regulations providing interpretations and definitions that prevent protections from applying in particular instances have also increased. Understanding the full legal environment and navigating among the multiple agencies and laws poses continuing challenges for individuals with disabilities, their families, and their advocates.

This *Guidebook for People with Disabilities* provides much-needed help for anyone looking to understand the rights of individuals with disabilities. The American Health Lawyers Association has crafted an easy-to-use, well-organized, and very practical guide to the most significant questions that arise over the wide spectrum of disability rights. This guidebook stands as an important resource for all those focusing on the rights of the disabled, whatever their profession or vocation. We all have work to do to better enshrine the rights of those with disabilities and to better define the boundaries of the laws now in effect, but this guidebook provides a blueprint showing just how far our society has come and how we can go farther.

These days, I do not take cases to court. I view disability rights as a lawyer for a medical center, involved in matters that may implicate the rights of our patients, our employees, and the hospital. And I have also acted as an advocate for individuals with disabilities for my family and friends. Recently, I was hitting golf balls, badly, at a driving range. Next to me, another golfer hit balls with a similar lack of success—only he had a prosthetic leg. I smiled at the thought that he had not needed to get a court order to allow him to hit golf balls as badly as I did. The *Guidebook for People with Disabilities* will not make him (or me) a better golfer, but it will make a difference for many who need more information to fully understand and utilize the complex web of disability laws that support so many who need help to become more fully integrated into our society.

Jamie Katz

General Counsel and Senior Vice President
Beth Israel Deaconess Medical Center
Boston, MA

I. INTRODUCTION

We are often inspired by those who live with severe disabilities and yet, overcome great odds and accomplish much—today’s wounded warriors and Olympic athletes come to mind. We have come a long way from the days when little or nothing was expected from a person with disabilities. Given the appropriate support, training, and opportunity, we have learned that a person with disabilities can contribute significantly and meaningfully to society. Although change did not come easily, change has occurred with the enactment of a number of laws requiring assistance in school, public accommodations, housing, and transportation. Laws now allow a parent more time away from work to address the special needs of his or her child who has a disability.

Federal and state disability laws can, however, be unclear and the services fragmented as they are sometimes provided by government agencies that do not communicate with each other. Caring for a person with a disability can be physically and emotionally draining at times, especially when having to navigate complex rules and regulations without having adequate information.

Everyone’s situation is different, but it is our hope that the *Guidebook for People with Disabilities* will be an informative starting point to help you better understand the protections provided by the Americans with Disabilities Act (ADA) and the Americans with Disabilities Act Amendments Act (ADAAA, also referred to as the 2008 Amendments). While not comprehensive, this resource attempts to address issues that most people with disabilities may need to address at some point in their lives, including, but not limited to, child custody decisions when a parent has a disability; employment issues for a veteran with service-oriented disabilities; an airline’s duty and responsibilities towards an individual with disabilities; or when planning for a successor caretaker for the adult who will continue needing a caretaker’s assistance when the current caretaker—often times a family member—is no longer able to provide care.

II. PROTECTIONS AGAINST DISCRIMINATION IN THE AMERICANS WITH DISABILITIES ACT

In 1990, Congress passed the Americans with Disabilities Act (ADA), intending to provide a “clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities” and provide broad coverage so that people with physical and mental disabilities would not be precluded from fully participating in “all aspects of society” due to “prejudice, antiquated attitudes, or the failure to remove societal or

institutional barriers.” Congress had expected that the ADA’s definition of “disability” would be interpreted consistently with how courts had applied the definition of “handicapped individual” under the Rehabilitation Act of 1973.

Through 1999 and 2002, however, three Supreme Court decisions narrowed the broad scope of protection that Congress intended for the ADA, resulting in eliminating protection for several individuals who otherwise should have been protected by the ADA. Lower courts began incorrectly ruling in individual cases that people with a wide range of substantially limiting impairments were not “people with disabilities.” In response, Congress passed the Americans with Disabilities Act Amendments Act (ADAAA), often referred to as the “2008 Amendments,” which essentially overturned the Supreme Court’s rulings by expanding the ADA’s definition of disability so that more individuals fall under the ADA’s protections and better clarified who is regarded as having a disability. The 2008 Amendments took effect January 1, 2009.

Employment

The ADA and its 2008 Amendments prohibit employers from discriminating against a “qualified individual” with a disability with respect to hiring, firing, training, and all other terms, conditions, and privileges of employment. The ADAAA expanded the definition of “disability” so that more individuals will be covered by the ADA’s protections from discrimination and be entitled to reasonable accommodations. The ADA defines an “individual with a disability” as a person who has a physical or mental impairment that substantially limits one or more major life activities. The definition also includes persons with a history or record of such an impairment or one who is perceived by others as having such an impairment. The ADA does not specify exactly which impairments constitute a disability as each individual situation should be evaluated on its own facts. The employment discrimination aspects of the ADA are enforced by the Equal Employment Opportunity Commission (EEOC), as well as state and local civil rights enforcement agencies.

The Qualified Individual

The ADA prohibits discrimination against “qualified individuals with disabilities” and against persons who are known to be associated with or have a relationship with an individual with a disability. A qualified individual is a person who meets the job’s requirements in terms of skills, experience, education level, or other requirements of the position and who can perform the “essential functions” of the job with or without reasonable accommodation. If you

meet the following criteria, you are likely protected under the ADA as a qualified individual:

- Your employer employs 15 or more employees;
- Notwithstanding your disability, you are otherwise qualified for the job and are able to meet the essential functions of the job in terms of skills and education level, with or without reasonable accommodation; and
- You have a disability as defined by the ADA.

Which employers are prohibited from discriminating against a qualified individual?

Private employers, state and local governments, employment agencies, labor organizations, and labor management committees are all prohibited from discriminating against an individual who has a disability but is otherwise qualified for the job. Certain aspects of the ADA enforced by the EEOC also prohibit job discrimination by employers that employ 15 or more employees.

In what areas of employment is discrimination prohibited?

Discrimination is prohibited in the hiring, firing, training, and recruitment of an individual with disabilities. Discrimination by the employer is also prohibited when it comes to promotional opportunities, job assignments, pay, benefits, leave, and all other terms, conditions, and privileges of employment. An employer is prohibited from retaliating against you if you choose to assert your rights under the ADA (e.g., complaining of discrimination or requesting reasonable accommodation).

What is a reasonable accommodation?

A reasonable accommodation is a modification or adjustment to a job that allows a qualified applicant or employee to engage in the job application process or perform the essential job functions in a way that is equal to applicants and employees who do not have disabilities. Examples of reasonable accommodation include:

- Providing or modifying equipment or devices;
- Restructuring a job;
- Modifying the work schedule;
- Reassigning the employee to a vacant position;
- Providing readers or interpreters; and
- Making the workplace otherwise accessible or usable for a person with a disability.

Do I have to tell my employer I have a disability?

To request reasonable accommodation, you will need to disclose to your employer that you have a disability.

Can my employer require that I undergo a medical examination?

Prior to receiving a job offer, an employer cannot ask you to undergo a medical examination. After the job has been offered, however, the employer may condition the offer on your ability to pass the required medical examination, but the employer may require this only if all other employees entering that job category are also required to pass such an examination. If your medical examination reveals information about a disability, the employer may not reject you based on this information unless the rejection is job-related and necessary for the employer to conduct her business.

Can my employer ask questions about my disability?

If you are applying for a job, the employer may not ask if you have a disability or ask about the nature or severity of your disability. The employer may, however, ask if you are able to perform the essential functions of the job with or without reasonable accommodation and can also ask you to demonstrate your ability.

How do I request reasonable accommodation?

Each employer's request process is different. Contact the employer's human resources manager to find out how you can request a reasonable accommodation.

Do I have to pay for the reasonable accommodation provided to me?

You do not have to pay for the reasonable accommodation provided to you. The ADA requires that an employer pay for the accommodation unless it would cause undue hardship on the employer. For example, your employer may refuse your requested accommodation if the cost of providing the accommodation is too great for the employer; if the accommodation will disrupt other employees or put them in danger; or if the accommodation violates other federal laws that regulate the workplace environment, such as regulations set forth by the Occupational Safety and Health Administration.

What if my request for accommodation is denied?

If your request for reasonable accommodation is denied, consult your human resources manager to determine the reason for the denial and to see if your employer might have an alternative accommodation and/or an appeal process.

When and how can I file a complaint with the EEOC?

Complaints must be filed with the EEOC within 180 days of the date of discrimination or within 300 days if the complaint is filed with a state or local civil rights agency. Complaints may be filed at any EEOC field office. For a listing of EEOC field offices, visit www.eeoc.gov.

Can I file a discrimination lawsuit against my employer?

You may file a lawsuit in federal court only after you have filed a complaint with the EEOC and the EEOC has provided you with a “right-to-sue” letter. Some states have similar laws with similar administrative requirements. Check with your state’s department of labor for specific information on how to file your workplace discrimination complaint.

Veterans with Service-connected Disabilities

The Uniformed Services Employment and Reemployment Rights Act (USERRA) provides additional rights to those already provided by the ADA for veterans with disabilities who are returning to work. USERRA also prohibits employers from discriminating against an individual because of his or her military status or military obligations. To be covered by USERRA, you must meet the following criteria:

- You have a civilian job or have applied for one;
- You have given verbal or written notice to your civilian employer prior to leaving your job for military training or service;
- You have five years or less of cumulative military service;
- You have been released from service under circumstances other than dishonorable; and
- You will be reporting back to the civilian job or be applying for reemployment in a timely manner.

How am I protected under USERRA?

If you are a present or past member of the military, have applied to the military or are obligated to serve in the military, your employer may not deny you the following based on your military status:

- Initial employment;
- Reemployment;
- Retention in employment;
- Promotion; or
- Any benefit of employment.

If you believe your employer has violated USERRA, contact the U.S. Department of Labor, Veterans Employment and Training Service, which investigates and resolves complaints of USERRA violations. For more information, visit www.dol.gov/vets or call 1-866-4-USA-DOL.

Family and Medical Leave Act

The Family Medical and Leave Act (FMLA) requires employers to provide eligible employees up to 12 weeks of unpaid leave over a 12-month period due to certain life circumstances. FMLA requires that the employer attempt to allow the employee to return to the same or equivalent position following leave. Recent amendments provide longer periods of leave for families of returning veterans who require care. You qualify for FMLA benefits if you:

- Work for an employer who is required to comply with FMLA;
- Have worked at least 1,250 hours over a 12 month period before your leave period begins;
- Have worked for the employer for at least a total of 12 consecutive or intermittent months.
- Work at a location where your employer employs 50 or more employees within 75 miles; and

What rights do I have under FMLA?

FLMA prohibits your employer from retaliating against you for requesting or taking FMLA leave. The Act allows you 12 weeks of consecutive or intermittent leave from work for the following circumstances:

- The birth of a child and for newborn care within one year of the child’s birth;
- Adoption of a child or placement of a foster care child within one year of adoption or placement;
- Care of spouse, child, or parent with a serious health condition;
- Your own serious health condition that makes you unable to perform the essential functions of your job; or
- Certain circumstances related to an immediate family member’s military service.

How do I request FMLA benefits from my employer?

If you need to request FMLA leave, you must give your employer 30 days advance notice of your need to take leave. If giving 30 days advance notice is not possible because your need for leave was not expected, you should give your employer notice as soon as possible.

What do I do if I believe my employer violated my FMLA rights?

If you think your employer may have violated your rights under FMLA, you may file a complaint with the U.S. Department of Labor, Wage and Hour Division. For more information, visit their website at www.dol.gov/whd or contact the Wage and Hour Division at 1-866-487-9243.

Government Vocational Assistance

Federal and state governments have developed a wide range of programs aimed at encouraging and assisting persons with disabilities obtain employment. The Social Security Administration provides return-to-work incentives for people receiving federal benefits, such as not considering the person's income from a trial work period when making income eligibility determinations. When looking for employment, you should consider the impact that wages from a job might have on the government benefits you are currently receiving.

Ticket to Work Program

The Ticket to Work Program is a free, voluntary program sponsored by the Social Security Administration. The program provides career counseling, vocational rehabilitation, and job placement and training. If you are between the ages of 18-64 and receive Social Security Disability Insurance (SSDI) and/or Supplemental Security Income (SSI) benefits because of a disability, you can participate in the Ticket to Work Program.

State Vocation Rehabilitation Programs

States may also offer other vocation rehabilitation programs, but their application and eligibility requirements may vary, so check with your state's department of labor to find out more about your state-specific programs.

Public Accommodations

Several federal statutes, including the ADA, the Fair Housing Act (FHA), and the Air Carriers Access Act protect the rights of persons with disabilities to access public accommodations such as housing, government properties, businesses, and transportation. These laws set accessibility standards for public areas and public transportation and prevent discrimination by landlords and businesses.

Housing

The FHA generally prohibits discrimination in the rental or sale of housing to persons with disabilities. It also requires landlords to make reasonable policy and access-related adjustments so that individuals with disabilities can live on the property.

Most types of housing are covered by the FHA except for owner-occupied buildings with four or less units; single-family homes that are sold or rented without using a broker; and housing operated by organizations or private clubs that limit residents to members only.

Am I eligible for protection under the FHA?

You are eligible for protection under the FHA if you have a mental or physical impairment that substantially limits one or more major life activities. A major life activity generally includes, but is not limited to, caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, communicating, and working.

What types of activities are prohibited by the FHA?

Landlords and sellers are prohibited from refusing to sell or rent a property; refusing to negotiate for housing; making housing unavailable; and setting different terms and conditions for the sale or rental of housing based on a person's disability.

Who should I contact if I believe my rights under the FHA have been violated?

You can file a complaint with the Office of Fair Housing and Equal Opportunity of the U.S. Department of Housing and Urban Development (HUD). Depending on where you live, the regional office you contact to file a complaint will be located in Boston, New York City, Philadelphia, Atlanta, Chicago, Ft. Worth, Kansas City, Denver, San Francisco, or Seattle. For more information, visit HUD's website at www.hud.gov.

Transportation

The ADA prohibits public transportation authorities from discriminating against persons with disabilities in providing transportation services. The ADA requires that disability access be provided in new vehicles and that proper repairs be made to older vehicles to make them accessible to persons with disabilities. All new, fixed-route, public transit vehicles must be accessible to persons with disabilities, including city buses, subways, commuter rails, and Amtrak. Public transit vehicles are required to provide:

- Sturdy handrails;
- Barriers on platforms to prevent wheelchairs from rolling off;
- Equipment to load wheelchairs, such as wheelchair lifts;
- Available priority seating for persons with disabilities; and
- Proper lighting on ramps and in doorways.

Paratransit services

Paratransit services are available for individuals who, because of their disability, cannot use the regular transit system independently. Paratransit services are typically van services that pick up and drop off the individual at his or her destination. Paratransit services are generally required to be provided wherever public, fixed-route transit bus or rail systems are offered unless, for example, providing such services would create an undue burden on the city or township that provides the regular transportation services.

How do I request paratransit services?

Requesting paratransit services typically requires completing an application and meeting eligibility requirements. For more information about how you might qualify for paratransit services, check with your local transit authority as the application process will likely vary from city to city.

Private transportation

The ADA requires that private transportation businesses provide accessible vehicles to persons with disabilities. For example, airport and hotel shuttles and private buses and taxis must provide accessible vehicles. Private transportation services must also make their facilities, such as bus stops, accessible to persons with disabilities.

Air transportation

The ADA prohibits U.S. and foreign air carriers that take off and land on U.S. territory from discriminating against persons with disabilities. Air carriers must provide reasonable accommodations unless it creates undue hardship for the airline. An air carrier may not require that you provide proof of your disability, such as a medical certification, except in limited circumstances, including:

- If you require a stretcher or incubator;
- If you require medical oxygen during flight;
- If you have a communicable disease; or
- If the carrier has reasonable doubt that you can make the flight safely.

An air carrier may not prohibit you from flying its airplane unless the airline determines that your flying would directly threaten other passengers' health and safety.

How do I request an accommodation from my airline?

Contact your airline as policies for requesting accommodations may vary from airline to airline. Request the accommodation in advance of your travel to ensure the accommodation can be made and no delays occur. If you

have additional questions about traveling by air, contact the U.S. Department of Transportation, which operates a toll-free hotline for persons with disabilities. Contact them at 1-800-778-4838 (Voice) or 1-800-455-9880 (TTY).

To file a complaint against an air carrier for discriminatory treatment, you may contact the Aviation Consumer Protection Division at the U.S. Department of Transportation. Visit their website at www.dot.gov/airconsumer for more information.

III. HEALTH CARE

The Patient Protection and Affordable Care Act of 2010 (PPACA, also referred to as ACA or the Affordable Care Act) contains a number of changes to the health insurance system, making it easier for individuals with disabilities to obtain private health insurance. In addition, several government programs exist that provide free or low-cost health insurance for individuals with disabilities.

Private Health Insurance

Eligibility and Coverage

Health insurance plans are no longer permitted to deny coverage or charge higher premiums for "pre-existing conditions." This means your disability should not negatively affect your eligibility or ability to purchase private health insurance. Health insurance is not required to cover your dependents. However, if your insurance plan provides dependent coverage, it must allow your child to remain on your insurance until he or she turns 26. In addition, your insurance plan cannot deny your child coverage or charge higher premiums due to your child's disability.

Obtaining Health Insurance

Most employers offer health insurance as part of their employee benefits. Any employer with 50 or more employees is required to offer coverage to full-time employees or pay a fine. If your employer does not offer coverage, you might be able to purchase individual insurance through a state or federal health insurance exchange. Visit www.healthcare.gov or call 1-800-318-2596 (TTY: 1-8555-889-4325) to see if this is an option for you. In addition, you might qualify for a subsidy to help you pay for the insurance if your gross pre-tax income is between 100% and 400% of federal poverty level. In other words, as of 2014, if an individual's gross pre-tax income is between \$11,490-\$45,960 or \$23,550-\$94,200 for a family of four, that individual or family may qualify for a subsidy. Keep in mind that the specific dollar amount changes annually.

Your income will also determine the amount of the subsidy you receive.

Government Benefits

Social Security

Two types of Social Security programs provide payments for individuals with disabilities: Social Security Disability Insurance (SSDI) and Social Security Income (SSI). SSDI benefits vary based on prior income while SSI benefits are fixed.

Who is eligible for SSDI?

SSDI covers individuals between the ages of 18-64 who are unable to engage in “substantial gainful activity” due to severe impairment. Substantial gainful activity is defined as employment that provides more than \$1,800 per month to an individual who is blind or \$1,070 per month for an individual who is not blind. Other forms of income are not considered. The severe impairment must be expected to last at least 12 months and medical evidence of the impairment is required. A list of recognized impairments is available at www.ssa.gov/disability/professionals/bluebook/AdultListings.htm.

To obtain SSDI, you must have a certain number of Social Security “credits” that are earned through paying your Social Security taxes. You can earn up to four credits per year. The number of credits needed to qualify for SSDI varies based on the age you became disabled but is generally 20 plus one per year over 42. The dependents of an individual who receives SSDI may be entitled to SSDI payments until the child turns 18 unless the child is also disabled, in which case the child can receive SSDI until he or she turns 22.

Who is eligible for SSI?

Like SSDI, an individual can qualify for SSI due to his or her inability to engage in substantial gainful activity because of severe impairment. In addition, SSDI and SSI use the same definitions for substantial gainful activity and severe impairment. Unlike SSDI, however, an individual can qualify for SSI if he or she is a child with a disability or at least 65 years old regardless of disability. SSI does not require a minimum number of Social Security credits like SSDI, but it does have additional maximum income and resource requirements for recipients (and their parents, spouse or sponsor, if applicable). Maximum income varies by state. Maximum resources are \$2,000 for a single individual, \$3,000 for an individual and spouse, \$4,000 for a child with a single parent in the household, and \$5,000 for a child with two parents in the household. In general, SSI requires legal residency in the United States, but does not require citizenship.

How do I apply for SSDI or SSI?

Contact your Social Security Office at 1-800-772-1213 (TTY 1-800-325-0778) to determine if you qualify for SSDI or SSI benefits. You can apply for SSDI online at www.ssa.gov/pgm/disability.htm. You cannot, however, apply for SSI benefits online.

What if my SSDI or SSI application is denied or my benefits are discontinued?

If your SSDI or SSI application is denied, you have 60 days from the date of denial to file an appeal. If, however, you file within ten days, you can continue receiving benefits. You can appeal the denial of your application online or at your local Social Security office. The first level of appeal is called “reconsideration” and is conducted by the Social Security Administration. If you are denied at reconsideration, you can file another appeal with an Administrative Law Judge

PRACTICAL TIPS ABOUT INSURANCE COVERAGE

- Keep a log of all conversations you have with your insurance company, including the name of the person you spoke with, the date and time of your conversation, and the issues you discussed.
- Keep a written log of medical information with dates of service, such as when your child had a doctor’s appointment or a therapy session.
- Ask the insurance company for explanations in writing.
- Ask health care providers to help you with an appeal.
- Do not accept a denial of your medical claim without seeking more information and/or appealing the insurance company’s decision.
- Provide medical information—including information from medical literature—to the insurance company if it will help explain the medical service or medical treatment being sought or proposed.
- Carefully read both the billing statement from the health care provider and the explanation of benefits (often referred to as an EOB) from your health insurance company. Pay special attention to the date of the medical procedure, service or therapy and whether all payments from you and your health insurance plan are properly credited (based on the rate that your health care provider contracted with your health insurance company).

(ALJ). If that appeal is unsuccessful, you can appeal further in federal court. As an alternative to an appeal, you can request an application be reopened or file a new claim. You may want to consider having an attorney assist you in preparing your application and when appealing the denial of SSDI and SSI benefits.

Medicare, Medicaid, and Children's Health Insurance Program

Medicare, Medicaid, and the Children's Health Insurance Program (CHIP) are government programs that provide free or low cost health insurance to individuals who meet certain requirements. Medicare benefits and eligibility are standardized nationwide and the program is administered by the federal government, but Medicaid and CHIP are administered jointly by the federal government and the individual states. As a result, eligibility and benefits for Medicaid and CHIP vary from state to state.

Who is eligible for Medicare?

Medicare is available if you are over the age of 65, a citizen or permanent legal resident, and have 40 Social Security credits. If you do not have 40 credits, you can still receive Medicare by paying additional premiums. If you are under the age of 65, you can qualify for Medicare if you have one or more of the following:

- SSDI for at least 24 total months (the months do not need to be consecutive);
- A disability pension from the U.S. Railroad Retirement Board;
- Permanent kidney failure requiring dialysis or transplant; or
- Amyotrophic Lateral Sclerosis, also known as Lou Gehrig's disease or ALS.

Who is eligible for Medicaid and CHIP?

In states that have chosen to expand Medicaid under the Affordable Care Act, all adults who make less than 138% of federal poverty level qualify for Medicaid benefits. However, Medicaid eligibility may vary in states that have chosen not to expand their Medicaid programs such that Medicaid may be limited to persons with disabilities and pregnant women. These states may also have a lower income threshold.

CHIP provides coverage to children whose families earn too much to qualify for Medicaid but not enough to afford private health insurance coverage. In general, CHIP beneficiaries must be under the age of 19 and have no other health insurance (including Medicaid). CHIP also requires

family income to fall below certain thresholds, but the exact amount varies greatly by state.

How do I apply for Medicare, Medicaid or CHIP?

You can apply for Medicare at your local Social Security office or online at www.ssa.gov/medicareonly. To apply for Medicaid or CHIP, you will need to contact your state Medicaid office. Note that this office may not be officially titled "Medicaid." For example, the state agency that administers Medicaid may be called the Department of Health and Family Services or other similar name. To apply for CHIP benefits in your state, call 1-877-543-7669. Finally, if you use the federal health exchange at www.healthcare.gov, you will be directed to the appropriate state agency if your income qualifies for Medicaid or CHIP.

How can I appeal a denial from Medicare, Medicaid or CHIP?

If your initial application for Medicare eligibility is denied, you may file a request for reconsideration with the Social Security Administration. If your request for reconsideration is denied, you may appeal to an ALJ. If you are not satisfied with the ALJ's decision, you can appeal to the Medicare Appeals Council. If the Council's ruling also is unsatisfactory, you can appeal to federal court.

If you already have Medicare, you may appeal denials of specific claims. If you are enrolled in Medicare Advantage, PACE, a Medicare Savings Account, or otherwise receive Medicare benefits through a health plan, you must make the initial request for reconsideration to your health plan. If you are enrolled in "original Medicare" and therefore do not have a health plan, your request for reconsideration should be made to the company that processes your Medicare claims, called a Medicare Administrative Contractor. Information on your Medicare Administrative Contractor and how to contact them is listed on your Medicare Summary Notice, which you should receive by mail every three months. If your initial request is denied, you may appeal to an "independent review entity" if you receive Medicare through a health plan, or to a "qualified independent contractor" if you have original Medicare. If the ruling made by the review entity or independent contractor is unsatisfactory, you may appeal to an ALJ, followed by the Medicare Appeals Council, and finally to federal court.

Medicaid and CHIP decisions about eligibility and coverage may likewise be appealed. The first level of appeal is either an evidentiary hearing or an administrative hearing, depending on the state. The notice informing you that your eligibility or claim has been denied will explain how to file the appeal.

Making Health Care Decisions

In general, every person has the right to make his or her own health care decisions as if he or she has capacity to do so. This standard does not change for individuals who are disabled. Unless a person's disability affects her capacity, she is entitled to make her own health care decisions in the same manner a non-disabled individual would be entitled to make her decisions.

Determining Capacity

Every person is presumed to have capacity until proven otherwise. Any challenge to this presumption typically involves a court hearing in state court. The exact standards for capacity and competency vary by state. Occasionally, those standards vary based on the type of decision being made. For example, California distinguishes between—and therefore has different standards for determining—“contractual capacity” (needed to enter into contracts) and “testamentary capacity” (needed to make wills). Although capacity determinations often involve the ability to understand and communicate information in a general sense, the courts do not usually ask whether a person is thinking rationally about a particular decision. The fact that someone may make a choice that seems foolish does not prove incapacity.

How are decisions made for adults who lack capacity?

While you still have capacity, you should consider expressing your health care wishes through a legal document called a living will, also referred to as individual instructions. Requirements for how living wills are created and executed (signed, witnessed, notarized) varies by state.

Alternatively, you may designate someone—the “attorney in fact” or “agent”—to make decisions on your behalf. Your attorney in fact or agent does not need to be a lawyer. If an incapacitated individual has left no explicit instructions as to his or her health care wishes, many states will permit family members to make those decisions. Typically, the family members include the spouse, the person's adult children if there is no spouse, and the person's parents or adult siblings.

If the incapacitated person has no living family, the state may have laws permitting certain non-family members who know the person's values and has special concern for the person's well-being—such as a close friend, the person's physician, clergyman or lawyer—to act as a “residuary decision maker.” A court may also appoint a decision maker for the incapacitated person, called a guardian or conservator. Usually, a “guardian” makes personal decisions and a “conservator” makes financial decisions, but not all

states make this distinction. The guardian may have plenary authority (the ability to make any decision the incapacitated person could ordinarily make) or be limited to specific areas, such as the selection of a long term care facility.

The court may appoint a “guardian ad litem” who acts as an attorney for the allegedly incapacitated person during the guardianship process itself. The court may also appoint a “visitor” to advise the court on the necessity of appointing a guardian.

How are decisions made for children?

The rules that apply to parental decision making for minor children also apply to children with disabilities. In general, this means the parent or legal guardian has authority to make decisions on the child's behalf as they are most likely to act in the child's best interests.

Some states permit teenagers to make health care decisions as they approach the age of 18. In addition, teenagers have a Constitutional right to make certain decisions about their reproductive health. In circumstances where teenagers may make their own health care decisions, capacity determinations apply in the same manner they apply for adults.

How do health care institutions affect decision-making?

Hospitals, nursing homes, and clinics may have their own policies about who can make decisions on behalf of the incapacitated person. In addition, some institutions may have religiously- or ethically-based policies that limit the patient's health care choices.

IV. EDUCATION

The Individuals with Disabilities Education Act

The Individuals with Disabilities Education Act (IDEA) provides federal funding to states and local school districts for special education of infants, toddlers, preschool, and school age children. In return, participating states must meet certain requirements and standards. Although states do not have to participate, all of them currently do. States often vary in how they implement IDEA, so you should contact your state's education agency if you have specific questions.

Under IDEA, every disabled child is entitled to a “free and appropriate public education,”—sometimes referred to as FAPE—meaning that education is paid for by the government and meets standards set by the state's educational agency. The education must be provided in the least restrictive environment, which means a child with a disability should be educated with children who do not have disabilities. Special classes or schools should be used only when the nature and

severity of the child's disability prevents education in the regular classroom setting, even with supplementary assistance. In addition, the child is entitled to free related services that will benefit the child's education, including:

- Transportation;
- Speech-language pathology and audiology services;
- Psychological services;
- Physical and occupational therapy;
- Recreation, including therapeutic recreation;
- Early identification and assessment of disabilities;
- Counseling services, including rehabilitation counseling;
- Orientation and mobility services;
- Medical services for diagnostic or evaluation purposes;
- School health services;
- Social work services in schools; and
- Parent counseling and training.

Infants and Toddlers

IDEA's Part C provides federal grants to states so that the states can provide early intervention services (EIS) to infants and toddlers with disabilities and developmental delays. EIS helps such children learn basic skills that are typically developed in a baby's first three years of life, including:

- Physical skills (crawling, walking, rolling over)
- Cognitive skills (problem-solving)
- Communication skills (listening, talking, understanding)
- Social/Emotional skills (playing)
- Self-help skills (eating, getting dressed)

Early intervention services can vary by state but may include:

- Speech and language services
- Hearing services
- Occupational therapy
- Physical therapy
- Medical services
- Nutrition services
- Assistive technology (devices for your child)
- Counseling/psychological services
- Social work services
- Transportation

Eligibility for EIS is based on the state's determination of whether the child has a developmental delay. States often rely on the opinions of clinical professionals to make this determination. Check with your local school or child care facility to learn about your state's specific eligibility requirements.

How is developmental delay determined?

IDEA allows each state to define developmental delay and determine how a child will be evaluated by using appropriate diagnostic instruments and procedures to measure physical, cognitive, communicative, social/emotional, or adaptive development. The presence of a developmental delay is often detected as early as the child's birth, at which time the parent may be referred to a local early intervention program. Talk to your pediatrician or contact your local early intervention office and request an evaluation if you feel your child might benefit from such testing. Conducting an internet search with the key words "early intervention services" and the name of the county or city in which the infant or toddler resides should help you locate your local early intervention office.

How will my child be evaluated?

Once you have connected with an early intervention program near you, a service coordinator will help you understand the process of having your child evaluated for a developmental delay. Individuals who are qualified in developmental training will observe and interact with your child to identify specific developmental areas that will need additional help. The results from your child's evaluation will help determine your child's eligibility. All evaluations require parental or family member consent and are generally free of charge as such services are usually covered by federal and state government programs related to children's health.

An eligibility evaluation may not be necessary in every situation. For example, if your child has already been diagnosed with a physical or mental condition with a high probability of developmental delay, the child will be automatically eligible. Conditions with a high probability of developmental delay include: chromosomal abnormalities; genetic or congenital disorders; sensory impairments; inborn errors of metabolism; disorders reflecting disturbance of the development of the nervous system; congenital infections; severe attachment disorders; and disorders secondary to exposure to toxic substances, including fetal alcohol syndrome. Once eligibility is determined, a more in-depth evaluation will be conducted to identify your child's specific needs, the family's ability to provide resources, and any concerns and priorities the family may have about the child's development.

What happens if my child is eligible for EIS?

Once your child is considered eligible for EIS, the evaluators will work with you to create a plan of action called an Individualized Family Service Plan (IFSP) that is specifically tailored for your child. Generally, the IFSP outlines your child's specific care plan and must be reviewed at least every six months and updated annually, if not more often. IFSP requirements vary by state, so your service coordinator will be able to explain in greater detail the requirements that are specific to your state. The IFSP will include several pieces of information about your child, including:

- Your child's developmental needs and the severity of those needs;
- Information about your family's resources, priorities, and concerns about your child's development;
- The goals expected to be achieved for your child and family;
- The services your child will receive;
- Where the services will be provided;
- The time and place your child will receive services;
- The number and length of engagements with the child through which the services will be provided;
- Who will pay for the services;
- Your service coordinator's name and contact information; and
- The steps that will be involved when your child transitions from early intervention at age three to another program that is more appropriate given the child's older age and progress.

How long does the EIS evaluation process take?

When the local office that is responsible for providing early intervention services (EIS office) receives a referral for a child with a suspected developmental delay, it has 45 days to screen, evaluate, and create an IFSP for the child.

How do I pay for EIS?

The initial evaluations, your service coordinator's time, and the written IFSP are free of charge, as these services or items are covered by state and federal funds. Depending on your state's program, you may be charged for other services and costs associated with early intervention. These costs may still be covered under your private or public health insurance. Your EIS office must obtain your written consent to bill your health insurance provider for the services.

Transitioning from to preschool to school age services

IDEA's Part C covers your child only until his or her third birthday, so it is important to plan your child's transition from EIS to school age services through an Individualized Education Program (IEP), discussed in more detail below, as required under IDEA's Part B. In fact, IDEA requires transition planning for children moving from Part C to Part B.

Is my Part C-eligible child automatically eligible for Part B benefits?

Not every child who was eligible for and received EIS under IDEA's Part C will be automatically eligible to receive secondary education services under Part B. If your child is determined ineligible for Part B, you should discuss with your service coordinator and care team the availability of other community-based services.

How long does the transition from Part C to Part B take?

Transition planning can start as early as when your child turns two, but planning typically begins at least three months before your child's third birthday. You will be involved in one or more transition meetings with your child's care team where you will develop an exit plan from Part C and discuss your child's needs and educational options. The transition plan will be a part of your IFSP.

How can I prepare my child for the transition?

Once you have made transitional decisions with your child's care team, start preparing your child for the transition. Talk to him or her about the transition and provide opportunities for the child to interact with other children who are the same or similar age. Update your child's medical, assessment, and educational records. You also may want to talk to other parents who have transitioned their child from EIS to preschool and school age services.

Educational Assistance for Preschool and School Age Children

IDEA's Part B is the federal law that addresses educational assistance for preschool and school age children. Part B requires that education be conducted according to an IEP. Children with disabilities who are between the ages of 3-21 are eligible for educational assistance under Part B, although certain exceptions may exist for those between 3-5 or 18-21. A disability may include an intellectual disability, hearing impairment (including deafness), speech or language impairment, visual impairment (including blindness), emotional disturbance, orthopedic impairment, autism, traumatic brain injury, a specific learning disability, multiple disabilities, or other health impairment. The disability must impact the child's educational performance and do so in a way that requires special education.

How is my child's eligibility for Part B services evaluated?

The state is required to identify and evaluate a child who has a disability, even if the child is homeless or enrolled in a private school. The programs designed for this purpose are generally referred to as "Child Find." A parent or public agency—such as the school system—may request an evaluation, although the public agency/school system must usually obtain parental consent to evaluate a child's disability and educational needs.

The evaluation must be conducted within 60 days of receiving parental consent unless the state has established a different time limit. The evaluation must include multiple assessments that are administered by trained personnel; occur in the child's native language; take into account any sensory, motor or language impairment; and cover all areas of suspected disability.

If the situation changes at some point after the initial evaluation, a reevaluation may be requested by the parent, teacher or public agency/school system to determine if the child continues to have a disability. Reevaluations may not occur more than once per year or less than once every three years unless the parents and public agency/school system agree otherwise.

If you do not agree with your child's evaluation or a reevaluation, you are entitled to an independent educational evaluation and can also request that the public agency/school system pay for the independent evaluation. If the public agency/school system will not pay for the evaluation, it must schedule a special education hearing. If the hearing determines that the agency's evaluation was not appropriate, the school must pay for the independent educational evaluation. If the hearing determines that the public agency/school system's evaluation was appropriate, you may still have an independent educational evaluation conducted, but you will have to pay for it yourself.

What is an IEP and how is it created?

The IEP is a personalized plan for your child's educational needs that describes the special education and services your child will receive from the school. The IEP must be created within 30 days after your child has been determined eligible for Part B services. The IEP is written by an IEP team that must include at minimum:

- The parents;
- A regular education teacher;
- A special education teacher;
- An individual who can interpret evaluation results; and
- The child (if appropriate).

PRACTICAL TIPS ABOUT EVALUATIONS AND ELIGIBILITY

- Start and attempt to keep every interaction and relationship with the school district positive, professional, and moving towards achievement of the mutually agreed upon goals in the child's IEP and IFSP.
- Document in writing all of your significant communications with the school district. For example, your request for an evaluation should be in writing, dated, and hand-delivered or mailed by certified mail, return receipt requested. 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 communications you have with the school district, including conversations with teachers and administrative personnel at the child's school. Document dates, times, names of persons with whom you communicated, and their titles or positions.
- If the school district refuses your request for evaluation, request a written notice of refusal (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 your child. Keep a copy of everything you provide to the evaluators.
- Ask the child's health care provider(s) to write a letter explaining the child's medical diagnosis and recommendations for assistance at school. Keep in mind, however, that the school is not required to provide the best or most ideal options for your child—the school is only required to provide education and services designed to provide some educational benefit. Therefore, the health care provider should avoid statements of "ideal recommendations" or "best options" for your child. Ask your child's health care provider to consider the school environment when writing the letter. Your child's health care provider may charge you for this service.
- If you do not agree with the school's evaluation, request an independent educational evaluation.

You and the school may invite others to the IEP meeting who may have knowledge or expertise about your child, such as a family member or the child's health care provider. The IEP must address the following issues:

- The child's present level of performance;
- Annual goals regarding the child's progress;
- The special education and related services to be provided;
- How progress will be measured;
- The extent (if any) to which the child will not be able to participate with children who do not have disabilities;
- Participation and modifications for standardized testing; and
- Transition services for post-school goals.

The school is required to provide reports on the child's progress towards the goals that have been defined in the IEP, and the IEP must be reviewed and revised at least annually. The IEP can, however, be updated more often if you or the child's school requests it.

PRACTICAL TIPS ABOUT YOUR CHILD'S INDIVIDUALIZED EDUCATION PROGRAM

- Feel free to invite family members and health care providers to your child's IEP meeting who can provide information about your child, take notes, or otherwise offer support.
- Do not be intimidated to ask questions. You are your child's best advocate.
- Bring someone who can take notes for you during the IEP meeting, or notify or ask the school about audio-recording the meeting for your reference later.
- Bring records or documentation about your child that may be helpful during the IEP meeting.
- Do not feel obligated to sign the IEP if you still have questions or do not agree with everything in your child's IEP.
- If the school does not agree to something you think is necessary for your child, ask for a Notice of Action Refused.
- Keep copies of all documents used or referenced during your child's IEP meeting.

Parents' Rights Under IDEA

Parents have the right to be informed of and to participate in all special education decisions about the child. These rights include receiving a written notice of action taken or notice of action refused; accessing the child's education record; being informed of findings made in the evaluations; and consenting to evaluation and placement decisions.

Parents may file complaints or disputes with the state education agency, and the information on how to do so must be available by phone or through the agency's website. The state education agency—also known as the state department of education—is the agency that oversees educational funding and policies. The complaint or dispute must receive due process, which typically involves a hearing. Some states, however, allow informal meetings or mediation instead of a formal hearing. The school must provide a notice explaining the procedural safeguards, including the complaint and appeals process, at least once per year.

Behavioral Problems and School Discipline

In general, a school district may not discipline a child with a disability in any manner that involves removing the child from his or her current educational placement for more than 10 days unless the child's behavior is not a manifestation of the disability. To determine if the child's behavior was a manifestation of his or her disability, a manifestation review—also referred to as a manifestation hearing—is conducted.

The manifestation review is conducted by the IEP team and involves the parent. If the review shows that the behavior was a manifestation or symptom of the child's disability, the child may not be removed from her current educational placement unless her behavior involved weapons, drugs, or serious bodily harm. If the child's behavior did involve weapons, drugs, or serious bodily injury, the child may be removed for up to 45 days. If the review determines the child's behavior was not a manifestation or symptom of her disability, she may be disciplined in the same manner as a child without a disability would be disciplined. In addition to the manifestation review, the school must conduct a behavioral assessment or review the child's existing assessment.

College Age Students and Postsecondary Education

IDEA does not apply to individuals entering postsecondary education; rather the Rehabilitation Act of 1973 and the ADA protect older individuals for whom IDEA's Part B no longer applies. The Rehabilitation Act and ADA prohibit discrimination in postsecondary education on the basis of one's disability.

How will my rights differ from the rights I had during secondary education?

Postsecondary schools such as colleges and universities are not required to provide free and appropriate public education to students with disabilities. A postsecondary school is, however, required to provide appropriate academic accommodations, which means modifications or services that provide the student the same opportunity it would provide to a non-disabled student. For example, if your school provides housing for non-disabled students, it must provide similar, accessible housing for students with disabilities.

Can I be denied admission to a postsecondary school because of my disability?

A postsecondary institution may not deny you admission simply based on your disability if you meet the essential requirements for admission.

Do I have to inform the school of my disability?

You are not required to inform the school of your disability, but you should consider informing the school prior to attending if you need special accommodations, such as convenient and accessible facilities and housing.

What academic accommodations must the postsecondary institution provide?

Academic accommodations are determined based on your disability and individual needs. For example, some individuals may need extra time for testing while others may need voice recognition software or a sign language interpreter. Although your school is required to make necessary accommodations, it is not required to do anything that would fundamentally alter the nature of the program or activity. For example, the school is not required to change the substantive content of an exam because of a student's blindness, although the school might be required to provide the test so that the student can listen to the questions on an audio device and submit the answers via computer.

If I need an academic accommodation, what steps should I take?

To request and receive an academic accommodation, you must first inform your school of your disability status. Your school may have a specific process, such as requiring that your request be made in writing. Most schools have a specific person or office that manages services for students with disabilities. You should contact that person or office for information about the school's specific procedure for making the request. The school's website may also provide additional information.

What if the academic accommodation provided by the school is not working?

If you do not feel the academic accommodation is working for you, inform your school as soon as you become aware of the problem. If you wait too long, it may be too late to correct the issue.

Do I have to pay for the academic accommodation provided to me?

Your school is not allowed to charge you more than it would charge a student without a disability to participate in the same program or activity.

What can I do if I believe the school has discriminated against me?

Generally, a postsecondary institution will have a person or office that coordinates disability services and ensures that the school is complying with federal and state disability laws. If you feel you are being or have been discriminated against, you should contact this individual or office to express your concerns. Your school is required to have a grievance or complaint process in place. The process will vary by school, but it must give you the opportunity to express your concern and provide a resolution to your complaint. If you are dissatisfied with your school's determination or you wish to use an alternative grievance procedure, you can file a discrimination complaint with the U.S. Department of Education's Office of Civil Rights.

Accommodations by Testing Entities

The ADA requires that reasonable testing accommodations be made by testing entities or testing centers for individuals with documented disabilities. An example of a testing entity might be the Law School Admission Council, which administers the Law School Admission Test or LSAT.

Each testing entity has specific requirements, such as documentation of a disability that supports your need for an accommodation or that your request be made in writing and within a specific period of time so that the testing service has sufficient time to make the accommodation for you. Contact the testing entity to understand its requirements for requesting and receiving an accommodation.

Financial Aid

Several financial aid options are available to students with disabilities through private and public grants and scholarships or from the federal government. To obtain financial assistance from the federal government, you will need to complete a Free Application for Federal Student Aid. Visit www.fafsa.ed.gov for more information.

V. FAMILY LAW

The legal principles of family law for the general population also apply to individuals with disabilities. The courts will, however, occasionally consider the disability of parents and children when deciding issues related to custody, child support, and spousal support. While the mere presence of a disability is not usually relevant, the consequences of a specific disability may impact the court's decision on certain issues. This determination is very fact-specific and is made on a case-by-case basis. In addition, family law differs significantly among the states.

Custody Determinations

In all states, the courts attempt to assign custody based on the best interest of the child. Parents are usually preferred over others, including non-parent relatives, when determining custody unless the parents are incapable of caring for the child. In most states, both parents are considered equally acceptable as custodians. Most states also presume it is in the child's best interest to spend relatively equal amounts of time with both parents.

When the Parent has a Disability

If a person seeking custody has a physical or mental disability, the disability is not necessarily a disqualifying factor. The court must decide whether the disability is a relevant issue in light of the child's best interests. In making that determination, the court may need to consider whether the disability affects the person's ability to care for the child. Custody disputes can be emotionally charged, so the courts are usually cautious of claims that a parent is mentally, psychologically or physically disabled without additional evidence. The court may also consider whether a parent has sought psychological help in the past, the reasons for seeking psychological help, and the length of time that has passed since the incident that caused or prompted the parent to seek help. If the court determines that neither parent can care for the child, it may assign custody to another party. The specifics of who can be considered for custody vary among the states.

When the Child has a Disability

When determining custody for a child with a disability, the court considers which parent or guardian has the time, energy, and financial resources to address the child's disability. The court will also consider whether a parent shows particular dedication to, experience in, or willingness to learn how to properly care for the child. Custody is usually not assumed for the parent who has the higher

income. If the court determines that the custodial parent will be financially strained in taking care of the child, the court can order child support from the other parent.

Child Support

When the Parent has a Disability

Just as the disability of a parent does not inherently eliminate his or her parental rights, the disability does not necessarily remove his or her parental obligations. As a result, a parent with a disability may still be required to pay child support, which is determined based on a formula using both parents' incomes. In most states, the courts will assign an income to a non-working parent for the purpose of determining child support. In other words, the court will calculate the child support based on what the parent could make if the parent was working, but if a parent cannot work as a result of disability, the court may decide that no assignment should occur, thereby treating the parent's income as zero.

When the Child has a Disability

Some states provide for increased child support for a child who has a disability to cover special expenses related to the disability, such as medical bills or counseling expenses. Generally, child support ends once the child reaches the age of majority (18 in most states). However, most states allow child support to be extended past the age of majority for children with disabilities. In a minority of states, parental obligations are renewed or revived when an adult child becomes disabled, even if the child was living independently prior to the disability. The states are split as to whether the amount obligated to adult children should be based on the state's child support guidelines. In states where this is not the case, the courts have usually considered the adult child's needs and the parents' financial situation.

VI. ESTATE PLANNING

The Social Security Administration considers gifts in wills to be income for purposes of calculating benefit eligibility. This means a gift made through someone's will could potentially be considered income and compromise your ability to qualify for government benefits. Families should therefore consider alternative means of estate planning to ensure that you or the loved one who has a disability can continue receiving government benefits while also receiving additional comforts from a parent or caregiver's estate. This section addresses several estate planning options and provides information about planning for your or a loved one's future care.

Special Needs Trusts

A Special Needs Trust, also referred to as a Supplemental Needs Trust, provides support to a person with a disability without that support being treated as income or property. This type of trust allows the person to keep receiving gifts without losing her eligibility for government benefits and is administered by a trustee who monitors the trust and distributes funds from the trust so that the needs of the individual for whom the trust was created can be met. Special Needs Trusts can be created to pay for items or services that go beyond the basic necessities of life, such as over the counter medication, treatment by specialists, legal representation, vacations, and education. Consider consulting an attorney and financial planner who have specialized knowledge in creating and funding Special Needs Trusts. Consider also the amount of funding the Special Needs Trust will require and whether government benefits will be sufficient to support the individual for whom the trust is being created. In making the funding determination, consider the individual's personal needs and unexpected, extraordinary circumstances that may arise.

State-based Trust Programs

State-based trusts, also referred to as pooled trusts or state pooled trusts, give families a relatively inexpensive way to provide supplemental funds for a family member who has a disability without losing government benefits. In state pooled trusts, the resources of multiple beneficiaries are pooled together and managed by a nonprofit organization. The organization acts as the trustee and the funds in the trust are used for the benefit of all of the trust's beneficiaries. Once funds are placed in a pooled trust, however, the caretaker no longer has the ability to direct the funds. This type of trust can be a good option for families with limited funds.

State pooled trusts vary by state and each state will have its own laws regarding them. States will also vary on whether funds from a pooled trust are considered income for the purposes of calculating one's eligibility for government benefits. When selecting a pooled trust in which to invest funds, it will be important to consider the trust's past financial stability, the length of time the trust has been in existence, and how the trust has cared for beneficiaries in the past. Consider also the needs of the individual who will need support from the trust and determine if the trust has the means to fulfill those needs.

Planning for a Successor Caretaker

The caretaker—who is often times a family member—for the person with a disability may want to consider how her loved one will be cared for in the event she can no longer provide care. Some important issues to consider when thinking about a successor caretaker include the following:

- The living situation of the disabled individual and whether he or she will be able to continue living in the current place of residence.
- The type of care the individual with disability will require.
- Whether the individual with disability will require live-in care and who will provide that care.
- If a professional caregiver is necessary, consider how that caregiver will be selected, how the care will be paid for, and who will be responsible for overseeing the professional caregiver.
- Consider leaving written instructions for the successor caretaker regarding necessary care that the person with a disability will need.
- Consider having the successor caregiver spend time with your loved one prior to taking on the responsibility of care.
- Consider who will be responsible for making medical, educational, employment, and financial decisions if the person with a disability is a minor child.
- Consider what necessary legal steps must be taken to provide the successor caretaker authority to make decisions on behalf of the individual who has a disability.

VII. CONCLUSION

Caring for a child or adult with a disability can present overwhelming challenges for the individual and her caretaker. Knowing what questions to ask, understanding the applicable laws, and knowing where to look for information is half the battle when it comes to ensuring that rights are protected and opportunities for the person with disabilities are not curtailed. AHLA hopes that this guidebook provided a good starting point in helping you better understand your protections under federal law. States differ significantly in their laws and regulations, so it is important you research information that is specific to the location where the child or adult resides.

GLOSSARY OF COMMON TERMS

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.

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

FAPE – Free and appropriate public education. Under Part B of the Individuals with Disabilities Education 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, religions, 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 for eligible students with disabilities.

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.

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).



American Health Lawyers Association

1620 Eye Street, NW, 6th Floor | Washington, DC 20006-4010 | (202) 833-1100 Fax (202) 833-1105 | www.healthlawyers.org