

# With Open Arms

## Table of Contents

With Open Arms .....	1
Table of Contents .....	1
Copyright .....	2
Rethinking Your Future .....	3
Finding Sources of Support .....	3
Taking Care of You .....	4
Taking Time for Everybody.....	4
Tim and Michelle.....	5
Respite Care.....	5
Planning for Your Family's Future .....	6
Estate Planning and Finding the Right Lawyer .....	6
Wills.....	7
Trusts.....	8
What is a Trust? .....	8
Conservatorship/Guardianship.....	8
Conservatorships Defined.....	9
Letter of Intent .....	9
Worksheet: Writing a Letter of Intent.....	10
Medical History .....	10
Daily Life .....	11
Hopes and Dreams .....	11
Siblings .....	13
Bequests .....	13
Disinheritance .....	13
Traditional Support Trusts .....	13
Special-Needs Trusts .....	14
Funding the Special-Needs Trust.....	14
Managing Your Money Today and Tomorrow .....	15
Will You Have Enough Money to Retire and Provide for Your Child?.....	15
Start Saving Now .....	15
Making a Spending Plan .....	16
Step 1: List Your Monthly Income .....	16
Sources: Per Month.....	16
Step 2: Identify Your Monthly Expenses.....	16
Expenditures Per Month .....	17
Step 3: Compare Your Income and Expenses.....	18
Step 4: Make Appropriate Changes .....	18
Savings Options .....	19
Saving and Investing.....	19
Retirement Planning.....	21

Your Government Benefits .....	23
Medicaid .....	24
Medicaid Waiver Programs .....	24
Medicare .....	24
State Children’s Health Insurance Program (SCHIP).....	24
Children With Special Health Care Needs (CSHCN).....	25
Provision of the Social Security Act.....	25
State-Mandated Insurance Programs .....	25
Nonmedical Benefits From Social Security Available to Children With Disabilities .....	25
Supplemental Security Income (SSI).....	25
Social Security Disability Insurance (SSDI).....	26
Insurance .....	26
Your Health Plan .....	26
Health Care Plans Defined.....	27
Health Care Plans.....	27
Becoming Your Own Insurance Advocate .....	28
Disability Insurance .....	30
Your Special Child’s Life .....	31
Services for Children Ages Birth to Two Years .....	31
Services for Children Ages Three to Five Years .....	32
Services for School-Aged Children .....	32
Beyond School .....	33
Life Skills and Work Skills Training .....	33
A Place to Live.....	34
Funding an Adult Life.....	36
Embracing the Future.....	36
Resources .....	36
Acknowledgments.....	39

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## **Rethinking Your Future**

Before your child was born, you imagined what his or her life would be like. You dreamed about future soccer games, ballet classes, sleepovers, and a college education. You anticipated family camping trips, happy holiday celebrations, and homework scattered on the kitchen table. It was a life you understood. Then, one day, you learned that your world might be different. You wondered how your child's special needs would change your dreams.

Would your son's or daughter's life include only some of the things you imagined? Where could you go for information?

In the years immediately following a diagnosis, parents of children with disabilities struggle not only with caring for their special needs, but also with realigning their expectations and dreams. What will their child's education look like? Will their child be independent? Will their child need financial support for the rest of his or her life? If so, how can parents save enough for retirement AND a child's lifetime of care?

Caught up in the daily responsibilities of caring for a child with disabilities, parents can tend to neglect their own needs and push this planning for the future to the back burner. Although understandable, postponing this kind of planning can result in a probate court choosing your child's destiny should you die — even if your spouse survives.

This is why Easter Seals and the National Endowment for Financial Education<sup>®</sup> (NEFE<sup>®</sup>) have collaborated to create this booklet. Inside, you will find information on how to begin the estate planning process, how to unravel the mysteries of government benefits, and how to enhance your family's life. We also have included lists of additional resources where you can go for help.

The future may look different from what you had imagined, but that doesn't mean it can't be a rich and full one. This booklet is designed to help parents open their arms and their eyes to the challenges and opportunities ahead.

## **Finding Sources of Support**

When parents learn that their child has a disability, they experience a complex array of emotions ranging from grief, fear, and disappointment, to love and hope. You may feel jealous of your friends with nondisabled children, or angry that the hopes and dreams you had for your child must change. Because your friends and family may never have faced these challenges, you also may feel very alone.

The fact of the matter is you are not alone. Although it seems like nobody understands what you're going through, there are tens of thousands of people

who have experienced what you are experiencing right now. A network of support is available to you, composed of other parents who have had to wrestle with redefining their expectations and their lives after learning about a child's disability.

Experts in the field of disabilities suggest that you connect yourself as soon as possible with other families whose children share your child's disability. These are people who care about the issue as passionately as you do. You can benefit from their experience with health insurance, early intervention programs, special home care, or financial planning. These also are people who, because of their experience, can help you understand the often-conflicting emotions you're dealing with, especially if they've already addressed their own situations in a positive and proactive manner.

Local Easter Seals affiliates, as well as advocacy organizations, can help you meet other parents. Ask your doctor or hospital staff about these organizations in your community. Contact your state disability office or agency for assistance. (To do this, visit your state's Web site to determine the appropriate agency providing resources to families; every state does business differently.) By talking to people who understand your situation, you will begin to learn how you can best care for your child, your family, and yourself.

### ***Taking Care of You***

When attending to your child's special needs, it is easy to forget the one thing your child needs most— you! In an attempt to uncover information, make your doctors' appointments, and tend to your child's special needs, you may devote less attention to your spouse, work, other children, or health. While a natural response to the challenge of raising a child with special needs, this kind of behavior is not sustainable for the long term.

To gain a broader perspective, you, as a caregiver, may need to take time to have dinner out with your partner, play a game of golf with your friends, or attend a yoga class by yourself. Finding that delicate balance between caring for your special-needs child, your needs, and the needs of your entire family will ultimately nourish all the people in your life.

### ***Taking Time for Everybody***

Living with an exceptional child can change the dynamics of your entire family. Suddenly, most of your family's energy and resources are being focused on the individual who needs the most assistance and care. This is as it should be. But what about your relationship with your partner, if you have one? What about your other children?

Keeping your marriage healthy and managing cases of sibling rivalry are challenging under the best of circumstances. But adding a child with special needs to the mix means it is more important than ever to ensure that everyone feels special. Ask other families how they have balanced the various needs of individual family members. Take time off for yourself, your partner, and other children. Establish enjoyable rituals such as making a homemade pizza, watching videos, or playing board games. Most importantly, don't be ashamed to ask for help whether from friends, family, or a health professional. After all, your family is your most precious asset.

### ***Tim and Michelle***

*Six months after Michelle and Tim's baby, Brittany, was born with cerebral palsy, the two looked at each other after an exhausting day and realized they hadn't had a conversation in months that didn't involve Brittany. Michelle started to cry. "Tim," she said, "if we don't pay some attention to our marriage, we're not going to do our best for Brittany."*

*So the couple called Michelle's sister and asked her to baby-sit two weekday nights a month. They also called their friends Janet and Rudy, whom they met through Easter Seals, and asked if they would trade child care two weekend nights a month. Janet and Rudy eagerly agreed.*

*After training Michelle's sister about how to care for Brittany and checking and rechecking that she had their cell phone number, Tim and Michelle had their "first" date at a nearby Italian restaurant they both loved. As time passed, Michelle's sister grew to know Brittany better, and Brittany enjoyed spending time with her aunt and with Janet and Rudy's son.*

*"Getting out one night a week alone," Michelle says, "helps us reconnect as a couple. I can't tell you how nice it is for us to just talk about our days."*

### ***Respite Care***

It is not unusual for parents of a child with a disability to feel protective and have difficulty relinquishing him or her into someone else's care. But everybody needs a break, whether it's from work or from a much-loved child with special needs. That's where respite care comes in.

Defined as temporary relief for families and caregivers, respite care is delivered in several ways: it might involve an individual coming to your home, or your child attending an outside day program. Whatever the form, respite care can help reduce stress for both you and your family. By giving you a chance to get back to yourself and to connect one-on-one with other family members, respite care can help strengthen all your relationships, renew your inner resources, and replenish

your health. Also, it teaches your child that he or she can survive without you being there all of the time.

Bob McGee, an Arkansas banker, and his wife take regular respite weekends together while Bobby, their 14-year-old who has cerebral palsy, spends time at an Easter Seals program. During the summer, they also travel with their 17-year-old daughter while Bobby attends an Easter Seals camp. The time the McGees spend with each other and their daughter is good for everybody.

“It helps out a lot,” Bobby’s dad explains. “At his age, Bobby wants to be with other kids. We get a break and he gets to have a blast with his friends.”

Easter Seals and other local advocacy groups provide programs or can refer you to respite care services. (For information on Easter Seals’ Camping and Recreation programs, refer to [www.easter-seals.org](http://www.easter-seals.org). Check with the **National Respite Locator Service** at [www.chtop.com](http://www.chtop.com) or by calling **1-919-490-5577**.) Remember to see if your state will help pay for all or part of those services.

Of course, you want to do what’s best for your child, but you must begin by taking care of yourself. Keeping your emotional and physical health intact will go a long way toward providing a happy life for your child.

## **Planning for Your Family’s Future**

You have more to think about than most parents. Retirement and estate planning may seem almost irrelevant compared to the daunting task of finding the experts you need to help your child — not to mention tackling the stacks of medical bills and insurance statements awaiting your attention.

But taking the time to think about the future gives you a chance to dream again. What do you want life to look like years from now? Maybe, with the help of a personal care assistant, your child could own his or her own condo. Maybe, you’ll have the necessary funds to send your oldest daughter to college. Perhaps, you and your spouse will get to take that second honeymoon.

What’s important now is that you not only begin to dream about the future, but that you also begin to plan for it. By giving yourself the permission and time to plan, you will position yourself and your family for a more secure future.

## ***Estate Planning and Finding the Right Lawyer***

Planning for future uncertainties can seem over-whelming to the parents of a child with disabilities. In addition to choosing a qualified guardian for their special-needs child, parents also may need to prepare to provide their son or daughter a lifetime of financial support should it be necessary.

It may be true that nobody will ever love your child the way you do and that you will never save the millions of dollars necessary to provide the kind of estate you'd really like to pass on. But preparing for the future is the single most important thing you can do for your child's lifetime well-being.

Fortunately, there are people who have walked this path before, as well as laws and systems in place, to help you.

As you begin the estate planning process, find a good lawyer. Because laws affecting Americans with disabilities change frequently and require special expertise, you will not be able to handle your estate on your own, nor will the average lawyer. While you may know someone who specializes in estate planning, this individual may not be familiar with the legal issues specific to your situation. Only a lawyer who specializes in estate planning for families who have a child with special needs can guide you through the complicated details of your estate.

To find a lawyer who specializes in this area, ask other parents for references. Check with a local advocacy agency such as The Arc for recommendations. The National Academy of Elder Law Attorneys (NAELA) also may provide some names. Interview prospective lawyers by asking questions like, "How many special needs trusts have you written?" and "Are you familiar with recent developments in disabilities law?" If the lawyer writes only a handful of special-needs trusts every year, this person may not have the specific skills you need.

After you find the right lawyer, he or she can help you begin planning your estate.

## ***Wills***

Your last will and testament is the document that explains how you want your estate to be distributed after you die. First, a will can name a guardian for your child. Second, it provides a road map for loved ones on how you would like things handled after you're gone. A bequest (or legacy) is a gift of personal property made by a will.

Finally, it is important to note that your will should prevent your estate's assets from going directly to your child with disabilities. While it's natural to want to give everything to your special-needs child, assets of more than \$2,000 can disqualify your child from receiving government benefits like Supplemental Security Income (SSI) or Medicaid. As we will discuss later on, there are special planning techniques that can be used to safeguard your child's eligibility for government benefits.

There are many pitfalls involved in leaving your estate to chance. If you die without a will, the state could distribute your estate without regard on how it might affect your child. Then, there's the matter of probate charges and taxes, that

could consume a chunk of your hard-earned wealth if you die without a proper estate plan.

If you die without a will and your child should need a conservator or guardian, a state court could appoint that guardian on its own. Therefore, your will (or trust) should name a guardian or conservator for your child. This will enable a court to consider your wishes before appointing a guardian.

Review your will occasionally. You may need to make changes as your children marry, parents die, or an appointed guardian or conservator moves away. A will is a dynamic document that should reflect your current situation and wishes.

## **Trusts**

After you die, a trust can be used to manage your child's financial affairs regardless of his or her age. A trust is a sophisticated legal document. Therefore, you must hire an estate planning attorney to draft the trust document. Income from the trust can be accumulated or distributed as needed. A spendthrift provision can be used to protect the assets held by the trust from your child's creditors. As we will discuss later on, a special type of trust is best suited for your disabled child.

### ***What is a Trust?***

*A trust is a legally enforceable agreement in which a person (called a trustee) is named to hold property or assets for the beneficial use or enjoyment of another person (called the beneficiary). The grantor (or settlor) is the person who established the trust. The principal of the trust is referred to as the corpus (or res) and is distinguished from the income of the trust. In making this distinction, the principal of a trust can be invested to provide income over the life of a beneficiary. However, a trust can be drafted to permit the principal to be used in case of an emergency.*

## **Conservatorship/Guardianship**

Until your child is 18 years old, you are legally responsible for his or her welfare. That means you have legal powers to make certain decisions for your child. By law, your child is considered to be an adult when he or she turns 18, or (in some states) marries before the age of 18. Therefore, it may be necessary to appoint a guardian or conservator to manage the affairs of your adult child.

Because conservatorship limits the ability of people to make decisions for themselves, establishing conservatorship is not something to undertake lightly. Everybody wants to control his or her own destiny. As your child approaches adulthood, you will have to determine whether your child can make decisions in his or her own best interest. If you determine that conservatorship is right for your



child, and you and your spouse are still in good health, you probably will want to serve as your child's conservator after he or she turns 18.

As you plan your estate, you will have to make the difficult choice of selecting a conservator if you die before your child. You will want to name this person in your will. This is a tremendous responsibility for someone. Sometimes, siblings or other family members can fulfill this role. But in some cases that's not appropriate. Make sure that whoever is appointed understands the magnitude of the responsibility and willingly accepts it.

### ***Conservatorships Defined***

#### **General Conservatorship or Guardianship of the Person and Estate –**

This type of conservatorship usually gives full decision-making powers about someone's life to the appointed person. With a general conservatorship, the conservator can make decisions about housing, clothing, medical care, food, contracts, etc. This type of conservatorship is established for people who can't make decisions on their own. A conservator or guardian is the individual who is legally responsible for performing the duties of a conservatorship or guardianship. This individual must be approved by a court of law. Therefore, you must hire an attorney to represent you in court. Your attorney will petition the court for its approval. After a court names an individual as guardian or conservator, the conservatorship or guardianship comes into existence. If you serve as a conservator or guardian, your attorney will explain to you what your responsibilities are.

**Limited Conservatorship or Guardianship –** This kind of conservatorship limits the powers of the conservator to mirror the needs of the individual. A limited conservatorship is established for someone who may not be in a position to handle everything, but can make certain life decisions by himself or herself. (For example, a limited conservatorship may apply only to health care decisions.) A limited conservatorship encourages self-determination and independence by granting the conservator powers only for those areas the individual can't manage.

### ***Letter of Intent***

A letter of intent or a letter of direction is your message to the future. The letter of intent is a document that you will share with trustees and future guardians. It is not legally binding, but provides a guide for your child's care-givers or the courts on how you would like your child to live after you're gone.

Typically, a letter of intent includes three major sections. The first gives a complete medical history of your child, including hospital visits, doctors, allergies, and medications—anything related to your child's health. The second section

offers practical advice, including housing and services needed, names of advocacy organizations, and daily care requirements (even down to listing your child's hairdresser, clothing sizes, favorite foods and colors, or behaviors that anger your child). The third part states your hopes and dreams. It might name favorite teachers who share your life vision, as well as people who may work with your child who have different views. List everything you can think of that might affect your child's future. As much as possible, involve your child in writing a letter of intent.

Theresa Varnet, an attorney in Chicago who specializes in disabilities law, wrote an 18-page letter of intent for her daughter with a developmental disability, in which she gives the trustee permission to "be a little frivolous" with the trust. If necessary, Varnet writes, she wants the trustee to hire a driver to take her daughter swimming, as well as offering perks to high-quality caregivers as incentives to continue their employment.

In general, she wants the money used to make her daughter's life better. Varnet updates the letter every year to reflect her daughter's changing life, using her daughter's birthday as a reminder date.

Share your letter of intent with the person who will be responsible for your child and ask how he or she feels about it. If you doubt that this person will respect your wishes, you may want to choose another guardian. While the letter of intent may have nothing to do with the legal aspects of your estate, it is the one document that really speaks to your survivors about how you want your child to be treated.

### ***Worksheet: Writing a Letter of Intent***

Following is a worksheet to help you begin writing your letter of intent. This worksheet suggests options to think about and is not designed to limit you in any way. Take some time to do this. Consult with your child as you write. After you finish your letter, share it with your other children, your child's appointed conservator, trustees, and possibly other caregivers. Keep the letter in an easily accessible place and send other interested parties copies. Also, it is a good idea to update the letter to reflect your child's constantly changing needs.

### **Medical History**

1. Describe your child's current medical condition.
2. List your child's doctors.

3. List your child's current medications, if any.
4. If your child has had a poor reaction to a medication, please list it.
5. List all allergies.
6. Describe any hospital stays and reasons for those stays.

### ***Daily Life***

1. Where does your son or daughter now live?
2. Is this where you see your child living in the future? If not, what vision do you and your child have for his or her future living situation?
3. What plans do you have in place to make this vision a reality?
4. What does your child like to do for fun?
5. What size clothing does your son or daughter currently wear? What styles and colors does he or she like?
6. What life skills does your child possess? What limitations does your child have around the house?

### ***Hopes and Dreams***

1. What are your child's strengths and weaknesses?
2. Describe your child's education now.
3. Describe your child's work history.
4. What goals (educational, career, personal) does your child have for his or her life?

5. What activities and friends make life special for your child?
6. Are there people your child dislikes?
7. Does your child worship at a church, synagogue, or mosque? If so, where?
8. Name your choice for your child's guardian/conservator and share this document with that person.
9. Name your choice for the person who will manage your child's trust (trustee) and share this document with that person.

## ***Siblings***

Although you may wish to divide your estate equally among your surviving children, your child with disabilities may need more assets. As you begin planning, work with your lawyer and/or financial planner to develop a plan for your child's future while considering your other children as well. If appropriate, include your children in the planning process and explain your decisions. Siblings of special-needs children may be quite willing to give up a share of an inheritance if it means that their special-needs brother or sister can live independently. Studies show that sharing information helps relieve concerns siblings have about their special-needs brothers and sisters.

Also, you will have to work closely with your other children to define the nature of their caregiving role after you're gone. Insisting that an unwilling sibling take responsibility for a brother or sister with a disability ultimately will lead to unenthusiastic care. Make sure your children are "on board" and capable of any care-giving responsibilities they accept.

## ***Bequests***

There's a part of you that may want to leave everything to your special-needs child — especially if there are no siblings. Reconsider this. Your good intentions could cause serious problems for your child and other survivors.

Current federal law stipulates that assets exceeding more than \$2,000 disqualify individuals with special needs from receiving many government benefits. Because an inheritance is considered a "countable" asset, it could cause your child to lose SSI, Medicaid, or other benefits, such as vocational support, subsidized housing, or transportation. With this reality, how do you address your child's exceptional needs in your will?

## ***Disinheritance***

Some families address this problem by "disinheriting" their special-needs child in their will and leaving a larger gift to a sibling instead. The bequest "morally obligates" the sibling to provide for the brother or sister but does not legally require them to do so. While it is uncomfortable to contemplate, there's always a chance that a sibling won't do the "right" thing. Plus, even if a sibling is highly responsible, the inheritance could get caught up in the quagmire of a divorce or end up with his or her legal heirs in the event of the sibling's death. Leaving a morally obligated gift tends to expose assets to too many whims of fate.

## ***Traditional Support Trusts***

Establishing a traditional support trust also can open the door to potential problems. If a person with a disability has a support trust and receives government benefits, the state may bill the trust for the cost of those benefits. Consequently, the trustee may have to turn over trust assets to the state. The mere fact that an individual receives support from a traditional trust also could jeopardize that person's eligibility for government benefits like SSI and Medicaid.

## ***Special-Needs Trusts***

A special-needs or supplementary-needs trust offers families a reliable way of safeguarding their child's eligibility for benefits, while also providing for additional needs not covered by the government.

Here's how it works: A special-needs trust enables a trustee to pay for items and services beyond the bare necessities the government provides. For example, if your child's television were to break, the trustee could purchase a new one. If your child wanted to vacation with friends in Florida, the trust could pay for that as well. A special-needs trust can pay for everything from ball games and movies to private rehabilitation and vitamins. This is where your letter of intent really comes into play. Should your child's trustee perceive a Florida trip as a waste of resources, your instructions could help relieve the trustee's concerns about squandering money. Also, without a letter of intent, it is possible that a representative of your child could sue the trustee for inappropriate expenditures. Consequently, a trustee might deny the vacation request for fear of being sued.

Rather than your child receiving direct bequests, the trust should serve as the recipient of all inheritances or gifts. Notify grandparents, other relatives, and friends who might want to leave a bequest to your child and ask them to leave it to the special-needs trust instead. If necessary, you can explain that by doing so they are providing a much greater benefit to the child.

## ***Funding the Special-Needs Trust***

*How do you amass sufficient money to fund a special-needs trust? You may have more assets than you realize — although some may not be available until your death. Ask your financial planner for other ways to boost your resources. Here are some ideas:*

- *Life insurance*
- *Standard government benefits, such as Social Security survivor benefits*
- *Savings and investments, including money in retirement funds*
- *Assistance and inheritances from friends and family members*
- *Property, such as a home or rental property*
- *Military benefits*

1. *If you have listed your special-needs child as a beneficiary on any life insurance policies, individual retirement accounts (IRAs), or other assets that transfer according to the terms of a contract and not your will, change the beneficiary designation to the **special-needs trust**.*
2. *Ask grandparents and other relatives interested in making gifts or bequests to your child to direct them to the special-needs trust or to an account in your name designated for your child's care.*

In setting up your child's special-needs trust, work with a qualified lawyer. This is a very complicated area of the law and you will need an expert to draft it correctly. During this process, you will select a trustee to manage the trust. **Keep in mind that a trustee and guardian are not the same thing. Trustees oversee trusts; guardians or conservators handle personal and legal affairs.** Typically, trustees are close family members or friends, but the trustee also could be a lawyer, a bank, or a committee composed of one or two family members and a financial advisor. Good trustees generally are people with good hearts and good money skills.

## **Managing Your Money Today and Tomorrow**

As the parent of a special-needs child, you will deal with financial issues most families could barely imagine, such as paying for technology to help your child navigate through his or her world or remodeling your home to accommodate a wheelchair. How can you finance these immediate needs, let alone save for your child's future?

Chances are, it will be difficult, which is why you will have to watch your money more closely than most people.

### ***Will You Have Enough Money to Retire and Provide for Your Child?***

The question, "How much is enough?" is tougher to answer than it first appears. "Enough" is a moving target complicated by many variables, including longevity, health, economic fluctuations, and the level of care your child will require as an adult. Remember, you may be saving for the lifetimes of three people — you, your spouse, and your child.

### ***Start Saving Now***

As intimidating as it seems, there are realistic, practical ways to reach your financial goals. Even if you are not wealthy, you can make a big difference in your future and your child's future if you start planning today. Although you may never save vast sums of money, you can set priorities and find ways to bridge the shortfalls if you begin tackling these things now.

## ***Making a Spending Plan***

How can you meet your goals? You can begin by creating a basic spending plan ... in four easy steps:

1. **List your monthly income.**
2. **Identify your expenses.**
3. **Compare your income and expenses.**
4. **Make appropriate changes.**

### ***Step 1: List Your Monthly Income***

On the income side, in addition to your regular paychecks, list all the funding you can reasonably expect to receive for your child's disability, such as government benefits and gifts from community, civic, and religious organizations. Try not to guess or rely on memory for your numbers. Refer instead to paycheck stubs, bank or investment statements, and other records to be as accurate as possible.

#### ***Sources: Per Month***

After-tax wages (your own)	\$ _____
After-tax wages (others in your household)	\$ _____
Bonuses/tips	\$ _____
Gifts	\$ _____
Child support	\$ _____
Tax refund	\$ _____
Interest on savings	\$ _____
Investment income	\$ _____
Unemployment compensation	\$ _____
Public assistance	\$ _____

#### ***Sources of funding related to your child's disability:***

State programs \$ _____	\$ _____
Social Security Disability Insurance (SSDI), Supplemental Security Income (SSI), or Social Security Retirement Income (SSRI)	\$ _____
Assistance from fraternal and civic organizations	\$ _____
Assistance from family and friends	\$ _____
Other	\$ _____
<b>Total income: \$ _____</b>	<b>\$ _____</b>

### ***Step 2: Identify Your Monthly Expenses***

On the expense side, obtain expert advice about the long-term costs related to your child's disability. Talk with other parents whose children are older and have



disabilities similar to your child's. Ask doctors and other medical providers for a projection of costs. There may be associated expenses related to your child's disability. For example, if your child will outgrow a wheelchair in a few years, consider the replacement cost. Talk to other parents and your social service caseworker (if you have one) — he or she may be able to help you anticipate future expenses. Other parents might suggest less expensive, but equally effective, alternatives to buying new items as your child outgrows old ones.

Consider all of your expenses, even if they are trivial. (Include personal expenses you have that are not listed on this sheet.) For expenses paid only once or twice a year or for one-time-only expenses, determine the number of months it will take to pay off the item. Then divide the cost of the item or expense by the number of months. List this amount on the worksheet below. For example, if you buy a device that costs \$6,000 (including interest), and you believe you can pay off that amount in 60 months, list \$100 ( $\$6,000 \div 60 = \$100$ ) as a monthly amount below. Only include the portion that is not covered by insurance. For bills that vary each month, such as your telephone bill, use averages.

### ***Expenditures Per Month***

House payment or rent	\$ _____
Homeowners' or renters' insurance premiums	\$ _____
Condo/townhouse association fees (if applicable)	\$ _____
Home repairs/improvements	\$ _____
Household goods/furniture	\$ _____
Life insurance premiums	\$ _____
Natural gas or heating fuel	\$ _____
Electricity	\$ _____
Water	\$ _____
Telephone (including local, long distance, special services, mobile)	\$ _____
Computer and Internet services	\$ _____
Groceries	\$ _____
Meals eaten out	\$ _____
Transportation (public transportation, car payments, gasolines, insurance, maintenance, repairs, etc.)	\$ _____
Vacations	\$ _____
Dental bills	\$ _____
Pet care	\$ _____
Union and professional dues	\$ _____
Clothing costs	\$ _____
Church or charitable donations	\$ _____
Loan payment	\$ _____
Credit card payment(s)	\$ _____
Personal (toiletries, allowances, etc.)	\$ _____
Miscellaneous (cable TV, newspapers, magazines, classes, etc.)	\$ _____

### ***Costs specifically associated with your child's disability***

Special diet	\$ _____
Medical costs (not paid for by insurance or others)	\$ _____
Medical insurance co-payment (other than Medicaid or Medicare)	\$ _____
Therapy (occupational, physical, etc., not covered by insurance)	\$ _____
Transportation to/from special care or hospital	\$ _____
Lodging and meals incurred during treatment away from home	\$ _____
Costs for disability-related adaptations to vehicle (if not covered by other organizations)	\$ _____
Disability-related home renovation	\$ _____
Child care/nursing care (if not covered by insurance)	\$ _____
Devices not covered by insurance	\$ _____
Assistance for daily living	\$ _____
Legal fees	\$ _____
Other costs	\$ _____
<b>Total Expenses:</b>	
<b><i>Per Month</i></b>	\$ _____

**Note: The best way to fully grasp your expenses is to keep an expense log. Write down every expenditure, regardless of size, for at least a month — preferably longer. This will help you clearly see where your money goes.**

### ***Step 3: Compare Your Income and Expenses***

Write down your total monthly income (from step 1 on page 25)	\$ _____
Write down your total monthly expenses (from step 2 on page 27)	\$ _____
Subtract your expenses from your income and list the amount here	\$ _____

### ***Step 4: Make Appropriate Changes***

At the end of the month, do you have money left to save? Can you start to meet other goals, such as saving for your child's education, investing for retirement, or preparing for your child's future needs? If so, establish some saving priorities and channel money into your various savings accounts (you'll learn more about how to manage and invest that money later in this book).

If you are running at a deficit, examine your spending patterns and see if you can find ways to save. Doing simple things like paying off credit cards, taking your lunch to work, or checking out videos at the library can slash expenses without compromising your quality of life. Also, make sure you are taking advantage of the funding sources available to you, which could help pay for things like assertive equipment or special services.

## ***Savings Options***

Saving money can be exciting! As people develop strong saving habits, they will know they are taking care of themselves and their families.

A good rule of thumb, as you save with a special-needs child in mind, is to keep all beneficiary designations out of your child's name. If you want your child to remain eligible for government benefits as an adult, this is essential. Experts in the area of disabilities planning stress that the type of investment vehicles you own are less important than the beneficiary designation.

If you die and your child with disabilities is listed as the direct beneficiary of any of your investments or savings, it could directly affect your child's ability to collect government benefits after he or she inherits those assets. In many cases, people list their spouses as the primary beneficiary and then their child's special-needs trust as the secondary beneficiary.

## ***Saving and Investing***

Because you have ambitious financial goals, you want your money to work for you as much as possible. This is easier said than done. The art of saving and investing requires discipline, skill, and patience. You may want to consider seeking the advice of a financial planner, especially one who specializes in disabilities planning. This kind of specialist can help not only with your general finances but also can look at your life, taking into account your family's special considerations. To find someone who cares to address your specific issues, check with your lawyer, other parents, local advocacy organizations, or NAELA.

You also can begin to investigate saving and investing on your own. Following are some saving and investment vehicles:

**Dollar-cost averaging** is an investment strategy whereby you invest a consistent amount (such as \$50 or \$100) at regular intervals (say each month or quarter). Dollar-cost averaging does not guarantee investment success, but it does take the emotion out of it. You follow your plan, regardless of what is happening in the stock market. Also dollar-cost averaging makes investing a regular habit and fits perfectly with payroll deduction plans offered by employers or through periodic automatic transfers from checking accounts.

**Mutual funds** pool your money with that of many other investors. Instead of buying just a few assets, a professional fund manager purchases many stocks, bonds, and/or other assets, which diversifies your investment. In other words, you don't end up with all your eggs in one basket. The specific kinds of investments that are contained within a mutual fund are listed in the fund's prospectus. This allows you to choose a fund with a specific investment philosophy while letting someone else make the investment decisions.

**Treasury securities** include federal government bills, notes, and bonds. Interest payments are guaranteed. Your principal is safe as long as you retain the security until it matures — the time when the government agrees to pay back the principal. However, if you sell the security before it matures, you risk losing some of the principal if interest rates have risen.

**Stocks** are an investment in a company; to put it simply, you own part of the business in which you invest. Stocks tend to be a higher-risk investment because they are affected by a company's performance, the economy, and political events. Over time, however, many stocks do increase in value. To lower the risk associated with stock ownership, it's a good idea to own stock in more than one company. It's also wise to purchase stock across different industries or sectors, a tactic that diversifies your investments. Also, most experts advise investors to hold their stocks for the long term.

**Company-issued and government-issued bonds.** When you purchase a bond, you are lending your money to the issuer. A bond is a legal promise to pay you interest for the use of your money, as well as repaying the principal. While there are some risks associated with bonds, the potential return can often be greater than if your money was simply sitting in a savings account.

**Life insurance** is one of the foremost tools people use to fund their special-needs trusts.

**There are two basic types of life insurance: term and permanent coverage.**

**Term insurance** is about protection; it is not an investment. This is not the type of life insurance experts usually suggest as a vehicle to fund special-needs trusts. Written only for a set period of time, most term policies last until age 70 or beyond, but many end sooner. With a policy that has a 10-year premium guarantee, one possibility is that the policy will automatically renew at a higher premium (usually much higher) once the 10 years pass. The other possibility is that you can reenter the plan. Reentering may require you to prove that your health is still good. If that's the case, you may be able to reenter without a significant increase in premium. However, if you can't requalify, your premiums will likely increase a great deal.

**Permanent life insurance** covers you permanently without your having to prove insurability (as long as you don't let the policy lapse). In time, the cash value of your policy can add up to a large sum of money, an amount against which you usually can borrow. You will pay more at first for a permanent policy than you will for term insurance, but your premium won't change. Also, the younger and healthier you are when you first purchase the policy, the lower the cost. So, in the long run, the policy may cost you less than term coverage. It turns out that

many of these policies pay for themselves during retirement if purchased early enough. This is the type of policy most people use to fund special-needs trusts. (Remember to list the special-needs trust, not your child, as the beneficiary of your life insurance policy).

### **Other thoughts:**

Depending on your financial situation, you may have to think creatively to acquire the necessary insurance. Although purchasing term isn't ideal, term insurance allows you to purchase enough to get started. Then, as soon as you can, convert all or a part of it to permanent insurance. The most important rule of life insurance is to have enough to cover your needs.

Maintaining adequate liability insurance coverage (both auto and homeowners) also is prudent for the caretakers of a special-needs child. For instance, additional car travel because of various medical reasons could mean you are at greater risk for an auto accident. With a family already facing the potential of increased medical and personal expenses for a special-needs child, a legal claim from an accident could easily wipe out any remaining financial resources.

### ***Leveraging Real Estate***

*John Nadworny is a financial planner who specializes in special needs and has a 10-year-old son, James, who was born with Down's syndrome. John owns two rental 25, the mortgages on the properties that he hopes will provide a nest egg to subsidize college for his other two kids as well as a home for James. By the time James is age rentals will be paid off and the Nadwornys can sell their investment or use the cash flow from rent to buy a condo for him.*

**Real estate investment** might include residential rental property, raw land, a real estate investment trust (REIT), or commercial (business) real estate. Many investors find real estate investments quite attractive because they are something that can be seen and touched. But property values fluctuate, meaning you could lose some of your initial investment. As you think about purchasing real estate, consider that you will have to pay property taxes. Also, the property might be difficult to sell if you need the money right away. Over the long term, real estate can yield high returns but there is potential for great losses as well.

### ***Retirement Planning***

A big part of your savings strategy involves your future retirement.

### **Employer-Sponsored Plans**

It's a good idea to participate in employer-sponsored retirement plans. Some companies augment your contributions with matching funds; this is like extra pay. Also, some plans allow employees to contribute to the plan before taxes, a feature that reduces your taxable income and your current tax bill. While your company may administer the plan, you often will have a choice of investments, such as money market funds, mutual funds, annuities, or company stock. These plans usually are called 401(k) plans or, for people working for nonprofit groups, 403(b) plans.

## Individual Retirement Accounts

To encourage savings for retirement, the federal government gives you the chance to accrue some tax advantages by putting money into individual retirement accounts, or IRAs. IRAs are available from mutual fund companies, stock brokerage houses, banks, credit unions, savings and loans, and insurance companies. There are three main types of IRAs: traditional IRAs, Roth IRAs and the lesser used Coverdell Education Savings Account (formerly known as the Education Savings Account). If you are single and have a job, you may be able to put away as much as \$3,000 a year into a traditional IRA or Roth IRA. Or if you are married and your spouse has a job, the two of you may be able to put away as much as \$6,000 each year — this is in addition to the money you contribute to your plan at work. (Rules change and the amount you can deduct depends on your income, so be sure to check this figure with your financial advisor.)

The benefits of a traditional IRA are:

- The money you place in a traditional IRA often can be deducted from your taxable income, thereby reducing your annual taxes.
- Your traditional IRA money is not taxed until it is withdrawn — a big advantage because it allows more of your money to compound year after year.

The benefits of a Roth IRA are:

- The money you place in a Roth IRA comes from after-tax dollars, meaning you will pay the tax on the money now, but not when you withdraw it upon retiring.
- You can withdraw the original money you put into a Roth IRA without paying penalties or taxes. Of course, this slows down your potential earnings for retirement.
- You will face penalties and taxes if you can touch the *interest* before age 59 <sup>1</sup>/<sub>2</sub>.

## Coverdell Education Savings Account

For people with children, the government has provided an incentive for parents to save for education expenses through the tax-deferred Coverdell Education Savings Account. Check with a knowledgeable financial planner about whether a

Coverdell Education Savings Account could jeopardize future government benefits for your child with special needs. In addition to a \$3,000 per year personal IRA contribution, you may contribute up to \$2,000 per child per year to a Coverdell Education Savings Account – until the child reaches the age of 18.

Like the Roth IRA, contributions to the account are not tax deductible, but earnings accumulate tax-free. What's more, withdrawals from these ESAs can pay for tuition, books, supplies, and room and board (for full-time students). If the child doesn't attend college, the money must be withdrawn by the time he or she turns 30; otherwise, those earnings are subject to income tax and the 10-percent penalty. Or you can roll an ESA over to another member of the family without penalty. Rules about ESAs can change. Check with your financial advisor regarding the latest information and whether an ESA makes sense for your situation.

### **How Grandparents Can Help**

Grandparents can be a tremendous source of both emotional and financial support. If possible, include both sets of grandparents in your financial planning process; they may have some great ideas about where they could contribute, from purchasing assistive devices like hearing aids to offering carpentry skills to make your home more accessible. If grandparents are in the position to do so, they might be willing to pay the premiums on a parent's life insurance policy that will eventually fund the special-needs trust.

Or, if a grandparent wants to leave a trust for the child, encourage him or her to leave a bequest to your child's special-needs trust instead. Remember, a traditional support trust left to your child could jeopardize his or her government benefits. Ask your accountant or financial planner about any tax advantages your parents might receive from making a significant gift. There may be ways they can save on their taxes by helping those closest to them.

### **Your Government Benefits**

Deciphering government disability benefits is like trying to untangle an enormous knot. To uncover what you may or may not qualify for, you will have to persevere and call on all your patience.

Begin by asking other parents about programs they've found useful. Ask your local advocacy organization about possible benefits. Do your research on the Internet. If you do qualify for benefits, it will prove well worth the effort because of the money you save.

Here are some programs that may help:

## ***Medicaid***

Medicaid is a program, paid for by the federal government and the states, that covers the cost of certain medical care and procedures for low-income people. To complicate matters, every state administers its own program and handles things a bit differently. For a child under 18 to receive Medicaid benefits, your income and assets must fall below a certain level. Some people who might qualify for Medicaid include low-income families with medically needy children under the age of 21 who meet certain requirements, Supplemental Security Income (SSI) recipients, infants born to Medicaid-eligible women, children under six years old, and pregnant women whose family income falls at or below 133 percent of the federal poverty level. To find out more, visit [www.cms.gov](http://www.cms.gov) or call **1-410-786-3000**.

## ***Medicaid Waiver Programs***

Waiver programs are for children with disabilities who would otherwise not qualify for Medicaid or Supplemental Security Income (discussed on page 41) because of their parents' income.

In addition to medical coverage, waiver programs may cover a number of targeted services and supports. You must qualify before you can sign up for most waiver programs. If you do qualify, enroll even if you must add your name to a waiting list. In some states, there is a co-pay for services based on parents' income. For more information, call **1-800-633-4227** or call your state Medicaid office.

## ***Medicare***

This government health insurance program is available to children with certain disabilities, such as chronic renal disease, which requires a kidney transplant or maintenance dialysis. These children can qualify for Medicare if they have a parent who is receiving Social Security or who has worked enough to be covered by Social Security Disability Insurance. Contact Medicare for specific information by calling **1-800-633-4227** or visiting [www.medicare.gov](http://www.medicare.gov).

## ***State Children's Health Insurance Program (SCHIP)***

This program is administered through individual states, which set eligibility and coverage following broad federal guidelines. Recipients must be qualified as low income, be ineligible for Medicaid, and be uninsured. Programs differ, but all must offer at least these services: in-patient and out-patient hospital services, doctors' surgical and medical services, lab and X-ray services, and well-baby/child checkups, including immunizations. Some states may provide additional benefits. SCHIP is available in all states and the District of Columbia. You can apply for SCHIP for your child at state public schools. In some states,



you can apply through the or public health departments, state social service agencies, or state welfare agencies. Contact **1-877-543-7669** or **[www.insurekidsnow.gov](http://www.insurekidsnow.gov)**.

### ***Children With Special Health Care Needs (CSHCN) Provision of the Social Security Act***

If your child is eligible for Supplemental Security Income (SSI), he or she also will be eligible for CSHCN, a program administered via state health agencies. Although there are differences, most CSHCN programs help provide specialized services through arrangements with clinics, private physicians, hospital-based out-patient and in-patient treatment centers, and social services. CSHCN programs are known by a variety of names, including Children's Special Health Services, Children's Medical Services, and Handicapped Children's Program. Even if your child is not eligible for SSI, a CSHCN program may be able to help you. The Institute for Child Health Policy publishes the *Directory of State Title V CSHCN Programs: Eligibility and Scope of Services*; visit **[www.ichp.edu](http://www.ichp.edu)** or call **1-352-392-5904**.

### ***State-Mandated Insurance Programs***

State-mandated insurance programs are for those who have been refused health insurance, offered health insurance at a higher-than-standard premium, or have been offered health insurance with a rider that substantially reduces coverage. A small business owner may obtain this type of coverage for an employee who has a child with special needs. It is definitely worth exploring your state's program.

### ***Nonmedical Benefits From Social Security Available to Children With Disabilities***

There are several ways a child may be able to claim nonmedical benefits from Social Security.

### ***Supplemental Security Income (SSI)***

Supplemental Security Income (SSI) benefits are available to children with disabilities, under age 18, whose disability is expected to last more than 12 months or result in death and whose parents' income and resources are limited. When your child reaches age 18, he or she then becomes eligible for SSI if his or her income and assets meet Social Security guidelines and if the disability interferes with employability. (The ability to qualify for SSI after the age of 18 is a major reason financial advisors suggest that you keep assets out of your child's name.) If a child qualifies for SSI, he or she also will qualify for Medicaid.

The process of applying for SSI often is lengthy. You will need to document your income and expenses. You will be asked many questions about your child's

disability, which will need to be supported with medical records and written statements from teachers and others who know your child.

### ***Social Security Disability Insurance (SSDI)***

When you qualify for Social Security retirement or disability benefits, your disabled child also may qualify to receive benefits based on your entitlement to benefits. The definition of child includes your biological child, adopted child, or stepchild. If the parent has died, children under the age of 18 may collect dependent SSDI benefits on the parent's record (if qualified.) These benefits are available to all children, regardless of whether the child has a disability. SSDI benefits can continue into adulthood if the child has a disability that began before age 22. For information about SSI or SSDI, contact the Social Security Administration at **1-800-772-1213** or [www.ssa.gov](http://www.ssa.gov).

### **Insurance**

Making sure you have adequate insurance is particularly important for families who are dealing with disability issues. Health, life, and disability insurance policies are your buffer against catastrophic expenses and losses.

#### ***our Health Plan***

To maximize medical coverage for your child, it is essential that you understand your policy. The policy explains what is covered and what isn't, the insurance company's obligations, your obligations, and how to appeal if a claim is denied.

Naturally, you don't have expert knowledge of health insurance. But, if you understand the basics, you can begin developing your skills as an advocate.

**Consider:** Because your family's situation is special, you must examine your policy and its coverage. There are many types of medical coverage, including health maintenance organizations (HMOs), preferred provider organizations (PPOs), point-of service-plans, indemnity plans, and exclusive provider organizations.

What type of medical plan do you have? Does it cover certain kinds of therapy? Are there any provisions for mental health care, emotional behavioral disorders, or other mental health disabilities? Even if your health care plan pays for your child's mental or physical health care needs, you may still be subject to paying deductibles, co-insurance, and/or co-payment fees. Factor these costs into your spending plan.

Most importantly, understand the benefits and limitations of your plan as soon as possible. Ask your insurance agent to clarify these issues:

- Does my plan allow me to seek out and use the specialists my child needs? Will I need a referral?
- Which hospitals can we use?
- Does my policy cover the types of medications my child needs?
- Does my plan cover the specific procedures and therapies my child requires?
- Does my plan limit the number of times I can collect per year for a given item or procedure?
- Does my policy cover assistive technology?
- Does my policy cover assessment for mental and physical disabilities?
- If my child has a long-term condition, are there lifetime maximum limits on coverage?

## ***Health Care Plans Defined***

### **Health Maintenance Organization (HMO).**

Under this type of plan, you must use the HMO's doctors and hospital affiliates. You will need permission from your primary care doctor to see a specialist. A primary benefit of HMO coverage is low co-payments for doctor visits (typically \$10 to \$20). Emergency room visits and hospitalizations typically require a higher co-payment. There is seldom any paperwork to be submitted unless an outside specialist is recommended by the primary care physician. Many HMOs today provide for services outside the HMO network.

## ***Health Care Plans***

### **Preferred Provider Organization (PPO).**

This type of plan allows you to choose from a network of providers. You will pay a co-pay for provider visits and you will have the option of seeing out-of-network providers for a higher fee. When a nonparticipating provider is used, the plan typically works as an indemnity plan with a deductible and coinsurance. Also, you may not need a referral from your primary-care physician to see a specialist if the specialist is in the network.

### **Point-of-Service Plan.**

This is the most flexible plan, combining characteristics of HMOs, PPOs, and indemnity plans. You pay the least out-of-pocket when you use certain participating providers. When you see other listed providers, you pay a bit more. Your greatest expenses come from using providers that are not affiliated with the plan at all. With these providers, the plan operates as an indemnity plan (see

below). One way to think about this plan is to remember the name — the “point” (or place) where you receive the “service” affects your out-of-pocket cost.

### **Indemnity Plan.**

This is a more traditional fee-for-service plan. You choose a doctor, as well as your specialists. Unlike HMOs, PPOs, or POS plans, indemnity plans typically only pay for expenses related to an illness or accident and not for preventive care. You will have to pay a specified dollar amount before your plan pays out. This dollar amount is called a deductible. Even after you meet your deductible, you may still have to pay a portion of the expenses (often an 80/20 split; you pay 20 percent while the insurance company covers 80 percent).

Unlike other types of plans, you may have to pay for services up front and then submit your bills to your insurance company for reimbursement.

### **Exclusive Provider Organization (EPO).**

An EPO usually operates like a HMO or a PPO, but providers are not EPO employees. This type of plan typically is associated with a single employer. An insurance company or third-party administrator generally manages an EPO, while an HMO is a business unto itself.

## ***Becoming Your Own Insurance Advocate***

Obviously, the more your health plan covers, the more money you will save — and the less stress you will experience from worrying about bills. In some cases, though, your understanding of a policy may differ from how your provider interprets it. While it may seem that you have no control over your coverage, in reality, you do. Remember, insurance claims processors are attempting to fit your unique claim into a general model. They may misunderstand the costs and the necessity of certain treatments. It’s your job to make your child’s case clear so that the processor gets the information he or she needs. Here are some helpful tips when working with your insurance company:

- 1. Ask for one insurance case manager and get his or her name.** This will save you time and help you avoid the frustration of explaining your child’s case. Sending your case manager a picture of your child will personalize your situation.
- 2. If you are denied coverage for a therapy, a treatment, or assistive device, don’t take “no” for an answer.** Insist on the exact reason for the denial. Collect all documentation explaining the need for treatment along with the reason for the denial. Consult your policy for the proper appeals

process. Insist that your insurance company or other health care provider supply all information relating to a claim denial *in writing*.

3. **Keep detailed, written records of every-thing related to your child's condition.** Keep all your bills and insurance claims. These records are essential for calculating tax deductions and for appealing decisions through administrative channels or the courts. You have the right to copies of your child's medical records and tests, so ask for them. These records may be helpful when filing appeals and in improving your knowledge of your child's condition. Keep notes on all discussions with claims representatives. Record names, dates of calls, and resolutions to your questions or concerns.
4. **Appeal unfavorable decisions.** Health insurance plans do have an appeals process. Ask your health provider to send you a copy of its process and use it. Obtain letters of support from primary care doctors and other professionals familiar with your child's needs. In one case, a mother discovered that her child's laboratory work, which cost hundreds of dollars each week, was reimbursed at 80 percent for an outside laboratory but at 100 percent if done in the hospital lab. The nurse could have easily submitted those samples to a hospital lab where the costs were covered at 100 percent. Eventually, the insurance review committee decided to cover even the nonhospital lab work at 100 percent.
5. **Ask your employer to change the benefits in your company's plan if the current benefits exclude what you need covered.** Self-insured employers are those that pay claims themselves. These employers, and large employers with fully insured plans, can (to some extent) design their own plans, which means they decide exactly what benefits will fall under the plan. Smaller employers that purchase insurance do not have quite as much flexibility as self-insured employers do, but they can choose which plan to buy. Some parents have successfully worked with their employer to change company plans to include a previously excluded benefit. Do this only if you feel comfortable disclosing personal medical information to your employer. Remember, a change such as this could result in some tax consequences.

### **Lifetime Maximums**

If you are reaching the lifetime maximum on your family's medical plan (often around \$2 million), you have a few options: Look into changing insurance carriers during an open enrollment period if your employer offers health insurance from more than one source. If you change jobs and your new employer has health coverage, your coverage starts over. If you are without coverage for too long, you may have to wait a certain time period before the new plan will pay for your child's preexisting condition (a condition that predates your relationship with this

company). The wait could last as long as one year. For parents of a child with a severe medical condition, such a wait would be insupportable.

For additional help, you also can turn to certain federal and state programs or find special grants from civic, fraternal, and charitable organizations.

### **Can You Change Jobs?**

If you have had medical coverage with an employer, you may be covered by the Consolidated Omnibus Budget Reconciliation Act (COBRA). COBRA is a federal law with two purposes: First, it can extend your health care coverage for 18 months past the end of your employment. Second, it can help you qualify for a private health care policy. For example, if you stay on COBRA until it runs out, you cannot be refused coverage when you go to purchase a private health care policy. **The insurance company cannot make you prove insurability or make you face a preexisting condition exclusion period.** But, you must buy the private policy within 180 days from the date your COBRA expires. Keep in mind that private policies often provide lesser coverage and cost more than group or COBRA plans. Also, if you obtain group insurance with a new employer, the new employer cannot charge you higher-than-standard prices, even if your child has a long-term health problem.

Some states provide special insurance coverage for children while their parents are seeking insurance coverage after changing jobs or for other reasons. Be sure to check to see if your state offers this kind of coverage. Such a program could expand your employment choices considerably, even making it possible for you to accept a position at a small company.

Alternatively, under the Health Insurance Portability and Accountability Act (HIPAA), you can be covered by a new employer's health plan without regard to preexisting conditions. This applies as long as you meet the requirements of having been fully covered under a prior plan and have not been without coverage for too long.

### ***Disability Insurance***

Disability insurance is designed to protect a parent's income stream in case of an accident or illness. Some insurance agents consider disability insurance to be as important as health care coverage for families. As the parent of a child with a disability, you may want to protect your earning power as much as possible and add disability insurance to your coverage mix. At the very least, discuss disability coverage with your financial advisor or insurance agent.

Essentially, there are two types of disability insurance: short term and long term. Typically, both types replace 50 percent to 70 percent of the income lost by a wage earner because of a disability. However, short-term disability plans typically have much lower maximum benefit amounts than long-term disability. While long-

term disability plans may protect up to \$12,000 of monthly income, short-term disability plan benefits will seldom exceed \$500 per week.

Short-term disability insurance benefits typically start soon after the onset of a disability and last 90 days to two years. Long-term disability insurance benefits usually start 30 to 180 days after the onset of a disability. Both are almost always obtained through a job, although individual long-term disability income policies are available to the self-employed and those people whose employers do not offer it. Depending on the policy, disability benefits may replace income for a period of a few years to, in rare cases, the life of the insured.

If a person is covered by short-term and long-term disability insurance, the short-term plan usually stops when the long-term plan starts. The policy may pay for a rehabilitation program or training for a new job if it appears the disabled person may someday return to work.

Defining “disability” usually is the stickiest part of these policies. To determine eligibility, read the policy carefully. Some policies pay benefits only if the person is totally disabled — in other words, the person cannot perform any work in any field. Other policies pay benefits if the person can’t perform the duties necessary to his or her “own occupation.” Some policies allow you to work part time and still receive reduced benefits. If you do not understand your policy, call the provider or ask your agent.

If an individual receives disability benefits from other sources, such as Social Security, worker’s compensation, veteran’s benefits, and so on, the amount received from employer-provided disability plans and some personally owned policies may be reduced. Generally, the sum of all disability payments will not exceed 70 percent of a worker’s average monthly earnings before the accident or illness. It’s also important to note that if you pay the premium on your disability policy, the benefits are not taxable. If your employer pays the premium, the benefits will be taxed.

## **Your Special Child’s Life**

Just like every parent, you have hopes and dreams for your child’s future. You’ll find there are many public resources available to help your child reach his or her fullest potential.

### ***Services for Children Ages Birth to Two Years***

Every state has a comprehensive system of early intervention services for infants and toddlers with disabilities and their families. (You can find a list of contacts for all 50 states at [www.nectas.unc.edu/contact/ptccoord.asp](http://www.nectas.unc.edu/contact/ptccoord.asp).) Early intervention

services include things like occupational speech, and physical therapy; case coordination; and other essential supports.

By law, the early intervention program is required to develop an Individualized Family Services Plan (IFSP) for each young child with a disability and the child's family. The plan is developed by a team of people that includes the child's parents. In this plan, you will find a statement of, the child's current level of development, the outcomes you and your child hope to achieve, and the specific services necessary to meet your child's unique needs. The early intervention system then is charged with assisting you in using these services.

In some states, you will pay for services based on a sliding fee scale for early intervention services; in other states, those services are provided at no cost.

### ***Services for Children Ages Three to Five Years***

Each state must provide special education services to preschool-aged children with disabilities. (You can find a list of contacts for each state at [www.nectas.unc.edu/contact/619coord.asp](http://www.nectas.unc.edu/contact/619coord.asp).)

Services to preschool children are provided by your school district and can occur in a variety of settings: a public school, a child-care program, or even at home. As parents, you and the school district will develop an Individualized Education Plan (IEP) for your child that spells out the services your child needs. Based on a comprehensive evaluation of your child, these services are selected to meet his or her unique educational requirements. (IEP services do not include services directed to a child's family.) Special education services for preschool children are part of the federal Individuals with Disabilities Education Act (IDEA) and are provided at no cost to families.

### ***Services for School-Aged Children***

The federal Individuals with Disabilities Education Act (IDEA) requires that each state and local school district provide every disabled child with a free and appropriate public education. This guarantee begins when an eligible child turns three and ends when the child turns age 21. Some states continue eligibility until age 26. Each child has an IEP that is developed by the school district and the child's parents, which is updated annually. The IEP contains the specific special education and related services the child needs to succeed in school.

IDEA requires that the vast majority of students with disabilities have access to the general curriculum. It also requires that children with disabilities are included in state and district-wide assessments. These requirements are designed to ensure that special-needs children achieve the highest educational standards possible.



Because IDEA is a partnership between parents and schools, it provides families with due process protections if they disagree with the school district regarding their child's education. If you believe your school district is not meeting your child's needs, seek the advice of a parent advocate to determine a solution. Each state has a Parent Training and Information Center and a Protection and Advocacy agency. These two organizations can help you learn how to advocate for your child within the public school system. A list of Parental Training Information Centers is available from the National Parent Network on Disability at [www.npnd.org](http://www.npnd.org). You also can locate a list of protection and advocacy agencies at [www.protectionandadvocacy.com](http://www.protectionandadvocacy.com).

### ***Beyond School***

All children have interests beyond the classroom. Seek out after-school recreation programs at Easter Seals, your community's recreation department, your local library, and elsewhere. All of these programs must be accessible to and usable by all students, including students with disabilities.

### ***Life Skills and Work Skills Training***

Because many disabled students have physical, as opposed to developmental challenges, they often will graduate from high school along with their class. Typically, after a student graduates from high school, the state no longer assumes any educational responsibility for that student. Students who remain in the special education system, must receive education from the state until the age of 21. Some states, like Michigan, educate children with special needs through age 26. Be aware, however, that many school districts urge you to graduate your child early even if he or she isn't ready for a job or independent living. A child with special needs due to a physical, mental, or emotional condition, including a learning disability, usually requires additional time to complete his or her education. A later graduation may be appropriate for a special-needs child.

But what happens after your child turns 21 and no longer has school? It is vitally important for people to use their talents and gifts in ways that are meaningful. Your child may love other people, enjoy creative arts, or have other interests. Depending on your child's disability, there will come a time when he or she may want to gain the self-satisfaction that comes with employment.

Your child's IEP will begin to address your child's transition needs at around age 14. The transition period is designed to ease your child's adjustment from the public school system to adult life. The IEP will describe the courses your child must take to attain his or her goals for life after school, whether those goals include some kind of additional education, career, or other options. Also, the IEP will indicate services, such as life skills acquisition and job training that the district will provide for your child through age 21.

## **College**

If your child has a learning disability, many colleges and universities offer special programs to help students complete a higher education. Likewise, if your child has a physical disability, many institutions of higher learning have made their campuses more accessible and have improved their computer centers and assistive technology services, adding devices like Kurzweil reader-scanners that scan documents and then “read” them aloud.

## **Career**

The workforce is filled with Americans with disabilities in a full spectrum of careers. From broadcasters and politicians to teachers, athletes, and actors, people with disabilities are an integral part of our economy.

An individual’s talents, interests, and disability will determine to what degree he or she will participate in the workforce — and to what degree government benefits will apply to his or her situation. People working full time in high-paying jobs are not eligible for government benefits, while people earning less money may be entitled to certain benefits. Today, the government allows people with disabilities to earn a gross maximum of \$740 a month without losing their full entitlement to government benefits. (This amount may vary for people who are blind or visually impaired.)

Organizations such as Easter Seals provide comprehensive job training and employment services ranging from vocational evaluation and employee development to skills education and placement services. States have vocational rehabilitation services offices and disabilities offices that may provide some of these services. Visit [www.pueblo.gsa.gov/crh/vocational.htm](http://www.pueblo.gsa.gov/crh/vocational.htm) for a state-by-state list.

## **Adult Day Services**

In cases where adult children with disabilities aren’t in a position to work, there often are adult day services or rehabilitation programs available. Adult day service programs offer health and personal services, as well as cultural and creative opportunities based on an individual’s needs and disability. Organizations, such as Easter Seals, provide high-quality day service programs. To find appropriate programs for your child, contact Easter Seals, your local advocacy organization, or other parents.

## ***A Place to Live***

Depending on your child’s disability, he or she will need a place to live as he or she reaches adulthood. While many and more families are trying to encourage

adults with disabilities live with their parents, more and more families are trying to encourage and educate their children to live independent lives.

If independence is a goal, ask yourself: how much can your child do alone? What tasks require some assistance? Can your child do laundry, iron, make a bed, load a dishwasher, and shop? Can he or she clean house, use public transportation, or answer a telephone? Whether your child lives alone or in a group setting, these skills will ease the transition from your home to his or her home.

## **Housing Options**

Finding or acquiring housing for your young adult may prove to be one of the most challenging areas of all. Like any parent, you will have to address your own issues of letting go. But unlike most parents, you may have greater anxieties about financing your child's independent life or wonder whether potential caregivers will provide compassionate care. Compounding these concerns maybe worries about money or the shortage of housing options available for people with disabilities.

There are several ways to approach future housing for your child. You can purchase housing yourself. You can develop an alternative housing situation for your child alone or in cooperation with other families. You can rent housing. Or, you can find an appropriate placement for your child in a residential facility. Your child's job may enable him or her to rent or own independently, too.

Some parents accomplish their child's independent living goals by purchasing a condo or townhouse in their own names. The parents may even modify the home to meet their child's accessibility requirements as a way of protecting their child's government benefits. The adult child lives in the condo and often pays rent. Then, when the parents die ownership of the condo passes to the special-needs trust.

Another creative way to help finance your child's home is to purchase a duplex housing unit, where the rent from the second unit helps cover the cost of your child's home. Be sure to ask your financial advisor or lawyer about the best ways to designate ownership if your child is receiving government benefits.

There are many residential models available to you, but you may have to be creative. More and more states, for example, are interested in developing public/private partnerships with families. One such way a partnership might work is that parents would provide housing, while the state contributes a paid caregiver. (Keep in mind, if a caregiver is paid out of a special-needs trust, it could cause liability problems under worker's compensation.)

For some people, a residential placement, such as a group home, might be appropriate. Waiting lists for residential placements can run up to 10 years. Begin researching placement options when your child is relatively young. If the facility you want for your child is part of a nonprofit organization, volunteer for that group. Not only are you investing time in a cause you believe in, you might increase your chances for a placement.

### ***Funding an Adult Life***

As a young adult, your child may lead a completely self-sufficient life with no need of your financial support or government assistance. Other young adults with disabilities will receive SSI and Medicaid and have an income from a part-time or full-time job. Everyone's situation is different. In certain instances, Medicaid might cover costs related to personal-care assistance. Rental subsidies might be available through state programs. Uncovering all the supports available to you will require a lot of work. But if you get involved in the disabilities community early on, you will have friends to help you and shared knowledge of government and community programs to draw on.

### **Embracing the Future**

Although parenting is always enormously complex, parenting a child with special needs means entering a world where the financial, educational, and logistical rules are very different. It means acquiring an education through networking, connecting to advocacy groups and nonprofit organizations. It means learning how to manage a more challenging life than you ever expected by reading articles, conducting research on the Internet, and incorporating the expert advice of doctors, lawyers, financial advisors, teachers, and other parents into your routine.

This guide offers general suggestions; there is no one way to address your family's specific needs. The solutions you create will come from trial and error, experience, newfound knowledge, and the character of your special family. While it is true that money can't buy happiness, sound money management and an understanding of how society's resources can help your child can buy some peace of mind and perhaps inspire a dream or two.

### **Resources**

#### **Alliance of Genetic Support Groups**

4301 Connecticut Ave. NW #404

Washington, D.C. 20008

1-800-336-GENE

[www.geneticalliance.org](http://www.geneticalliance.org)

**The Arc of the United States**

1010 Wayne Ave., Suite 650  
Silver Spring, MD 20910  
1-301-565-3842  
www.thearc.org

**Autism Society of America**

7910 Woodmont Ave., Suite 300  
Bethesda, MD 20814-3067  
1-800-3AUTISM  
1-301-657-0881  
www.autism-society.org

**Certified Financial Planner Board of Standards**

1700 Broadway, Suite 2100  
Denver, CO 80290  
1-888-CFP-MARK  
1-303-830-7500  
www.CFP-Board.org

**Easter Seals**

230 West Monroe St., Suite 1800  
Chicago, IL 60606  
1-800-221-6827  
1-312-726-6200  
TTY: 312-726-4258  
www.easter-seals.org

**Exceptional Parent Magazine**

555 Kinderkamack Road  
Oradell, NJ 07649  
1-201-634-6550  
[www.eparent.com](http://www.eparent.com)

**Financial Planning Association**

1-800-322-4237  
[www.fpanet.org](http://www.fpanet.org)

**Atlanta Office**

5775 Glenridge Dr. NE, Suite B-300  
Atlanta, GA 30328

**Denver Office**

3801 E. Florida Ave., Suite 708  
Denver, CO 80210

**National Academy of Elder Law Attorneys, Inc.**

1604 North Country Club Road  
Tucson, Arizona 85716  
1-520-881-4005  
[www.naela.org](http://www.naela.org)

**The National Alliance for Hispanic Health**

1501 16th St. NW  
Washington, D.C. 20036  
1-202-387-5000  
[www.hispanichealth.org](http://www.hispanichealth.org)

**National Alliance for the Mentally Ill**

Colonial Place Three  
2107 Wilson Blvd., Suite 300  
Arlington, VA 22201  
1-703-524-7600  
NAMI HelpLine: 1-800-950-NAMI  
[www.nami.org](http://www.nami.org)

**National Association of Protection and Advocacy**

900 2nd St. NE, Suite 211  
Washington, D.C. 20002  
1-202-408-9514  
[www.protectionandadvocacy.com](http://www.protectionandadvocacy.com)

**National Council on Disability**

1331 F St., NW, #1050  
Washington, D.C. 20004  
1-202-272-2004  
[www.ncd.gov](http://www.ncd.gov)

**National Information Center for Children & Youth with Disabilities (NICHCY)**

P.O. Box 1492  
Washington, D.C. 20013-1492  
1-800-695-0285  
[www.nichcy.org](http://www.nichcy.org)

**National Organization for Rare Diseases (NORD)**

P.O. Box 8923  
New Fairfield, CT 06812-8923  
1-800-999-6673  
[www.rarediseases.org](http://www.rarediseases.org)

**National Parent Network on Disabilities (NPND) Pacer Center Parent  
Advocacy Coalition for Educational Rights**

1130 17th St. NW, Suite 400

Washington, D.C. 20036

1-202-463-2299

[www.npnd.org](http://www.npnd.org)

**Parents Helping Parents**

3041 Olcott St.

Santa Clara, CA 95054

1-408-727-5775

[www.php.com](http://www.php.com)

**The Sibling Support Project**

Children's Hospital and Medical Center

P.O. Box 5371, CL-09

Seattle WA 98105-0371

1-206-527-5712

[www.seattlechildrens.org/sibsupp/aboutsiblingssupportproject.htm](http://www.seattlechildrens.org/sibsupp/aboutsiblingssupportproject.htm)

**S.N.A.P. (Special Needs Advocate for Parents)**

West Coast Office: 1801 Avenue of the Stars, Suite 401

Century City, CA 90067

1-888-310-9889

1-310-201-9614

[www.snapinfo.org](http://www.snapinfo.org)

**United Cerebral Palsy**

UCP National (United Cerebral Palsy)

1660 L St., NW, Suite 700

Washington, DC 20036

1-800-872-5827

1-202-776-0406

TTY: 1-202-973-7197

[www.ucpa.org](http://www.ucpa.org)

**Acknowledgments**

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For more than 80 years, Easter Seals has helped people with disabilities across the country. Easter Seals has a nationwide affiliate network with more than 400 Easter Seals service sites helping more than one million people every year. Easter Seals' primary services are medical rehabilitation, including early intervention, physical therapy, occupational therapy, and speech and hearing therapy; job training and employment; inclusive child care; adult day services; and camping and recreation. Easter Seals' mission is to create solutions that change lives of children and adults with disabilities or other special needs and their families. For more information about Easter Seals, visit <http://www.easter-seals.org>.

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