



PEACE *of* MIND

A Guide to Supporting Special Kids with Special Needs

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TEXAS YOUNG LAWYERS ASSOCIATION

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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.”

– Helen Keller

Parents of children who have been diagnosed with a disability or special need are often confronted with unique and unfamiliar issues that result in many questions. You may have found yourself asking questions such as:

- What laws protect my child in school?
- What laws protect my child if he or she chooses to live on his or her own?
- What laws protect my child if he or she wants to work?
- How do I financially plan for my child’s future?
- How do I plan for my child’s future after I am gone?
- What benefits and resources will be available to my child when he or she turns 18?
- What resources are out there for parents of special needs children?

“Peace of Mind: A Guide to Supporting Special Kids with Special Needs,” a publication of the Texas Young Lawyers Association, is intended to identify and generally explain the following unique issues that parents of children with special needs commonly face:

- The Individuals with Disabilities Education Act
- Housing Laws
- Disabilities Laws and Protection in the Workplace
- Financial Planning
- Estate Planning
- Supplemental Security Income & Medicaid
- Resources for Parents with Special Needs Children

This handbook is meant to be a tool to help you find the resources needed to help with the challenges involved with raising a special needs or disabled child, while also planning for their future. We hope it can provide you with some peace of mind knowing that your child is protected and that there are laws that can help ensure your child’s future is bright.

Please note that this handbook is intended solely to provide general information and is not a substitute for legal counsel. Any laws described in this handbook are subject to change at any time. If you have a specific legal question or problem, we strongly suggest that you consult an attorney.

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THE INDIVIDUALS WITH DISABILITIES EDUCATION ACT (IDEA)

What is the Individuals with Disabilities Education Act?

The Individuals with Disabilities Education Act (IDEA) is one of several federal special education laws. It covers school-aged children with particular disabilities who, because of those disabilities, need special education and related services. IDEA provides and promotes funding for state and local educational agencies to meet their obligations for students impacted with learning, cognitive, or physical disabilities. In Texas, most laws, regulations, and procedures relating to IDEA are administered by the Texas Education Agency (TEA).

IDEA also covers infants and toddlers who need early intervention services because they are diagnosed as delayed in cognitive, physical, communication, social, emotional, or adaptive development. It also covers infants and toddlers who have a high probability of being diagnosed with developmental delay.

IDEA also covers certain 3- to 5-year-old toddlers. These children are covered if they are diagnosed as delayed in physical, cognitive, communication, social, emotional, or adaptive development, and if that delay results in the toddler's need for special education and related services.

Phrases To Know and Understand

FAPE: Free, Appropriate, Public Education

Under IDEA, your child is entitled to a *free* and *appropriate public education*. Each word plays a significant role in the special education process.

Free

A child with a disability is entitled to a free education and free related services. These services may include transportation, hearing devices, adaptive technology, and speech or occupational therapy. The school must provide the resources necessary to implement the services deemed appropriate for your child.

Appropriate

Your child's education must be appropriate to your child. Every child is different and learns in a different way. Your school should assess your child's needs and determine the appropriate education plan, textbooks, adaptations, and services particular to your child. An appropriate education should have a child ultimately mastering educational and developmental goals instead of just making progress toward the goals. A school does not have to provide the best education; only an appropriate one.

A school must first consider placing your child in a general education classroom. In a general education classroom, students should receive supplemental aids and services. This can include a special education teacher or aide and adaptations or modifications to classroom materials, textbooks, tests, or assignments.

Some children may be allowed to use a "content mastery room" to complete an assignment given by the general education teacher. Others may be taught by a special education teacher in a special education setting during a portion of the day. Some children may need to be in a special education classroom or school all day.

Public

Your child is entitled to a publicly funded education, usually through the public schools. A child may be entitled to attend a private school at public expense if the child cannot obtain an appropriate education in a public school. If you believe your child needs a private placement but the school disagrees, or if you disagree with a school's determination that your child needs a private placement, you may request a Due Process Hearing to determine whether your child can be appropriately educated in the public schools.

Education

The school must actively educate your child. There must be goals set each year, and your child's progress must be assessed on a routine basis. You and the school need to ensure that appropriate goals are set and are being reached. If there is no progress, then either the goal or the education process must change.

How Your Child is Identified and Classified

What is my role as a parent?

Depending on the type of disability, early intervention can be critical to a child's long term success. Therefore, it is important that potential disabilities be identified as soon as possible.

To receive special education and related services, your child will have to be identified with a disability. As a parent, you know your child better than anyone else. Any time before your child turns 21 (under 18, in some circumstances) you can ask that your child's school conduct tests to see if your child has a disability that requires intervention, special services, or an individualized education plan. Because school districts have a duty to locate and evaluate children who may need special education and related services, the school may ask you if it can test your child for a disability.

Services are available even for very young children, so if you suspect that your child may have a disability, you do not need to wait until the child is of school age to request testing. In Texas, children younger than age 3 may qualify for services under a program known as Early Childhood Intervention (ECI). Once the child turns 3, services from ECI can be transferred, if necessary, to special education programs.

You might not realize until school begins that your child may need special education services. You might notice poor performance in school or a change in your child's behavior. Remember that you have the right to ask the school for testing at any time. You should always put your request for testing to the school in writing.

Identifying Your Child: The FIE

IDEA requires local public school districts to identify, locate, and evaluate every child who may have a disability requiring special education services. Either a parent or the appropriate educational agency can request the evaluation. If the initial evaluation is requested by the school, the school district, or the local or state educational agency; one of the parents must consent.

Within 15 days of a written request for an evaluation, the school district must provide written notice to a parent of its proposal to conduct the evaluation or the

school district's written notice of refusal to conduct the initial evaluation. This notice is not optional regardless of the decision of the school district. The notice must contain at least the following:

1. A description of the action proposed or refused by the agency;
2. An explanation of why the agency proposes or refuses to take action;
3. A description of each evaluation procedure, assessment, record, or report the agency used as a basis for the proposed or refused action;
4. A statement that the parents of a child with a disability have protection under the procedural safeguards of IDEA;
5. Sources for parents to contact to obtain assistance in understanding the services for school-aged children;
6. A description of other options that the Individualized Education Program team considered and the reasons why those options were rejected; and
7. A description of other facts relevant to the agency's proposal or refusal.

The first test of your child is called a Full and Individual Evaluation (FIE). The school has 45 days to complete an FIE after you consent to the test. If consent is received close to the end of the school year, within 35 to 45 days of the last day of school, the school has until June 30 of that year to evaluate and prepare the written report. A similar extension applies if the student is absent from school for three or more days during the period of time the school has to conduct the initial evaluation. These evaluations are provided at the public's expense.

Your observations and concerns regarding your child's developmental, educational, physical, and social needs are an important part of your child's assessment, so share them with the evaluator. Provide copies of evaluations or reports from your child's doctors or therapists. The school may ask that you sign a release or permission form that will allow it to exchange information with your child's doctors and specialists.

The FIE should determine all of your child's individual needs. These include not just educational needs, but needs for related services such as transportation, occupational therapy and physical therapy, the need for an aide, etc.

If you disagree with the assessment, you have the right to ask for an Independent Educational Evaluation (IEE). Your child will be evaluated at the school's expense by a private party who is not related to the school district. The evaluator will give the IEE results to you and the school. The school must then consider

the recommendations from the IEE. The school must also consider the recommendations from an evaluation that you pay for yourself.

A school can refuse to perform an FIE if it does not suspect a disability. If a school decides not to evaluate your child and you do not agree with that decision, you have due process rights and may request a Due Process Hearing through the Texas Education Agency.

A school district must either pay for the IEE or request a due process hearing. As a result, a school district cannot simply refuse or ignore your request for an independent evaluation.

ARD: Admission, Review and Dismissal

Once your child qualifies for special education and related services, you will be asked to attend an ARD—an Admission, Review, and Dismissal meeting. The purpose of an ARD is to develop plans for your child's education. The ARD must be conducted within 30 days of the FIE.

There are many rules and regulations governing ARDs. This pamphlet is designed to give you basic information about those rules and regulations.

What is the ARD process?

An ARD involves you as the child's parent and several school personnel such as your child's teachers, a school administrator, a special education representative, and a person who can interpret evaluations of your child. It can also be attended by anyone else who has knowledge or special expertise regarding the child. The school must hold an ARD at least once a year. Both you and the school can request an ARD at any time. There are often ARDs throughout the year so you and the school can assess your child's progress.

You have the right to receive written notice of the ARD five school days before the meeting. The notice should list the topics to be discussed. If you have something to discuss at the ARD, inform the school about it in writing a reasonable amount of time before the ARD.

If you want to attend but cannot because of your schedule, give the school a written request to reschedule the ARD. If you do not, the school can hold the ARD

meeting without you. If you wish to bring a parent advocate or lawyer with you, inform the school in writing. If you do not inform the school, the school may postpone the meeting so that its lawyer can also attend.

The ARD attendees will discuss the child, the child's educational strengths and weaknesses, the disability, and the need for services. They will then discuss your child's placement in the general or special education classroom, along with appropriate adaptations, modifications, and related services for your child.

During the ARD, voice your concerns or observations regarding your child's needs or lack of progress. Discuss evaluations of your child by doctors or therapists. If you do not understand something or disagree with something, say so. If you do not, no one will know and the issue cannot be addressed.

At the end of the ARD, you will be asked if you agree with what was discussed and the plans the school proposed. Ask any questions and raise any concerns that you might have. By signing the ARD documents, you are agreeing to the plan that defines your child's education.

If you do not agree with something, you can disagree in writing with the disputed portions. Check "I Agree" to the undisputed portions on the ARD paperwork so those portions can be implemented immediately. If you disagree with something, you have the right to have another ARD meeting within 10 school days to discuss and try to resolve the disputes. If you still cannot agree, the school can implement the entirety of its proposed plans after giving you five school days notice. You can challenge this by asking for a Due Process Hearing. The school will then continue educating your child under the old plans until that hearing is concluded.

IEP: Individual Education Plan

The ARD Committee develops a written Individual Education Plan (IEP) for each child. This is the plan for how to ensure that the child receives the benefits of a public education. The plan lists the special education and related services the child needs, sets goals, and states how progress on the goals will be assessed. The plan will also list any accommodations your child will require and the special education services your child will receive. The Texas Education Agency provides a sample IEP form to assist with preparation for and guidance through the meeting.

An IEP must be in place before each school year starts. This usually means that there will be an ARD in the spring semester of the prior school year. Refer to this IEP throughout the year to ensure the school is following it. The school must give you periodic reports on how your child is progressing on the IEP. You will usually receive these reports at the same time grades are reported.

The school must review the IEP at least once a year unless everyone agrees it is not necessary. Your child should be making progress toward mastering the majority of the goals. If your child is not making this progress, you and the school should re-evaluate whether the education is appropriate to meet your child's individual needs.

BIP: Behavior Intervention Plan

An IEP may also contain a Behavior Intervention Plan (BIP). The BIP will include a list of goals, progress points, and modifications about your child's behavior in the classroom. The BIP determines how the school will handle your child's behavior and discipline matters, which will most likely differ from the other children in the classroom. A BIP is just as individually tailored as an IEP.

As with the IEP, be sure to monitor carefully whether the BIP is being implemented by the school. In addition, monitor your child's discipline throughout the year. A BIP that sounds good on paper could be unworkable in the classroom. If that happens, request an ARD and have the BIP modified. The teacher is bound by the BIP, so simply discussing your concerns will not ultimately change the situation. The BIP must be followed until it is formally changed in writing.

Informed Consent

Before the school can change your child's IEP, BIP, or other resources or education plan, it has to inform you of the changes and obtain your consent to the changes. This is called informed consent. Generally, changes can only be implemented after a parent is informed of the changes and consents to the changes in writing.

Changes to your child's placement, special education, IEP, and BIP must be made in writing. If the changes are not in writing, either in an agreement or a decision following an ARD meeting, the school will not have to follow them.

Dispute Resolution

There may be times when, despite your best efforts, you simply do not believe your child's needs are being met. If this occurs, you have several options.

Informal discussion. Consider an informal meeting with the teacher, therapist, principal, special education director, other district administrators, or an advocate (such as a lawyer or parent advocate). You can discuss problems and see if you can reach an amicable solution. If you do reach such a solution, agree to the changes or resolution in writing. If the changes affect the IEP or BIP currently in place, be sure to hold an ARD to have the paperwork reflect the changes made.

Request an ARD. If talking directly with the teacher or others does not solve the problem, request an ARD to attempt to resolve any disputes.

Mediation. Mediation is not required under the law, but it often helps to resolve problems. Mediation is when parties work together in an informal setting in an attempt to reach an agreed solution. You may contact the Texas Education Agency and ask for an unbiased, independent mediator who knows special education laws. The mediator does not make decisions, but instead helps the parties reach their own agreements. Attempts to settle in mediation cannot be used in a later hearing.

File a TEA complaint. You may file a formal Special Education Complaint with the TEA. Visit the TEA website tea.texas.gov and search for "Special Education Complaint Forms." The deadline to file a complaint is one year after the violation. You must give a copy of the complaint to the school district or public agency involved in your child's education. The TEA will review the complaint and may conduct an investigation. It must issue a decision within 60 days after the complaint is filed. The 60-day timeline begins to run on the next business day after the day the TEA receives the complaint and all requirements for filing the complaint have been met.

Request a Due Process Hearing. You may also file a request for a Due Process Hearing with the TEA. IDEA requires that you send a copy of the request to the school district at the same time that you send it to the TEA. Once you file a request, the TEA will contact you within five business days with the name of the hearing officer assigned to your case.

A school district has 15 days after receiving notice of the hearing request to schedule a "resolution meeting" with you. If the district cannot resolve the matter

within 30 days of the hearing request, the hearing process must move forward. A matter must be fully resolved within 45 days following the 30-day resolution period unless the hearing officer extends that deadline.

The Due Process Hearing is much like a courtroom proceeding. You have the right to have the district give you information about your child's case before the hearing, but the district can charge for copying. At the hearing, there are opening statements, a presentation of evidence through testimony and introduction of exhibits, and closing statements. There is usually a court reporter and the hearing officer usually follows the Texas Rules of Evidence and Texas Rules of Civil Procedure.

The hearing officer must make a written decision addressing each disputed issue. If you win, the school may be required to pay your legal fees. But if the hearing officer finds that your request was (or became) frivolous, unreasonable, or without foundation, you may have to pay the school's legal fees.

If you disagree with the hearing officer's ruling, you have 90 days to appeal the decision to a state or federal district court.

Resources

Special Education in Texas Resources

tea.texas.gov/special.ed

This page of the Texas Education Agency website provides family resources, webinars, dispute resolution guides, and other information.

Special Education Rules and Regulations

tea.texas.gov

The TEA website has a Special Education Rules and Regulations page that lists federal and state regulations, including Commissioner's Rules, and other guidance.

Wrights Law

wrightslaw.com

Pete and Pam Wright are lawyers who routinely practice before the U.S. Supreme Court on behalf of special education students. They have authored several "How-To" manuals and have prepared several forms for parents to use as a guide when writing letters, attending ARDs, reviewing and understanding IEPs and BIPs, etc. This site links to many other parent advocacy sites.

HOUSING LAWS

Under federal and state law, a landlord must accommodate a person's disability by changing or modifying a rule or policy if necessary to allow a disabled person equal opportunity to enjoy his or her housing. The requested accommodation must be reasonable and necessary because of the person's disability. Whether a request is reasonable depends primarily on whether it will cost the landlord money or significantly alter the nature of the administration of the housing provided by the landlord.

Your child may qualify for a reasonable accommodation if he or she has a physical or mental impairment that substantially limits one or more of his or her major life activities.

What are some common reasonable accommodations?

- Providing enough handicapped parking spaces
- Allowing a person with a disability to have a service animal even if the landlord has a “no pets” policy
- Allowing a disabled person who was living in a hospital to submit other types of references since that person may not have other landlord references
- Allowing a person with a disability to pay rent by mail rather than going to the office in person

What can I do if my adult child needs a reasonable accommodation in order to apply for housing?

A landlord must grant an accommodation if necessary to allow for an individual to apply for housing unless it costs too much or will result in a significant change in the housing program. For example, if an individual needs assistance in filling out the application or needs the application mailed to his or her home instead of going to the office to pick it up, the individual needs to disclose the disability and ask for the accommodation.

If my adult child did not have a disability when he or she moved in, is he or she entitled to a reasonable accommodation if he or she now has a disability?

Yes. An individual is entitled to a reasonable accommodation the moment one is needed. It does not matter that the individual did not have a disability when initially moving in.

If my adult child had a disability when applying for housing but did not notify the landlord, did he or she give up the right to ask for a reasonable accommodation later?

No. An individual is entitled to request a reasonable accommodation whenever one is needed.

How should a reasonable accommodation be requested?

A request for a reasonable accommodation may be made orally or in writing. An individual may wish to first make the request orally and follow up with a written request if the landlord does not act promptly on the request. A copy of the request for a reasonable accommodation should be retained so there is proof that an accommodation was requested. Be sure the following is included in the written request:

- List the specific accommodation needed and explain why the accommodation is needed;
- Give the name, phone number, and address at which the landlord may contact your adult child to verify the need for your accommodation; and
- Sign and date the request.

Does my adult child have to prove that a reasonable accommodation is needed?

Yes, if the landlord requests that information. A landlord has the right to ask for proof that the individual has a disability and that an accommodation is needed. The proof necessary will depend on the disability. The most common way to show the need for the requested accommodation is a letter from a medical professional stating that the accommodation is needed.

Make sure that the landlord is provided with documentation that shows the requested accommodation is necessary. If the landlord refuses to grant the requested accommodation even after proof of the need has been submitted, then contact an attorney or file a discrimination complaint with the Texas Workforce Commission's Civil Rights Division or the U.S. Department of Housing and Urban Development (HUD). Learn more about housing laws and discrimination at twc.texas.gov/civilrights. More information and a HUD online complaint form can be found by going to hud.gov and searching "discrimination."

What if a reasonable accommodation is requested but the landlord offers to provide a different accommodation?

Decide whether to accept the alternative accommodation offered by your landlord. Under federal and Texas law, a landlord must make an effort to provide the accommodation requested. However, if a landlord can still accommodate the needs with an alternative accommodation and it will work just the same, then the alternative accommodation may suffice. If the landlord's proposed accommodation will not work, explain to the landlord why it will not work. If the landlord still believes that it will work, the individual has the following choices:

1. Agree to the accommodation;
2. Give the landlord a letter from a doctor explaining why it will not work;
3. Contact an attorney to help; or
4. File a housing discrimination complaint with HUD the Texas Workforce Commission's Civil Rights Division at (twc.texas.gov/civilrights) or HUD (hud.gov).

Is there a limit on the number of reasonable accommodations an individual can request?

No. An individual can request any number of reasonable accommodations so long as they are necessary to allow the individual to enjoy the housing in the same manner as other tenants.

Who pays for a reasonable accommodation?

Reasonable modifications are usually made at the resident's expense. However, there are resources available for helping fund building modification. Additionally, if you live in federally assisted housing, the housing provider may be required to pay for the modification if it does not amount to an undue financial and administrative burden.

What if the landlord wants to evict my adult child because of a request for an accommodation?

An individual has the legal right to a reasonable accommodation under federal and Texas law. Therefore, if a landlord wants to evict your adult child because he or she exercised their legal right, he or she will have a defense to the eviction. Contact

an attorney if you believe your adult child's legal rights are being violated, or file a complaint with TWC's Civil Rights Division or HUD.

What if my adult child violated the lease but thinks he or she would not be in violation if the landlord provides a reasonable accommodation?

Immediately request a reasonable accommodation in writing.

How do you recognize Housing Discrimination?

Under the Fair Housing Act and Texas Fair Housing Act, it is against the law for a landlord to do any of the following as a result of an individual's disability:

- Refuse to rent or sell an individual housing
- State that housing is unavailable when it is in fact available
- Show an individual apartment or homes only in certain neighborhoods
- Advertise housing only to preferred groups of people
- Refuse to provide an individual with information regarding mortgage loans, denies a mortgage loan, or imposes different terms or conditions on a mortgage loan
- Deny property insurance
- Conduct property appraisals in a discriminatory manner
- Refuse to make certain modifications or accommodations for people with a mental or physical disability
- Fail to design and construct housing in an accessible manner
- Harass, coerce, intimidate, or interfere with an individual's fair housing rights
- Harass, coerce, intimidate, or interfere with an individual because that individual assisted others in exercising their Fair Housing Rights

What should my adult child do if he or she experience housing discrimination?

First, file a discrimination complaint with the Texas Workforce Commission Civil Rights Division. View how to submit a housing discrimination complaint at twc.texas.gov/civilrights. There are several ways to file a complaint alleging housing discrimination:

1. The preferred method for submitting a housing discrimination complaint is by filling out the TWC's Housing Discrimination Inquiry

Form located on its website.

2. Submit the complaint in person or mail it to the division's office located at 101 E. 15th Street, Guadalupe CRD in Austin, Texas. 78778-0001.
3. Email the complaint to HousingComplaint@twc.state.tx.us
4. Fax the complaint to 512-463-8465

Complaints cannot be provided over the telephone.

An investigator will then be assigned to the complaint. The investigator will explain what is required to file a complaint, how the complaint will be investigated, and assist in preparation of the complaint.

Also, an individual may file a complaint with the U.S. Department of Housing and Urban Development (HUD). You may file a complaint online at hud.gov/program_offices/fair_housing_equal_opp/online-complaint or call the Housing Discrimination Hotline at 800-669-9777. You may also contact HUD's Office of Fair Housing and Equal Opportunity Region VI Office at 801 Cherry St., Unit #45, Suite 2500, Fort Worth, Texas 76102.

DISABILITIES LAW AND PROTECTION IN THE WORKPLACE

Are there resources for people with disabilities who seek pre-employment training and employment?

The Texas Workforce Commission provides vocational rehabilitation services for people with physical or cognitive disabilities, including blindness or visual impairment. To receive vocational rehabilitation, a person must (1) have a disability which results in substantial barriers to employment; (2) require services to prepare for, obtain, retain, or advance in employment; and (3) be able to obtain, retain, or advance in employment as a result of the services. Disabilities served include hearing impairments, physical disabilities, and intellectual, learning, and developmental disabilities. For more information, visit the Texas Workforce Commission website at twc.texas.gov and search “vocational rehabilitation.”

Do discrimination laws protect my adult child if he or she receives Social Security disability benefits?

Your adult child may be protected, but it is not automatic because the definition of “disability” is different under the Social Security Administration and the Americans with Disabilities Act.

What is the purpose and scope of the Americans with Disabilities Act?

The purpose of the Americans with Disabilities Act (ADA) is to dispense with misconceptions and stereotypes regarding individuals with disabilities and to prevent disability discrimination in employment. The U.S. Equal Employment Opportunity Commission (EEOC) is the federal agency responsible for enforcing the ADA and for establishing the regulations regarding the scope of protections offered by the Act. For more information, visit the EEOC’s website at eoc.gov.

Title I of the ADA applies to private employers that employ 15 or more employees for 20 or more calendar weeks in the current or preceding calendar year. The ADA prohibits discrimination against a qualified individual with a disability and offers protection for both employees and job applicants.

What is a “disability” under the ADA?

An individual is “disabled” under the ADA if he or she: (1) has a physical or mental impairment that substantially limits one or more major life activities; (2) has a record of such impairment; or (3) is regarded as having such an impairment.

ADAAA Expanded Definition of “Disability”

Under the Americans with Disabilities Act Amendments Act (ADAAA), the legal definition of “disability” is more broadly defined. The ADAAA expanded the list of major life activities and added a category to include “major bodily functions,” specifically: the immune system, digestive system, cell growth, neurological and brain functions, respiratory and circulatory systems, endocrine, and reproductive functions. The regulations also added hemic, lymphatic, musculoskeletal, special sense organs and skin, genitourinary, and cardiovascular to bodily functions. In this same vein of broadening the definition of “disability” the regulations also call for a “common sense approach” to determining protection under this statute. The regulations also provide even more specific examples of impairments that will consistently meet the definition of a disability.

What is a “major life activity”?

Major life activities are those activities that the average person in the general population can perform with little or no difficulty. Major life activities include, but are not limited to, caring for oneself, performing manual tasks, interacting with others, speaking, seeing, hearing, learning, sleeping, walking, standing, lifting, bending, learning, reading, concentrating, thinking, communicating, working, breathing, eating, and reproduction. In some instances, “working” can be considered a major life activity, but only where the individual is significantly restricted in a class of jobs or broad range of jobs in various classes as compared to the average person having comparable training, skills, and abilities.

What does it mean to be “substantially limited” under the ADA?

Determining whether an individual is “substantially limited” in a major life activity requires a case-by-case assessment of the individual’s condition, including: (1) the nature and severity of the impairment; (2) its duration or expected duration; and (3) its permanent or expected permanent or long-term impact. This determination

is made by comparing the individual to the average person in the general population. Therefore, occasional or intermittent occurrences of an impairment are often not severe and permanent enough to be considered substantially limiting under the ADA.

However, impairments that are episodic or in remission are nonetheless considered disabilities so long as they would substantially limit a major life activity when active. How are “mitigating measures” considered? In determining whether an individual is substantially limited in a major life activity under the new regulations, the ameliorative effects of mitigating measures (with the sole exception of eye glasses) are not to be considered in weighing a disability. Therefore, an individual’s use of medication, and other medical equipment or supplies will not preclude an individual claiming impairment, and thus the individual may still meet the substantially limited requirement in order to be “disabled” under the ADA.

Who is entitled to a reasonable accommodation under the ADA?

Under the ADA, a covered employer is required to provide reasonable accommodations to the known physical or mental limitations of an otherwise qualified individual with a disability, unless the employer can demonstrate that the accommodation would impose an undue hardship on the operation of its business. However, persons “regarded as disabled” are not entitled to a reasonable accommodation. Moreover, while persons associated with persons who are disabled may be entitled to protection from discrimination (such as a family member of a disabled person); they are not entitled to an accommodation.

Who is a “qualified individual with a disability”?

An individual is a “qualified individual with a disability” when that individual meets legitimate skill, experience, education, or other requirements of an employment position and can perform, with or without a reasonable accommodation, the essential functions of the position held or desired. Essential functions are those functions that are fundamental to the position, not marginal. A function may be essential if: (1) the reason the position exists is to perform that function; (2) there are a limited number of employees available to perform the function; and/or (3) the incumbent in the position is hired based on specialized expertise relating to such function. In determining whether a function is essential, several factors are considered, including: (1) the employer’s judgment as to which functions are essential; (2) written job descriptions for the position; (3) the amount of time spent on the job performing the func-

tion; (4) the consequences of not requiring an employee to perform the function; (5) the terms of any collective bargaining agreement with a union (where applicable); and (6) the past and current work experience of employees in the same position. This determination must be made on a case-by-case basis.

How does my adult child request a reasonable accommodation?

There are no magic words necessary to request a reasonable accommodation. Rather, the employee need only provide sufficient information to put the employer on notice that he or she needs an accommodation based upon a covered disability. Once the employee has requested an accommodation, the “interactive process” between the employer and employee begins. This process is an interactive and ongoing discussion between the employer and employee to determine whether the employee needs an accommodation and, if so, what accommodation is reasonable and appropriate under the circumstances. Throughout this process, the employee and, where applicable, the employee’s doctor, will inform the employer of the nature and limitations of the employee’s disability and suggest possible accommodations to enable the employee to perform the essential functions of the position.

What are some examples of reasonable accommodations?

Reasonable accommodations must be tailored to the specific individual in need of an accommodation. Indeed, there may be as many possible accommodations as there are individuals requesting them. Examples of such accommodations include: (1) job restructuring; (2) providing time off of work or a modified schedule (for treatment or other medical needs); (3) simple physical changes to the workplace; (4) modifying a workplace policy; (5) reassigning non-essential functions to others; and (6) reassigning the employee to a different (vacant) position. Importantly, the accommodation selected by the employer need not be the one the employee selects or prefers, as long as it effectively accommodates the employee. But an employer is not required to provide an accommodation that results in an undue hardship.

Your adult child does not have to pay for the accommodation if one is needed. In addition, an employer cannot pay your adult child less because a reasonable accommodation is needed.

Can an employer request medical certifications and other documentation in response to an accommodation request?

Yes. An employer may request reasonable medical documentation, including, but not limited to, documents substantiating that the employee: (1) has a covered disability under the ADA; and (2) needs a reasonable accommodation. The employer may not, however, seek the employee's entire medical file or any documents that do not otherwise relate to the employee's reasonable accommodation request. Documentation will generally be considered sufficient if: (1) it is offered by a health care professional with the necessary expertise; (2) it describes the nature, severity, and duration of the impairment; (3) it describes the activities limited by the impairment; (4) it explains the extent to which the impairment limits the employee's functional ability; and (5) it substantiates why the requested accommodation is needed. An employer may not use such requests as a means of retaliating against an employee who has requested an accommodation under the ADA. If the employee fails to provide sufficient documentation, the employer can request the missing information. The employer, however, should explain why the previous documentation was insufficient and give a reasonable period of time for the employee to provide the additional information needed. The employer can also ask the employee for permission to consult directly with the employee's physician (with a release from the employee) or even request an examination by an employer-selected doctor, as long as the examination is limited to determining whether the employee is disabled under the ADA, the scope of any functional limitations, and any possible accommodations needed by the employee. All costs related to an employer-requested medical examination must be paid by the employer.

What is an "undue hardship"?

An "undue hardship" is an action that requires "significant difficulty or expense." Factors considered in determining whether an accommodation constitutes an undue hardship include, but are not limited to: (1) the nature and cost of the accommodation at issue; (2) the overall financial resources of the employer's facility, number of people employed at the facility, the effect on the expenses and resources of the facility, or the impact otherwise of such accommodation on the operation of the facility; (3) the overall financial resources and overall size of the business of the employer; and (4) the type of operation engaged in by the employer, including the composition, structure, and functions of the workforce. If costs cause an undue hardship, an employer also must consider whether funding for an accommodation is available from an outside source and if the cost of providing the accommodation can be offset by state or

federal tax credits or deductions. An employer also must provide the employee with a disability the opportunity to provide the accommodation or pay for the portion of the accommodation that causes an undue hardship.

Are there any limitations on pre-employment medical examinations or inquiries?

Yes. An employer cannot inquire into whether an applicant has a disability before the potential employer has made a conditional offer of employment. For example, an employer cannot inquire as to whether the applicant has or had a disability. But the employer may inquire as to whether the applicant can perform job-related functions. Once a conditional offer of employment has been made, an employer may conduct medical exams, but only if: (1) all applicants for the same job category are required to take such examinations; and (2) any examination criteria that screens out individuals is based on medical standards that are job-related and consistent with business necessity (and a reasonable accommodation will not allow the individual to perform the essential functions of the job).

Employers who are federal agencies or federal government contractors/subcontractors may ask a person who is applying for a position to self-identify as a person with a disability. This is because these entities are required to maintain affirmative action plans, which require them to report certain numbers to the Department of Labor and other government agencies.

An employer need not give your adult child preference because he or she has a disability. An employer is obliged to select the most qualified applicant for a position; however the decision must be based on reasons that are not related to a disability.

Are there any limitations on medical examinations or inquiries of employees?

Yes. An employer cannot conduct medical examinations or inquire as to whether an existing employee has a disability, unless the examination and/or inquiry is *job-related and consistent with business necessity*. This does not prohibit an employer from seeking medical examinations or making inquiries with respect to whether an employee can perform the essential functions of the position.

Also, if an employer asks about family medical history or conducts genetic tests, the employer may have violated other laws besides the ADA, such as the Genetic Information Nondiscrimination Act (GINA).

If a person with a disability is not hired because of the results of such a medical exam, or as the result of his/her answers to questions about a disability, the employer must show that the person (1) would probably not be able to perform the job, even if they were given a reasonable accommodation, or (2) would pose a “direct threat” in the workplace (i.e. a significant risk of substantial harm to the health or safety of the individual or others) that cannot be eliminated or reduced below the level of a “direct threat” by giving a reasonable accommodation.

What does it mean to be “regarded as” disabled, or have a “record of” a disability?

The ADA also offers protection to those “regarded as” having or with a “record of” a disability. Thus, an employer may not treat an individual differently based on the individual’s “history” or “record of” an impairment that substantially limits one or more major life activities. Further, an individual may come within the “regarded as” protection of the ADA if an employer either: (1) mistakenly believes an individual has an impairment that substantially limits one or more major life activities; or (2) believes that an actual, non-limiting impairment substantially limits one or more major life activities.

Is extended leave a reasonable accommodation under ADA?

The EEOC takes the position that flexible leave policies should be considered as a possible reasonable accommodation where appropriate and that while any additional leave need not be a paid leave, employers should consider allowing the use of accrued leave or leave without pay, where it will not cause an undue hardship. Unlike the Family and Medical Leave Act, there is no annual limit for leave (as a reasonable accommodation) under the ADA. Still, some courts have held that lengthy, indefinite periods of time may constitute an undue hardship on the employer. Thus, while additional leave may be available as a reasonable accommodation, the requested time period must be reasonable under the circumstances.

Are lawsuits the best answer to a possible employment discrimination claim?

Not necessarily. In many cases, lawsuits can be costly and time-consuming endeavors that may not result in addressing the alleged discrimination in the best possible way. It is therefore advisable to take steps that reduce an employee’s exposure to potential discrimination. If the employee nevertheless experiences discrimination, he or she should attempt to resolve the matter internally with the employer. If these steps fail, then the employee should consult a lawyer and may consider pursuing legal action.

What steps can my adult child take to reduce or remove the chance of discrimination in employment?

There are several steps that your adult child can take to reduce or remove the possibility of discrimination in the workplace. These steps include: (1) not volunteering that he or she has or had a disability, unless necessary, such as when it directly impacts his or her ability to perform the job (and even then, only to those who have a need to know); (2) focusing on your adult child's ability to perform the essential functions of the position, rather than any limitations that he or she may have; (3) always being aware of your adult child's employment rights and the scope of permissible medical examinations and inquiries (ask for clarification if it appears that the employer has requested more than is permissible by law); and (4) applying for positions and promotions that your adult child is qualified to perform.

What initial steps can my adult child take in response to possible workplace discrimination?

At the outset of any employment relationship, you should familiarize yourself with the employer's equal employment opportunity policies, including any complaint-reporting procedure (usually contained in the employee handbook). If you believe your adult child has been discriminated against and/or the subject of retaliation for asserting his or her rights under the ADA or otherwise, your adult child should promptly follow the employer's internal procedure and report the conduct. The complaint reporting procedure may require reporting the conduct to a supervisor, member of management, or a member of the human resources department.

Once reported, your adult child should give the employer a reasonable amount of time to investigate and address the matter. Using this procedure may resolve the matter promptly and allow your adult child to stay focused on his or her job, rather than focusing on potential litigation and dealing with a likely adversarial relationship with the employer.

In some instances, failure to report the conduct internally can also adversely impact any future lawsuit. For example, under a number of state and federal employment laws, an employer can argue that it is not liable for the allegedly discriminatory conduct of its employees where a complaining employee failed to put the employer on notice of the conduct via the complaint-reporting procedure and, thereby, prevented the employer from investigating – and possibly resolving – the matter.

It is also important to note that a spouse or parent who assists with the adult child's care is also protected against discrimination and retaliation in the workplace. For example, an employer cannot discriminate against a family member that carries the medical insurance for fear of costly medical bills due to a disability.

The law also protects against disability-based harassment if the harassment rises to a requisite level.

How are legal rights enforced under the ADA?

In Texas, an individual will generally have 180 days (or a maximum of 300 days because Texas is a dual-filing state) from the alleged discriminatory incident or "violation" to file a Charge of Discrimination with the EEOC, which is a mandatory prerequisite to bringing a private civil action under the ADA. Failure to satisfy this administrative remedy can bar any further legal action by the person claiming discrimination. Once filed, the EEOC will process the charge and conduct an investigation. Thereafter, the EEOC will issue its determination and articulate whether it believes that there is "cause" or "no cause" to believe that discrimination took place. The EEOC will then issue a Notice of Right to Sue letter, which will allow the individual (or "charging party") to commence litigation. The individual can also request a Notice of Right to Sue before completion of the administrative process (without waiting on a determination). In any event, an individual will have 90 days from receipt of the Notice of Right to Sue to file a lawsuit.

If a Charge of Discrimination is filed with a state agency, such as the Texas Workforce Commission, the deadline to file a lawsuit is within two years of the day the charge is filed or 60 days from the date the right-to-sue letter is received, whichever comes first. Under state law however, an individual does not need to wait until the right-to-sue notice is received before filing suit. In fact, under state law, an individual must file any lawsuit before the two-year deadline regardless of whether the right-to-sue letter is received.

Employees of the U.S. government have a shorter period of 45 days to make a complaint of discrimination.

FINANCIAL PLANNING

Why should I plan for my child's financial future?

Planning for the long-term financial security of a special needs child can be very complex; however, there are many tools available to assist you in ensuring your child will be taken care of financially throughout their life. Careful planning is required when considering your child's financial future.

Should I consult particular types of professionals?

In addition to consulting a financial planner, you should consult a lawyer and an accountant. Special needs financial planning will require consideration of several aspects of estate planning and tax consequences. If your estate is valued at over \$1 million, you should consider working with a lawyer who is also familiar with special needs trusts and estate tax planning. You should also consult an accountant to determine any additional impact on your financial plan.

What should I consider when planning for the financial future of my child?

There are several financial considerations that families with a special needs child should think about to help them prepare for the child's future. A Letter of Intent is an informal letter that a parent or caregiver writes that emphasizes a day in the life of their child. It should address several items such as their likes and dislikes and what the parent's hopes and expectations are for them. It is a great tool to use in conjunction with an estate plan. The Letter of Intent should consider the following:

Family History

Include information about your family history such as where and when you were born, raised, married and other special or important information about siblings, grandparents, and other relatives, special friends. Also, include a description of your special child's birth, when, where, your feelings, etc.

General Overview

Include a brief overview of your child's life to date and your general feelings about the future.

Education

Include a summary of educational experiences and desires for future education (i.e., regular classes, special classes, special schools, related services, mainstreaming, extracurricular activities and recreation); types of educational emphasis, (i.e., vocational, academic, total communication, etc.); and names of specific programs, schools, teachers, and related services providers you desire for your child.

Employment

Include types of work your child may enjoy (i.e., open employment with supervision, sheltered workshop, activity center, etc.); and companies that you are aware of that may be of interest to your child that provides employment in the community.

Residential Environment

Include your desires for your child to live with relatives or friends or other people. Identify the specific people; and, if those people pass away or cannot take your child in, your other options (i.e., a group home or institution in your community). Describe the size of your child's preferred living arrangement – single room, small home, etc.

Social Environment

Mention types of social activities your child enjoys (i.e., sports, dances, movies, etc.); should they have spending money and how they should spend it; favorite foods and eating habits; and whether your child takes or enjoys vacations.

Religious Environment

Specify your family's religion; local place of worship; local clergy that may be familiar with your family; and whether there has been religious education that interests your child.

Medical Care

List current doctors, therapists, clinics, hospitals, including how frequently your special needs child visits and for what purpose; current medications, how they are given, for what purpose; and describe medications that have not worked in the past.

Behavior Management

Describe any current behavior management program that is being used, as well as other behavior management programs that have not worked.

Final Arrangements

Include desires for your child's funeral arrangements, including prearrangements you have made (if any), choice of funeral home, cremation or burial, cemetery, monument, religious service and clergy.

Other Information

You may include any other information you feel will help the person caring for your child provide the best possible care.

Once you write the letter, it should be signed and dated. You should re-evaluate the Letter of Intent each year and change it according to the changes in your circumstances. The Letter of Intent may be used effectively in conjunction with estate planning tools. It is common to share your Letter of Intent with a lawyer and financial planner and store it with other important legal documents. See the *Estate Planning* section for more information.

Should I obtain insurance to help plan for the future of my special needs child?

You may consider several forms of insurance, including life insurance, to help plan for the future of your special needs child. You should first examine your overall current financial situation in order to evaluate how much money your child will need in order to maintain stability in the future or in the event that something happens to you or the primary caregiver. You should also consider specifically designating the proceeds of the policy to be allocated to the special needs of your child. Your individual needs and the needs of your child will help determine which type of insurance is best for you. Insurance policies often contain limitations, exclusions, reductions of benefits and terms for keeping them in force. You should consult an insurance agent that specializes in helping families with special needs children. Be sure to ask for full details regarding the policy, terms, and its costs. See the *Estate Planning* section for more information.

What are the different types of life insurance to consider in funding a Special Needs Trust and what are the advantages and disadvantages of each?

Life insurance is a great financial planning tool. Your need for life insurance to plan for the financial future of your special needs child will depend on your personal circumstances, including your current income, expenses, savings and your family's goals.

It is important to know that life insurance comes in many forms, and not all policies are created equal. The type of insurance that is best for you will depend on your circumstances. You should consult a financial planner to assist with understanding insurance policies and how they can impact your estate. See the *Estate Planning* section for more information.

In addition, you should consider insurance as a way to fund a Special Needs Trust. There are several types of life insurance that are available to fund a Special Needs Trust:

Term Life Insurance

Term life insurance offers protection that insures the policyholder for a defined period of time, usually anywhere from 1 to 30 years, during which time premiums are paid. A term policy pays a benefit if the policyholder dies during the period covered by the policy. After that period ends, the policyholder can choose to continue to pay for the policy or end coverage. If the policyholder stops paying premiums, the insurance stops. Term life insurance policies do not build cash value. Generally, term life is the most inexpensive way to insure a parent or caregiver's life and is therefore a favored choice for short-term needs. The premiums for term policies typically increase each year as the insured gets older or are level for a specified number of years. However, a major concern with term life insurance is the possibility that the policyholder will outlive the term of the policy, leaving a trust short on necessary funds. If you already have a term policy and need to fund a Special Needs Trust, you could consider converting your term policy to a whole life policy with the same insurer.

Whole Life Insurance

Whole life insurance lasts for the policyholder's entire lifetime and provides both death benefit protection and cash value. Part of the premium paid by the policyholder

goes into a cash account which accumulates over time. The cash value tends to accumulate at a higher rate when the policyholder is younger and lessens as he or she ages. In addition, many whole life insurance policies pay dividends, which provide an additional value. Policyholders may withdraw money from their whole life policy but will be charged a fee or, in the case of a loan, the policyholder will have to pay back the borrowed amount with interest. Whole life insurance is advantageous because it could provide funds for a Special Needs Trust no matter when the parent or caregiver dies.

Universal Life Insurance

Universal life insurance is interest-sensitive and permits the policyholder to adjust death benefits and premium payments to fit any change of circumstances. As a general rule, premiums can be credited to an accumulation fund from which premium costs are deducted and to which interest is credited. Universal life insurance also builds cash value and the policyholder may withdraw it or borrow against it at any time.

Variable Life Insurance

With a variable life insurance policy, the cash value is tied to the performance of financial markets. The policyholder has the advantage of deciding among several investment options to invest the net premiums. While monies invested in the investment options have potential for growth, the disadvantage is that the policy needs a lengthier timeframe in order to endure unpredictability in the financial markets and policyholders should be ready to see fluctuations in cash value and premium payments. Variable life insurance may be risky because you may make or lose money depending upon the performance of the market and the investment options you select.

Survivorship Life Insurance

Survivorship life insurance is a special type of whole life policy that typically insures both parents (the mother and father) in one policy. This type of policy is also commonly known as a second-to-die policy. The policy only pays out upon the death of the second spouse. It is generally more favorable because it is less expensive than buying two separate life insurance policies for the parents or caregivers. The disadvantage is that after the death of the first spouse, the surviving spouse will have to consider whether he or she can continue the premium payments.

What other tools should I consider in my financial planning?

In addition to life insurance, it is important in caring for a special needs child to consider some legal options in conjunction with your financial planning activities. You will also want to consider other tools such as guardianship, powers of attorney (durable and medical), a living will, and a Special Needs Trust, in addition to your last will and testament that will dispose of your property. See the *Estate Planning* section for more information.

Is there other financial assistance available other than government benefits for my special needs child?

Some agencies have financial assistance specifically available to help defray costs of unique supplies, equipment, treatments, and procedures a special needs child may need. Consult state and federal government programs, community resources, private foundations, employee assistance programs and other special education resources for help in answering financial assistance questions.

What if my child has assets in his or her name?

Some of the most common mistakes in financial planning result from assets being held in a child's name. In some instances, assets held in a child's name may disqualify the child from certain governmental benefits and affect your long-term financial planning. That's because under federal law, any assets in a child's name totaling \$2,000 or more can disqualify an individual from federal assistance.

It is important to know that a child can acquire assets in his or her name in several ways: (1) titling assets in a child's name directly, such as opening a joint bank account in a child's name or the child's name is placed on property deed; (2) leaving assets to the child as an inheritance; or (3) specifically naming the child as a beneficiary, for example, of a life insurance policy, annuity or retirement plan.

All of these actions could disqualify the child from eligibility for critical government benefits and services. In addition, the child's assets could be subject to any bankruptcy or other legal proceeding, creditors, or seizure. One option to safeguard assets is to transfer the assets to a Special Needs Trust for that child's benefit. However, you should consult an attorney to discuss your options. See the *Supplemental Security Income and Medicaid* and *Estate Planning* sections for more information.

Am I eligible for any tax benefits for caring for a special needs child?

Parents and caregivers of children with special needs may be eligible for certain special tax benefits such as exemptions, deductions, and credits based on your child's disability. You may be able to claim your child as a dependent regardless of age if the child is permanently and totally disabled. Generally, for tax purposes, "permanently and totally disabled" means 1) that your child cannot engage in any substantial gainful activity because of a physical or mental condition; and 2) a doctor determines the condition has lasted or can be expected to last continuously for at least a year or can lead to death. Internal Revenue Service (IRS) publications are the most accessible form of guidance to the tax rules for the general public. In addition, you should consult your accountant for more information.

Credit for the Disabled (or Elderly)

You may be able to claim this credit if you are a citizen or a resident alien and you are under the age of 65 at the end of the tax year and retired on permanent or total disability.

Dependent with a disability working at a Sheltered Workshop

You may be able to claim a dependency exemption for a qualifying child or qualifying relative. Gross income does not include income from services the individual performs at a sheltered workshop; however, they must still meet the other dependency tests. See IRS Publication 501 for more information.

Adoption Credit

You may be able to claim an adoption credit and exclude employer-provided adoption benefits from your income if you adopt a child with special needs. See IRS Publication 907 for more information.

Earned Income Tax Credit (EITC)

You may qualify for this credit if your qualifying child is permanently and totally disabled regardless of age, as long as you meet the other requirements. This credit is based on the amount of your earned income. You can get the credit if your adjusted gross income for the tax year is less than the statutory limits. See IRS Publication 596 for more information.

Child or Dependent Care Credit

You may be entitled to this credit if you pay someone to come to your home and care for your dependent or spouse regardless of their age if they are unable to care for themselves. Generally, people who cannot dress, clean, or feed themselves because of physical or mental problems are considered not able to care for themselves. Also, people who must have constant attention to prevent them from injuring themselves or others are considered not able to care for themselves. To qualify, you must pay these expenses so you can work or look for work. There are several specific requirements that a dependent must meet in order to receive this credit. See IRS Publication 503 for more information.

Medical conferences

You can include in medical expenses amounts paid for admission and transportation to a medical conference if the medical conference concerns the chronic illness of yourself, your spouse, or your dependent. See IRS Publication 502 for more information.

Business credits may also be available for those who have made accommodations for those affected with disabilities.

Additional Resources

Special Needs Alliance
specialneedsalliance.com

Internal Revenue Service

IRS Publication 17, “Your Federal Income Tax” (the comprehensive guide)

IRS Publication 501, “Exemptions, Standard Deduction and Filing Information”

IRS Publication 502, “Medical and Dental Expenses”

IRS Publication 503, “Child and Dependent Care Expenses”

IRS Publication 596, “Earned Income Tax Credit”

IRS Publication 907, “Tax Highlights for Persons with Disabilities”

IRS Publication 969, “Health Savings Accounts and Other Tax-Favored Health Plans”

irs.gov/publications

Internet Special Education Resources

iser.com

ESTATE PLANNING

Why is estate planning important?

Estate planning is essential for parents with special needs children whether those children are minors or adults. The need for such estate planning is important to secure the future of the special needs child when the parent dies. If the parent of a special needs child does not plan properly, assets may go directly to the special needs child, leaving the child in jeopardy of losing public and other benefits.

What is a guardianship?

A guardianship is the most common method of pre-arranging who will take care of your child if you die or become incapacitated.

A guardianship is a court-supervised administrator designated for a minor child or an incapacitated person. There are two types of guardianships: 1) of the person; and 2) of the estate. Legally speaking, the child or incapacitated person is often referred to as the “ward.” A guardian of the person is in charge of the child’s care and custody. A guardian of the estate is in charge of the child’s property and finances, if there is any money or property in the child’s name. Because a guardianship is a court-supervised proceeding, there are specific rules regarding all areas of guardianship, and it is highly encouraged that you **consult a lawyer** about the requirements and specifications of appointing a guardian for your child, or yourself should you become incapacitated. This is especially true when you are not married to the child’s other parent.

Who cannot be appointed a guardian of my child?

Generally, the following types of individuals may not be appointed a guardian:

- a minor;
- a person whose conduct is notoriously inappropriate;
- an incapacitated person;
- a person who is a party or whose parent is a party to a lawsuit concerning or affecting the welfare of the proposed ward (your child);
- a person who is indebted to the proposed ward, unless the person pays the debt before appointment;
- person asserting a claim adverse to the proposed ward or the proposed ward’s property (real or personal);

- a person who, because of inexperience, lack of education, or other good reason is incapable of properly and prudently managing and controlling the ward or the ward's estate;
- a person, institution or corporation found unsuitable by the court; or
- a person disqualified in a declaration made by you in the event of your incapacity.

When appointing a guardian, you, like the court, should consider the best interests of the child. Under the law, it is presumed not to be in the best interests of a child to appoint a person as guardian of the child, if that person has been convicted of (1) any sexual offense or (2) aggravated assault. In addition, a guardian cannot have (1) injured a child, (2) injured an elderly individual, (3) disabled an individual, (4) abandoned or endangered a child, or (5) committed incest.

What does a guardian of the person do?

Generally, a guardian of the person has wide authority over the care, control, and protection of the ward, but that right of control is not unlimited under the law. The guardian's duties may be restricted by a court. The guardian is entitled to establish the ward's domicile; to care for, control, and protect the ward; to provide the ward with clothing, food, medical care, and shelter; and to consent to medical, psychiatric, and surgical treatment on behalf of the ward.

How do I create a guardianship for my child?

Because it is important that your wishes for your child's future are followed, and because the guardianship process is not easy, we strongly encourage you to seek an attorney to help you with this process. That being said, it is helpful to know that there are legal requirements for creating a guardianship for your child.

- When appointing a guardian for your child, it **MUST** be in writing. A guardianship can be created in a will or in a written declaration of guardianship.
- If you appoint an eligible person as a guardian in a will, the will must meet the requirements of a valid will under Texas law.
- If you appoint an eligible guardian by a written declaration, the written declaration **MUST** be signed by you. Also the declaration should be dated. If the declaration is handwritten, then it must be

entirely in your handwriting. A declaration that is not written wholly in your handwriting may be signed by another person for you under your direction and in your presence; or

- If the declaration is not handwritten, then you will need to have it witnessed (or “attested to”) in your presence by at least two credible witnesses 14 years of age or older, who are not named as a guardian or alternate guardian. This kind of declaration may have a “self-proving affidavit” attached signed by you and the witnesses attesting to your competence and the execution of the declaration. A self-proving affidavit is a document that would be attached to the declaration and would say you are competent, and that you intended to create the declaration.
- The declaration and any self-proving affidavit may be filed with the court at any time after the application for appointment of a guardian is filed and before a guardian is appointed.
- If the designated guardian does not qualify, is dead, refuses to serve, resigns, dies after being appointed guardian, or is otherwise unavailable to serve as guardian, the court shall appoint the next eligible designated alternate guardian named in the declaration. If the guardian and all alternate guardians do not qualify, the court shall appoint another person to serve.

Note: A declaration and affidavit in any form may be adequate to clearly indicate your intention to designate a guardian for your child.

Is there anything else I should know about guardianships?

In the event that you become permanently incapacitated or die, the declaration of guardianship and/or last will and testament will need to be filed with the proper probate court. Also, the guardian will need to fill out an application for guardianship with that probate court and abide by the guardianship requirements imposed by law and by the court.

What are Powers of Attorney?

A power of attorney is an instrument by which one person (the principal) grants to another (the agent) the power to perform certain acts on his or her behalf. It is important for families with special needs children to discuss actions that could greatly impact their special needs child with the named agent. For example, if the agent gives

the special needs child money, this could prohibit the child from qualifying for public benefits.

Two types of powers of attorney are common in the estate planning field, the durable power of attorney and the medical power of attorney.

Durable Power of Attorney

The durable power of attorney is an instrument that grants authority to a designated agent to manage the principal's property on his or her behalf. It can be distinguished from the medical power of attorney, which relates to health care decisions rather than to decisions concerning the management of property. The principal can either grant the agent one or more specific powers or grant the agent all of the powers listed in the power of attorney form. In addition, the principal can elect to have the power of attorney become effective immediately upon signing it or only upon the principal's future disability or incapacity. The durable power of attorney must be notarized, but it need not be witnessed.

Medical Power of Attorney

The second type of power of attorney is the medical power of attorney, which grants the agent the power to make health care decisions for the principal if he or she is unable to make them. The principal can revoke the power of attorney at any time, orally or in writing, and regardless of the principal's mental state. The medical power of attorney may be signed by two witnesses, one of which is not:

- The person designated as agent;
- Related to the principal by blood or marriage;
- An employee of the principal's health care facility who is providing direct care to the principal or who is involved in the financial affairs of the facility;
- The principal's attending physician or an employee of the physician;
- The principal's heirs; or
- A person who would have a claim against the principal's estate upon his or her death.

Instead of signing in the presence of the witnesses, the principal may sign the medical power of attorney and have the signature acknowledged before a notary public.

The forms of both the medical power of attorney and the durable power of attorney are prescribed by statute. You should consult an attorney if you desire to have either of these documents prepared for you.

What is a Directive to Physicians and Family or Surrogates (Living Will)?

Texas law allows any competent adult, by signing a Directive to Physicians and Family or Surrogates (or “living will,” as it often is called), to instruct his or her physician to withhold or withdraw artificial life-sustaining procedures in the event of a terminal or irreversible condition. The directive takes effect only after the patient’s physician determines that the patient is terminally ill and that death is expected within six months without application of artificial life-sustaining procedures.

The form and content of the directive are prescribed by Texas law. The directive should be in writing, signed by the patient, and witnessed by two competent adults. One of the witnesses cannot be the person designated to make a treatment decision for the patient, related to the patient by blood or marriage, the patient’s heirs, the attending physician, or an employee of the physician, a person who would have a claim against the patient’s estate upon his or her death, or an employee of the patient’s health care facility who is providing direct care to the patient or who is involved in the financial affairs of the facility. In lieu of signing in the presence of witnesses, the patient may sign the directive and have the signature acknowledged before a notary public. The directive may include a designation of another person to make a treatment decision for the patient if the patient is comatose, incompetent, or otherwise mentally or physically incapable of communication.

If you desire that your life not be artificially prolonged in the event of a terminal illness, you should consult with an attorney to have a directive prepared for you. It also may be desirable to inform your physician of your wishes and to provide him or her with a copy of the directive. Failure to sign a directive may result in disagreements among your family in carrying out your wishes with respect to terminating artificial life-sustaining procedures.

What is a Special Needs Trust and why should I consider establishing one?

It is natural for parents to worry about their children. No matter the child’s age, a parent worries about their child’s care. When a child has special needs, the amount

of care required increases, as does the parent's concern about their child's care. Simply naming a child as a beneficiary in your Last Will and Testament does not answer the question, "what will happen to my special needs child, when I am not here to take care of them?" Leaving a large inheritance to a child to cover their medical expenses, though nice, might do more harm than good, especially if your child is a recipient of public benefits.

One way to secure the future of a special needs child is to create a Special Needs Trust. A Special Needs Trust is a trust created to hold the property of a disabled person and distribute supplemental funds to that individual in a way that preserves his or her eligibility for public benefits. A Special Needs Trust is a revocable or irrevocable trust established with the assets of a person under age 65 who meets the SSI program's disability criteria described below. The trust must include a provision that the state is designated as the residuary beneficiary to receive funds, at the person's death, remaining in the trust equal to the total amount of Medicaid paid on their behalf. If a person is receiving disability benefits from SSI, their disability is already established.

Government programs such as Supplemental Security Income, Social Security Disability Insurance, Medicare, and Medicaid offer benefits and support to disabled individuals. Supplemental Security Income is a needs-based program that is only available to people who meet certain income and resource criteria. In Texas, people receiving Supplemental Security Income are automatically entitled to Medicaid. Contrary to popular belief, not all recipients of public benefits are poor. Governmental assistance is often utilized by families with significant resources to assist them in providing basic needs for their special needs child.

To qualify for Supplemental Security Income and Medicaid, a single person must not own more than \$2,000 in assets. Thus, giving assets, either as a gift or inheritance, directly to a disabled child can result in the loss of assistance that the child would otherwise receive.

Who can establish a Special Needs Trust?

A Special Needs Trust must be established for your child's benefit by a parent, grandparent, legal guardian, a court, or by your child. As of December 13, 2016, people who are under age 65 and meet the SSI program's disability criteria may establish a Special Needs Trust for their own benefit.

Are there different types of Special Needs Trusts?

There are two different types of Special Needs Trusts: (1) General Support Special Needs Trust; and (2) Supplemental Care Special Needs Trust. The majority of Special Needs Trusts are Supplemental Care Special Needs Trusts, which allows the Special Needs Trust to serve as a secondary source of benefits after exhausting all governmental benefits. The assets of Supplemental Care Special Needs Trusts are not counted as “available resources,” and thus do not prohibit the trust beneficiary from being disqualified for public benefits. A General Support Special Needs Trust is designed to serve as the sole source of benefits for the Trust beneficiary.

In determining the appropriate type of Special Needs Trust for a special needs child, the main factor to consider is whether the assets available to the special needs child will fully cover the cost of the child’s care during his or her lifetime. If the assets are insufficient to support the special needs child for his or her lifetime, and public benefits will also be needed, then a Supplemental Care Trust may be appropriate. If the assets are sufficient to support the special needs child for their lifetime, then it may be best to establish a General Support Trust.

How do you establish a Special Needs Trust?

Both types of Special Needs Trusts (General Support or Supplemental Care) can be established in one of two ways. A Self-Settled Special Needs Trust is created when the trust is funded by a disabled person under the age of 65, with assets belonging to the beneficiary. With Self-Settled Special Needs Trusts, the federal law requires that the trust reimburse all benefits provided by the government, prior to any other person receiving the remaining trust property.

Third Party Special Needs Trusts are funded with assets belonging to a third party, and unlike the Self-Settled Special Needs Trust, the Third Party Special Needs Trust is not subject to the payback/reimbursement requirement. In addition, there is no specific disability or age requirement needed before creating the trust.

A typical example of a Third Party Special Needs Trust is created by the parent for their child. A Third Party Special Needs Trust may be established while the parent is alive or at the parent’s death. A Special Needs Trust allows the child to receive supplemental income from the trust to meet his or her special needs while continuing to qualify for government benefits such as Supplemental Security Income and Medicaid.

Parents often choose to establish a Special Needs Trust so that their estates are used to enhance the life of their special needs child while continuing to allow the child to qualify for important government programs that provide benefits to disabled individuals.

How is a Special Needs Trust managed?

A Special Needs Trust enables the settlor, the creator of the trust, to set money aside in a trust on behalf of a special needs child, the trust beneficiary, which may only be used for supplemental needs—such as travel, entertainment, and other extras—above and beyond the benefits received from government programs. Supplemental Security Income benefits must be spent on food, clothing, and housing expenses. The trustee of the Special Needs Trust can use trust funds on the extras that would make a difference in the quality of life of a special needs child. The trustee of a Special Needs Trust can be a family member, friend, or private professional trustee.

To maintain eligibility for support from government programs, the beneficiary of the Special Needs Trust cannot have any control over the assets in the Special Needs Trust. That means that the beneficiary cannot manage the assets, have the right to demand distributions of income or property from the Special Needs Trust, name the Trustee, or change the terms of the Special Needs Trust. The use of the Special Needs Trust's assets for the beneficiary is determined at the discretion of the Trustee. The reason beneficiaries cannot have any control over the Special Needs Trust is to ensure that the trust assets are not countable resources when determining eligibility for public benefits. Beneficiaries of properly drafted Special Needs Trusts do not have legal claim to the property in the trust. As a result, the special needs child can continue receiving assistance for basic living expenses, while still enjoying the benefits of the property in the trust for supplemental needs.

Why is it important to communicate the existence of a Special Needs Trust to family and friends?

It is important for parents, grandparents, family, and friends to be aware of the Special Needs Trust when they are thinking about their estate planning. Often, family members think that leaving additional funds directly to the special needs child in their Last Will and Testament or naming the special needs child as a beneficiary on their IRA or other retirement account, will assist in the child's future care. Although the additional funds are helpful, it might also disqualify the child from being a recipient of public benefits. Coordinating with family and friends is the key. Simply informing

your family and friends that gifts to the special needs child need to be made to the Special Needs Trust, not the child directly, can allow the gift to be made without disturbing public benefits.

It is important that the Special Needs Trust be properly drafted by a lawyer skilled in estate planning with a thorough knowledge of rules of the government benefit programs.

SUPPLEMENTAL SECURITY INCOME & MEDICAID

SSI DISABILITY BENEFITS FOR A DISABLED CHILD

Who qualifies for Supplemental Security Income?

Anyone who is disabled and has little to no income or resources may be entitled to Supplemental Security Income (SSI) benefits from the Social Security Administration (SSA). However, the SSA has different definitions for “disabled” depending on whether your child is under age 18 or older than 18.

A child up to age 18 is considered “disabled” if the child has a physical or mental condition(s) that results marked and severe functional limitations, and is expected to last at least one year or is expected to result in death.

If your child is age 18 or older, your child may be considered “disabled” if your child has a medically determinable physical or mental impairment that results in the inability to do any substantial gainful activity and is expected to last at least one year or is expected to result in death.

In determining the income requirements, the SSA will also consider the family’s household income, resources, and other personal information.

Who determines eligibility and what do they consider?

A state agency makes the decision as to whether a child is considered “disabled” based on information submitted to the SSA. The state agency may also ask for information from medical and school sources and other people who know the child. If the state agency needs more information, it will arrange an examination or test for the child, which will be paid for by the SSA. It can take three to five months for the SSA to decide a child’s SSI disability claim.

What if my child wants to work?

Many young people who receive SSI disability benefits want to work. The SSA does not count most of a child’s earnings when determining the SSI payment. The SSA counts even less of a child’s earnings if the child is a student. The cost of certain

items and services that a child needs to work is subtracted from the child's earnings in calculating the SSI payment. If a child is 15 years of age or older, he or she can establish a "Plan to Achieve Self-Support" (PASS). With a PASS, a child can set aside income for a work goal. The SSA does not count this income in calculating the SSI payment.

Is SSI a medical assistance program?

No, SSI is not a medical assistance program. Your state Medicaid agency, local health department, social services office, or hospital can help you find your nearest health care agencies. Your local Social Security office can also help you find health care agencies. In most states, children who get SSI benefits can also get Medicaid. Even if the child cannot get SSI, he or she may be able to get Medicaid. Children may be able to get health insurance from the State Children's Health Insurance Program (SCHIP).

For More Information

- Visit the Social Security Administration website at ssa.gov where you can find extensive information, publications and forms.
- Contact the SSA and apply over the phone (800) 772-1213 or TTY: (800) 325-0778
- Visit your local SSA office. Regional and local offices can be found through the SSA website at socialsecurity.gov/locator/

What happens when my child turns 18?

When a disabled child who receives Supplemental Security Income (SSI) benefits turns 18, the Social Security Administration (SSA) reevaluates his or her eligibility under new medical standards designed for adults. This review is called an Age 18 Review.

In some cases, the SSA will decide that the person is disabled under the adult standard and he or she will continue to receive SSI and Medicaid benefits. In other cases, the SSA will decide that the person is not disabled, and therefore not eligible for SSI benefits under the adult standard. Typically, this would result in a termination of SSI benefits and possibly Medicaid. If the SSA decides that a person is not disabled during the Age 18 Review, he or she may keep receiving SSI benefits by filing an appeal within 10 days along with a request that benefits be continued.

What issues do I need to consider before my child turns 18?

There are several issues that families with a special needs child should think about to help them prepare for the future, starting about a year before your child turns 18.

- Who can provide evidence of their disability to the SSA for the Age 18 Review?
- Who will they live with (e.g., alone, or with family or roommates) and how will that affect the amount of their SSI check?
- Will their income or resources change when they turn 18? For example, will they inherit money or lose other public benefits or child support?
- Can they manage their own benefits, or do they need a representative payee? Is there a trustworthy person who can be the representative payee?
- Have they made future educational or vocational plans? How can work incentives help them reach these goals?
- Who can help them achieve their employment and other goals?

What happens to benefits if my child gets funding for college or other education or training beyond high school?

The SSA does not count as income any federal student financial aid received under the Higher Education Act, such as Pell grants and work-study funds. There is no time limit on this exclusion. However, some other forms of financial aid for education may be subject to special rules. Consult a SSA representative, legal advocate, or benefits specialist for more information.

It is often a good idea to put any education-related funds into a separate account. This arrangement can help show the SSA that these funds are intended only for educational expenses and should not be counted in the same way as other income or resources. A separate account can help prevent any misunderstanding about these funds that might otherwise cause an interruption in benefits.

For More Information

- Visit the Social Security Administration website at ssa.gov where you can find extensive information, publications and forms.
- Contact the SSA at 800-772-1213 or TTY: 800-325-0778

- Visit your local SSA office. Regional and local offices can be found through the SSA website at [socialsecurity.gov/locator/](https://www.socialsecurity.gov/locator/)

MEDICAID FOR CHILDREN

Medicaid benefits for children include home health care, health screenings, transportation, various types of therapy, and psychological services. Anyone can apply for Medicaid, but that doesn't mean everyone is eligible. Because the program is jointly funded by states and the federal government, eligibility requirements vary widely from state to state.

How does a disabled child qualify for Medicaid?

In order to qualify for Medicaid, the child must meet federal standards for either citizenship or be an eligible alien. The child must then fit in one of the various categories under Medicare, and his or her income and other resources must fall within the eligible range. Children who qualify for Social Security Disability Income (SSDI) automatically qualify for Medicaid. Even if the child does not qualify for SSDI, he or she can still qualify for Medicaid regardless of parental income if classified in the program's "severely disabled" category.

Qualifying for special education services at school does not automatically qualify that child for Medicaid, because the standards for the two programs are not identical. However, the same evaluation documents that qualified the child for special education programs may be submitted to Medicaid as evidence of the disability.

What services does Medicaid provide to disabled children who qualify?

Children with Medicaid coverage are eligible to receive a broader array of health care services than commercial health insurance policies or Medicaid services for adults typically offer. Medicaid for children provides certain health care services including long-term physical, occupational, and speech therapies, and comprehensive dental services.

In most states, a child who gets SSI benefits can get Medicaid to help pay medical bills. In some cases, a child may be eligible for Medicaid while in an institution, but not be eligible when living at home either because of the parents' income and resources or because of other income.

At the state's option, children under the age of 18 who need institutional-level care and live at home may keep Medicaid eligibility while getting home care, if that care is less costly to the government.

What if my child does not qualify for Medicaid?

In Texas, Children's Health Insurance Program (CHIP or Children's Medicaid) covers children in families who have too much income or too many assets to qualify for Medicaid, but cannot afford to buy private insurance. Both programs cover office visits, prescription drugs, dental care, eye exams, glasses, and much more. Families with children who get Children's Medicaid pay nothing and children with CHIP pay no more than \$50 a year for health care coverage. Some families with CHIP also may need to pay co-pays for some services.

To qualify for CHIP a child must be:

- A U.S. citizen or legal permanent resident
- A Texas resident
- Under age 19
- Uninsured for at least 90 days
- Living in a family whose income is at or below 200 percent of Federal Poverty Level
- Living in a family that passes an asset test if family income is above 150 percent of the Federal Poverty Level

For More Information

- Visit the Texas Health and Human Service Commission's website at hhs.texas.gov and view resources under its 'health' tab.
- The Texas Health and Human Services Commission has a web page dedicated to Medicaid and CHIP resources at hhs.texas.gov/services/health/medicaid-chip.
- Visit the CHIP web page at medicaid.gov/chip.
- Call the Texas Health and Human Services Commission's CHIP call center at 800-335-8957.
- Visit the Centers for Medicare and Medicaid Services website at cms.gov.
- Visit the Centers for Medicare & Medicaid Services website insurekidsnow.gov or call 877-KIDS-NOW toll-free.
- Visit yourtexasbenefits.com — a website of the Texas Health and Human Services agency.

MEDICAID FOR ADULTS

Medicaid clients include individuals who are eligible for full coverage of acute care services, prescription drugs, and long-term services and supports, depending on need. Medicaid clients also include individuals eligible for time-limited or specific services, such as emergency services or women's health services only.

If you receive Supplemental Security Income (SSI), Temporary Assistance for Needy Families (TANF), or Refugee Cash Assistance, you are automatically eligible for adult Medicaid in Texas.

Who is eligible for full benefits?

The three primary categories of Medicaid clients eligible for full benefits are:

1. Families and children – Based on income level, depending on age or pregnancy.
2. Cash assistance recipients – Based on receipt of Temporary Assistance for Needy Families (TANF) or Supplemental Security Income (SSI).
3. Aged and disabled – Based on income level, age, and physical or mental disability.

Who is eligible for limited benefits?

Medicaid clients eligible for limited benefits include:

1. Medicare beneficiaries – Based on income level and age, certain Medicare beneficiaries qualify for partial Medicaid benefits.
2. Non-citizens – Legal permanent residents and undocumented persons who are not eligible for Medicaid based on citizenship status may receive emergency services.
3. Women – Based on income level and age, women who do not qualify for full Medicaid benefits may receive women's health services through Medicaid.

What is needed to apply for Medicaid?

When applying for adult Medicaid services in Texas, you will need photo identification, such as a driver's license or a state ID card, Social Security card or proof of alien status, copies of medical and life insurance policies, current statements of any income sources and most recent bank statements.

For More Information

- Visit the Texas Health and Human Services Commission's website at hhs.texas.gov.
- Contact the Texas Health and Human Services Commission's Medicaid client hotline toll free 800-252-8263.

RESOURCES FOR PARENTS WITH SPECIAL NEEDS CHILDREN

TEXAS

- Connections Kids
specialneedskidsdirectory.com/
- Disability Rights Texas
Disabilityrightstx.org
- Texas Department of Family and Protective Services (DFPS)
dfps.state.tx.us
- Texas Department of State Health Services (DSHS)
dshs.texas.gov
- Texas Education Agency (TEA)
tea.texas.gov
- Texas Health and Human Services Commission
hhs.texas.gov
- Texas Workforce Commission
twc.texas.gov

National

The Arc – advocacy and innovation for individuals with intellectual and developmental disabilities
thearc.org

National Guardianship Organization
guardianship.org

Americans with Disabilities Act

- dol.gov/general/topic/disability/ada
- ada.gov

Social Security Administration disability benefits information
ssa.gov/disability

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