

Planning for Children with Special Needs



One of the most important questions parents who have a child with special needs ask themselves is...What's going to happen to my child when I'm no longer here? To a large degree, the answer to that question will depend on the steps you begin taking today in order to arrange for your child's future well being.

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What's going to happen to my child when I'm no longer here?

In order to begin answering that question, there are certain initial steps you should begin taking today:

- Assess Your Child's Prognosis:** Will your child ever be able to earn a living...manage assets...live independently? Your evaluation of issues such as these will then guide you in the type of planning you need to complete in order to provide for your child. If you're unsure about your child's future prognosis, be conservative in your assumptions. You can always change your plans in the future.
- Review Your Financial Situation:** What assets do you have available to provide for your child's future financial needs? What can you do to accumulate additional assets for your child's care?
- Evaluate Living Arrangements:** Where do you want your child to live after your death, or if you become physically unable to care for your child? Will your child need a guardian (or conservator)?
- Understand Government Benefits:** Do you know what government benefits are available and what the requirements are to qualify for these benefits? Government benefits and their requirements can play a major role in your child's future well being. Be aware, however, that improper or careless planning could make your child ineligible for certain benefits. Government benefits fall into two groups:
 - **Entitlement Programs:** Eligibility for entitlement programs is based on meeting certain requirements, such as age, disability or blindness. An individual who, for example, meets the required definition of disability is entitled to receive benefits, regardless of that individual's financial situation.
 - **Needs-Based Programs:** In order to receive benefits from a needs-based program, a disabled individual cannot have income or assets above stated amounts.

The Special Needs Questionnaire beginning on page 13 may prove helpful in beginning the planning process.

Once your initial assessment is complete, the care and well being of children (be they minor or adult) who are mentally, physically or developmentally disabled can be greatly enhanced by your planning in areas such as:

- Legal Planning:** How will your estate be distributed when you die? Who will care for your child with special needs when you're no longer able to do so? How can your estate be arranged to provide for your child, but not disqualify your child from receiving government benefits?
- Medical Planning:** How can you best obtain and pay for the specialized medical care your child may require? Who will oversee your child's medical care when you're no longer here?
- Financial Planning:** What steps can you take to guarantee that your child will have a financial safety net? What financial aid is available? How should your assets be arranged to best provide for your child's future financial needs?
- Education Planning:** What steps can you take to make sure that your child receives the best possible education?

Planning for children with special needs is a complex process. Particularly when it comes to legal planning/legal documents, you are strongly advised to consult an attorney with experience in estate planning for families with children with special needs. The National Academy of Elder Law Attorneys is a professional association of attorneys with skills in planning for the elderly and people with special needs.

More information is available at <http://www.naela.org>. Alternatively, a local organization that provides services to the disabled may be able to recommend an attorney with these specialized skills.

In planning for a child with special needs, there are four primary legal issues that should be addressed:

- Wills:** The primary purpose of a will is to state how you want your assets distributed at your death.
- Guardian:** If your child's condition warrants it, careful thought must be given to a future guardian or conservator for your child, after both parents are gone. Guardian of the person may be different from the trustee of financial assets.
- Letter of Intent:** A letter of intent serves as a blueprint of what you want your child's life to be when you can no longer care for your child.
- Special Needs Trust:** A type of trust that can receive and manage assets for the benefit of your disabled child, without disqualifying the child from receiving government benefits. Boilerplate wording from an attorney not experienced in this field will not suffice. Special Needs Trusts should be specific and include exact wording, so as not to disqualify the individual from receiving government support.

As your child reaches adulthood, you may lose authority to make decisions for him or her. The final two documents below provide you with an opportunity to continue assisting your adult child in making appropriate decisions throughout his or her lifetime. Both documents should refer specifically to the Health Insurance Portability and Accountability Act of 1996 (HIPAA). This allows disclosure of medical and hospital records and information to the "agent" and is not subject to federal regulation of privacy rules. Don't forget to identify "alternate agents" to carry on for you after you are no longer able to do so.

- Power of Attorney:** A Power of Attorney is a legal instrument that is used to delegate legal authority to another person, giving that person the authority to make property, financial and other legal decisions during the lifetime of the person who executes the Power of Attorney (the initiator). A Power of Attorney remains in effect only while the initiator is alive and is automatically canceled and of no effect on the initiator's death.
- Medical Directives:** In addition to recording the treatments an individual wishes to have or not have should he or she become unable to make those decisions, a medical directive also appoints a proxy...someone to make medical decisions for a person who cannot make medical decisions on his or her own.

Wills

A will is the legal document that states the actions you want taken after your death in regard to the disposition of your property, the guardianship of any minor or disabled children and the administration of your estate.

If you die without a will, the state in which you reside will determine the above through the state's intestacy law. This means that the state will determine who receives your property, who becomes the guardian of your minor and/or disabled children and how your estate will be administered. Consider the potential implications for your special needs child:

- The court-appointed guardian may not be someone your child even knows.
- Any inheritance received by your child in excess of \$2,000 could disqualify the child from receiving needs-based government benefits.

A will is an important first step in your legal planning...it sets everything else into motion.

Guardians

It's important to give careful thought to who will have responsibility for your child with special needs after both parents are gone. While the laws regarding a guardian or conservator vary from state to state, this is the individual who will care for your child and manage their affairs when you're no longer available to do so.

Among the various guardianship/conservatorship arrangements, there are two basic types you will need to select between. Your choice will be largely dependent on your evaluation of your child's developmental disabilities:

- Limited Guardianship or Conservatorship:** The powers of the guardian or conservator are limited to reflect the needs of the disabled individual. A limited guardian or conservator is appropriate in the situation where your special needs child is capable of performing some, but not all, of the tasks of daily living and/or managing his or her financial resources.
- General Guardianship or Conservatorship:** The guardian or conservator has full decision-making powers for a disabled individual, with respect to finances, living arrangements, medical care, etc.

Letter of Intent

A letter of intent is a blueprint of your child's situation and your wishes for your child when you are no longer there to carry them out. While not legally binding, the letter provides direction for the person or persons who will be caring for your child. You should start a letter of intent as soon as possible and update it as your child grows, including information such as:

- Medical information about your child, including diagnosis, care and support the child currently receives, medications, emergency instructions, physicians, therapies, etc.
- A "snapshot" of your child's capabilities in regard to daily living skills (bathing, dressing, toileting, money management, cooking, etc.).
- Any special equipment your child needs, such as wheelchairs, shower chairs, modified computers, voice recognition software, utensils or plates, etc. Also who to contact to maintain this equipment or where to go to repair or replace it.
- Education your child has received, as well as future education you'd like your child to receive.
- Living arrangements...where would you (and your child) like for the child to live if something should happen to you? What happens when you just can't physically care for him or her anymore? Indicate whether you feel your child can live independently or would be better in a group environment. Be aware this item may need a long lead time (years) to put into place for independent living, depending upon where you live.
- Employment opportunities that you feel might be open to your child as a disabled adult.
- Social/behavioral information, such as activities and the types of toys your child enjoys, who your child likes to play with, plus any behavior management issues, including how you discipline your child.
- Dietary information, including food likes and dislikes, any special diet restrictions, problems swallowing, etc.
- Religious information as appropriate.

In addition, the letter of intent should include the child's vital information (full name, nick name, place and date of birth, Social Security number), plus the name and contact information of anyone involved in your child's life, such as a caseworker, school or work contact, financial advisor, executor of your will and/or the child's guardian. It's also a good idea to either include a set of the child's medical records or make reference to where those records are located. Finally, provide financial guidance, including information on medical insurance, financial resources available to the child and who to contact for assistance/additional information.

You may find completion of the Special Needs Questionnaire that begins on page 13 a good starting point in writing a letter of intent. In addition, the letter of intent is a "living document"...it needs to be updated periodically.

The purpose of a special needs trust is to provide financial assets for your child's future care and well being, while maintaining the child's eligibility for government benefits.

Under current federal law, with the exception of an ABLE Account (see page 8), an individual with more than \$2,000 in assets is disqualified from most needs-based government benefits. State assistance programs may also be based on need. If your child were to receive an inheritance from you directly, it's highly probable that the inheritance would disqualify your child from receiving needed benefits. **Do not leave assets to the child directly.**

With a special needs trust, however, you leave assets to the trust. The trust is managed by a trustee, who then can use trust assets on your child's behalf. Special needs trust requirements are stringent, so it's important that you consult with an experienced attorney in setting one up.

In a properly-structured special needs trust, the trust holds title to the property for the benefit of the disabled child or adult. The assets in the special needs trust can then be used to provide for the needs of the disabled individual, as well as to supplement benefits received from government assistance programs. For example, trust assets could be used to provide your child with:

- transportation, including purchase of a vehicle;
- training, rehabilitation or education programs;
- equipment;
- payment of medical, dental and eyesight needs;
- entertainment;
- payment of insurance premiums;
- companion/home health aides; and
- items to enhance quality of life/self-esteem.

A special needs trust can hold cash, as well as title to stocks, bonds, mutual funds, real estate and personal property. In addition, it can own and/or be the beneficiary of life insurance policies. Another use for special needs trusts is to receive any proceeds from personal injury settlements without jeopardizing eligibility for government benefits.

In order to retain eligibility for government benefits, it's important that well-intentioned family members, such as grandparents, understand that their will should bequeath assets to the special needs trust, and not directly to the disabled individual.

Lifetime Alternative...an ABLE Account

The Achieving a Better Life Experience (ABLE) Program is designed to help individuals and families use tax-free savings accounts to help finance their longer-term disability needs, without the loss of federal benefits if savings exceed certain limits.

ABLE Accounts contain the following features and benefits:

- The **earnings on contributions** to ABLE Accounts **will not be taxed** and the funds in ABLE Accounts **will not be considered** for the Supplemental Security Income (SSI) program, Medicaid and other federal means-tested benefits. If, however, an ABLE Account exceeds \$100,000, SSI benefits will be suspended, but not terminated.
- To be eligible for an ABLE Account**, an individual must become blind or disabled before age 26 and (1) receive Social Security Disability Insurance (SSDI) or SSI or (2) file a disability certification under rules yet to be written.
- Any one**, including the disabled individual, **may establish an ABLE Account** for an eligible beneficiary. An eligible disabled individual, however, will be limited to one ABLE Account and total aggregate annual contributions to that account may not exceed the annual gift tax exemption (\$19,000 in 2026). Since ABLE contributions are **treated as gifts** by the contributor for tax purposes, if a donor puts the maximum \$19,000 in an ABLE Account in 2026, any other gifts to the beneficiary will trigger the requirement to file a gift tax return. No gift tax will be due in 2025, however, unless the donor has already made more than \$15 million of lifetime taxable gifts. In addition, **Section 529 plan assets may be rolled over to an ABLE account**, up to the maximum annual gift tax exemption (\$19,000 in 2026). Both accounts must have the same beneficiary or a member of the same family.
- Contributions to an ABLE Account** will be made with after-tax dollars, but earnings on contributions will be tax-free and **distributions from the account** for qualified disability expenses **will not be considered taxable income** to either contributors or the eligible beneficiary.
- Qualified disability expenses include** any expenses made for the benefit of the disabled beneficiary related to education, housing, transportation, employment training and support, assistive technology and personal support services, health, prevention and wellness, financial management and administrative services, legal fees, expenses for oversight and monitoring and funeral and burial expenses.
- Distributions used for nonqualified expenses** will be subject to income tax on the portion of the distribution attributable to earnings from the account, plus a 10% penalty.
- Assets in an ABLE Account can be rolled over** without penalty into another ABLE Account for either the qualified beneficiary or any of the beneficiary's qualifying family members.
- At the death of the qualified beneficiary**, it may be required that any assets remaining in an ABLE Account be used to reimburse a state Medicaid agency for the cost of benefits and services provided during the disabled beneficiary's lifetime. **As a result, an ABLE Account should not be considered a wealth accumulation mechanism.**

The medical treatment required for children with special needs can be expensive, often beginning at or shortly after birth. Without insurance, the cost of medical care is staggering!

- If You Have Private Health Insurance:** Make certain you understand what the policy will and will not cover, particularly in regard to any specialized services, equipment or therapy. Make sure you obtain prior authorizations, or you could end up paying the bill. If your coverage is provided through a health maintenance organization (HMO) or preferred provider organization (PPO), confirm that the specialists needed by your child are part of the network. Understand when you can seek out-of-network care and what the cost will be to you. If a claim is denied, get a written explanation of the reason...you may want to appeal and resubmit the claim. Finally, a helpful tip is to request that a case manager be assigned to your child, which will then enable you to work consistently with someone who is familiar with your child's situation and needs.
- Many private health plans cover students and disabled persons only until their 22nd birthday:** By no later than September 23, 2010, however, all young adults under age 27 may be able to continue health care coverage through a parent's policy. Some health insurance plans will provide extended coverage beyond age 22 (or 26) to a disabled dependent. Check with your benefits department or insurance company!
- If your private health insurance stops covering your child at his or her age 22 (or 26):** Your disabled child may be eligible for Medicaid coverage. Check with your county health or Social Security office. (In some states, disabled children can receive Medicaid coverage as early as age 14.)
- If You Do Not Have Private Health Insurance:** Check with your county social services or Social Security office to determine what assistance may be available. Medicaid is a health care program for people with low incomes and limited assets. In most states, children who get SSI (Supplemental Security Income) benefits qualify for Medicaid. In many states, Medicaid comes automatically with SSI eligibility. In other states, you must sign up for it. Also, some children can get Medicaid coverage even if they don't qualify for SSI. In addition, the State Children's Health Insurance Program (SCHIP) enables states to insure children from working families with incomes too high to qualify for Medicaid, but too low to afford private health insurance. Your state Medicaid agency can provide more information about SCHIP.
- Beginning at Your Disabled Child's Age 18:** Medicaid benefits are payable based on the child's own assets and income, even if your child is still living at home with you.

The Patient Protection and Affordable Care Act of 2010 (health care reform) has several provisions that may impact medical/insurance planning for your child with special needs.

As mentioned previously, by **no later than September 23, 2010**, all young adults under age 27 may be able to continue health care coverage through a parent's policy. Other provisions you should be aware of include:

- **Effective no later than September 23, 2010**, individual and group health insurance plans are prohibited from using pre-existing condition exclusions for children and cannot place lifetime limits on the dollar value of coverage.
- **Also effective in 2010**, insurers cannot deny or rescind coverage of insureds who become sick.
- **Beginning January 1, 2014**, insurers are prohibited from placing any annual limits on the dollar value of coverage.
- **Effective January 1, 2014**, most U.S. citizens and legal residents are required to have minimum essential health insurance coverage. Insurers are not able to deny or cancel coverage to anyone with a pre-existing condition. Health insurance premium subsidies are available to eligible individuals and families with incomes between 100% and 400% of the federal poverty level (e.g., \$32,150 to \$128,600 in 2025-2026 for a family of four). Individuals with incomes of less than 138% of the federal poverty level qualify for Medicaid coverage unless the state in which they reside opted out of the Affordable Care Act Medicaid expansion.
- **Effective January 1, 2019**, the penalty assessed to individuals who fail to maintain minimum essential coverage is \$0.

Government Benefits

Supplemental Security Income (SSI) benefits are payable to adults or children who are blind or disabled. SSI supplements a person's income up to a certain level, which varies from state to state.

- In the case of disabled children under age 18**, the parent's income and assets are considered when deciding if the child qualifies for SSI benefits.
- Beginning at age 18**, SSI benefits are determined based upon the disabled person's income and assets. As a result, a child who was not eligible for SSI before age 18 may become eligible at age 18. To qualify for SSI benefits, the disabled person cannot have "countable resources" (assets) in excess of \$2,000 or "countable income" in excess of the maximum Federal benefit rate. In the case of ABLE Accounts (see page 8), the first \$100,000 in an ABLE Account will be disregarded for SSI benefit purposes.
- Additional financial resources** may be available through state and community programs. Consult with the appropriate federal, state, county and/or local agencies for assistance.

Other Financial Considerations

A special needs trust with no assets is worthless in providing for your child's future care and well being. These are some sources that you can consider for funding a special needs trust:

- Savings:** Based on your estimate of your child's future financial needs, begin a regular savings program.
- Investments and Retirement Plans:** You may want to name a special needs trust as the beneficiary of an investment program and/or retirement plan.
- Life Insurance:** Many special needs trusts are funded, at least in part, by life insurance. Why? Because life insurance is the only alternative that can produce a stated amount of money exactly when needed...at your death. Life insurance death benefits are generally paid free of income tax and, if ownership is properly structured, can be removed from your estate for estate tax purposes. Another advantage of funding a special needs trust with life insurance is that the rest of your estate can then be preserved for other family members.

Undoubtedly, you want your child to receive the best education possible. To assure this outcome requires that you become your child's advocate and a participant in your child's education plan.

The first step is an understanding of the education laws that apply to children with disabilities.

Individuals with Disabilities Education Act (IDEA)

The Individuals with Disabilities Education Act requires that children with special needs receive:

- 1.** A free appropriate public education from ages 3 through 21.
- 2.** Education provided as close to home as possible with children who do not have disabilities.
- 3.** Additional services, such as speech therapy, occupational therapy or a classroom aide, which are designed to meet their unique needs and prepare them for employment and independent living.
- 4.** An assessment to determine their needs.

The law provides two guarantees:

- Individualized Education Plan (IEP):** The IEP is a written statement of your child's abilities and impairments. It's developed by a team that includes you, school district personnel and educational professionals who have evaluated your child and his or her abilities. The IEP must be reviewed at least annually.
- Due Process:** As a parent, you have both rights and responsibilities in relation to your child's IEP. Due process provides a mechanism for resolution of any disagreements regarding a child's IEP.

Before your child approaches age 22, you are advised to have a plan in place to address the issues that are sure to arise as your child transitions out of the public education system. Depending on the nature of your child's disability, this plan may include additional educational or vocational services, work, or ongoing rehabilitation and medical services. Planning for these needs requires research done on your part **years** before your child reaches age 22. Many children with special needs are of average or above average intellect. There are many colleges whose programs may be appropriate for your son or daughter. If he or she can obtain a college degree, it will greatly enhance employability.

Parenting a child with special needs has its own unique set of joys and challenges. While you are undoubtedly the foremost expert on your child and his or her needs, desires and future aspirations, it can be a daunting task to undertake special needs planning on your own.

Because of the specialized nature of special needs planning, seek out professionals - attorneys, trust officers, financial advisors - with experience in the special needs planning process. Guidance counselors, special education professionals and other parents with special needs children can also be great resources to tap into.

In addition, there are a variety of organizations whose purpose is to provide assistance to people with disabilities and their families. We offer a few here in the hope they will be of assistance to you:

- National Information Center for Children & Youth with Disabilities (NICHCY) (www.nichcy.org):** A national information and referral center providing information on disabilities and disability-related issues for families, educators and other professionals. Available in English and Spanish.
- National Association of Parents with Children in Special Education (www.napcse.org):** A place where parents of children in special education can find information on how to be their child's best advocate.
- Exceptional Parent Magazine (www.eparent.com):** A publication for families of children and young adults with disabilities and special needs.
- Parents Helping Parents (www.php.com):** A parental resource center whose mission is to help children with special needs reach their full potential.

A Final Note

The planning process shouldn't stop as your child gets older. As he or she ages, so do we. There are certain issues that we all need to address regarding our final arrangements. It is most helpful to your family members if pre-planning and/or pre-funding of your own final wishes are set in place when you feel it is appropriate.

In addition, there is currently a unique feature of the Social Security System that occurs when a parent of a disabled child or adult applies for retirement benefits. As part of the interview, you will be asked if you have a disabled child. The good news is that a "yes" answer provides that child with an additional income stream of Social Security benefits from your retirement income. The bad news is that it also complicates the situation since it eliminates the opportunity for the child to receive SSI and Medicaid benefits directly. Depending on your child's disability, Medicaid benefits may be particularly important. Medicaid, for example, will pay for home aides for your child, while Medicare will not. Be sure to check...additional Medicaid benefits may be available through your state Social Services Division.

Special Needs Questionnaire

1. Name of son or daughter:

2. Child's date of birth:

3. What are your child's primary disabilities?

4. What is the degree of disability?

Moderate:

Severe or Profound:

Other:

5. Does your child have any additional disabilities? If so, describe:

6. What are your child's capabilities and limitations (e.g., can he or she read, dress himself or herself, use public transportation, drive a car, etc.)?

7. Does your child have any special medical needs?

8. Does your child require regular medication? What kind?

9. What are your child's current living arrangements?

10. What are your child's wishes and your own wishes concerning his or her living arrangements after your death?

11. Is your child enrolled in an education or training program?

12. Does your child work? If so, where?

13. If your child works, is it in:

Supported Employment? **Yes** ____ **No** ____

Sheltered Workshop? **Yes** ____ **No** ____

14. If your child works, give a general idea of his or her earnings:

Special Needs Questionnaire (continued)

15. Does your child have any assets in his or her own name? If so, give nature and value:

Held by a custodian or in a Uniform Gift to Minors Act account?

Value: \$ _____

Name and address of custodian:

16. Has anyone other than the parents provided for your child through Will, insurance, or any other way? If so, in what way and in what amount?

17. Has a legal guardianship for your child or his or her property been established? Where? Who is the guardian?

18. Has a trust been established for your child? Yes No

What type? _____

By whom? _____

Who is the trustee? _____

Special Needs Questionnaire (continued)

19. Does your child presently receive any of the following:

a) **SSI Benefits** Monthly Payment: \$ _____

b) **Social Security Disability Benefits** Monthly Payment: \$ _____

c) **Other Disability Benefits?** (Specify source) Amount: \$ _____

d) **Other Regular Unearned Income?** Amount: \$ _____

20. Is your child covered by:

Medicaid? _____

Medicare? _____

Other government programs? _____

21. What are your child's current or projected monthly expenses?

Housing: _____

Transportation: _____

Personal Expenses: _____

Repair/Replacement Expenses: _____

Other: _____

Notes:

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