Dear Parent,

When your child is diagnosed with a disability, it can be overwhelming—emotionally and financially—on you, and perhaps your child and family as well. You realize, maybe suddenly, that you must change or modify plans for your child’s future. Even the most stable of families face financial challenges. Yet, in caring for your child with special needs, those challenges can make for urgent situations.

Considering the reality of this can be very difficult. That is why the Parent Advocacy Coalition for Educational Rights (PACER) Center and the National Endowment for Financial Education® (NEFE®) collaborated on this publication. Through it you will find ways to create a sense of order in your life and maintain control over your finances as you care for your child and prepare him or her for adulthood.

A Network of Parents and Organizations to Help You

Throughout the country exists a large network of parents of children with disabilities who stand ready to give you the benefit of their experiences in caring for their children. Over 100 Parent Centers across the country provide training, information, and assistance to families of children with all disabilities—ages birth to 26 years—and to the professionals who work with them.

Funded by the U.S. Department of Education’s Office of Special Education Programs (OSEP), Parent Centers assist families in understanding their rights and responsibilities under the Individuals with Disabilities Education Act (IDEA). The majority of Parent Center staff members and board members are parents of children with disabilities. They are able to offer personal experience, expertise and empathy when working with families.

The ALLIANCE National Parent Technical Assistance Center (NPTAC) is located at PACER Center, Minneapolis MN. The NPTAC provides 107 Parent Centers across the country with technical assistance, resources, and timeline information to help you:

- Understand your child’s disability
- Understand the Individuals with Disabilities Education Act (IDEA)
- Resolve school-related issues
- Obtain appropriate educational services
- Improve academic outcomes
- Connect your child with communities that provide important services

To find a Parent Center near you:

Call 1-888-248-0822 (Voice) or 1-952-838-0190 (TTY)

Visit www.ParentCenterNetwork.org
This publication was created for middle-income parents of children under the age of 18 who have disabilities. It is a simple, straightforward resource to help you manage your money, and plan for your and your child’s financial future and overall well-being. The financial management techniques presented here can help you, not just in times of crisis, but for the rest of your life.

There is an overwhelming amount of information available on caring for children with disabilities. Making your way through it all consumes too much of your precious time. So we designed this publication to accomplish several things:

- To be your starting point—to give you a broad outline of important issues you’ll deal with in caring for your child.
- Provide you with basic knowledge of these issues.
- Give you tools to create your own action plan.
- Point you in the right direction to get more detailed information.

Woven throughout this publication are possible answers to a nagging question you probably wonder about, “Who will care for my child after I’m gone?” The answers are displayed in suggested actions to take so you can, ultimately, do the four things that matter most:

- Protect your ability to make wise decisions as you care for your child and family.
- Create an environment of financial well-being for you and your family.
- Ensure continuation of your child’s important benefits and care for the rest of his or her life.
- Through your own actions, demonstrate to your child how to be determined in accomplishing goals, and how to advocate for the best possible outcome in all endeavors.

Developing your child’s self-determination and self-advocacy skills will help create a solid foundation for your child’s journey to adulthood and a life of happiness and fulfillment. There is a lot of information in this publication.

Use the buttons above to pick topics you need immediate help with.

We invite you to begin.
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This publication is intended to provide general financial information; it is not intended to substitute for, or supersede, professional or legal advice. The specific needs of every disability or life circumstance have not been covered in this publication. The best course of action must be based on individual circumstances. Note: The content areas in this material are believed to be current as of this publication's writing, but, over time, legislative and regulatory changes, as well as new developments, may date this material.

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# Organizing Your Thoughts

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Making the Most of What You Have—
Getting Organized

A lot goes in to caring for your child—making many decisions, keeping track of a lot of information, and wrestling with questions you find hard to answer are just a few things you deal with day-to-day. This chapter helps you find ways to put a sense of order to it all so you can go about providing the best possible care for your child.

Next Section: Organizing Your Thoughts
Organizing Your Thoughts: Perspectives of Your Reality

Organizing your thoughts—trying to assemble the big picture of how you will go about making decisions as you manage the practical realities of your child’s disability—is a beginning step in getting organized. Creating this big picture is hard work, but in it, you’ll find your guiding principles on how you want to care for your child. They will help ground you and keep you connected to the work you know you must do even as new and unexpected challenges arise.

Your priority is to provide your child with the best care possible. But how do you define “best care possible?”

Part of that answer will be based on experience. After you’ve cared for your child for a while—after you’ve met with doctor’s and other health care professionals, and have felt the financial impacts of that care—you may find a vision of the long-term care you want for your child begin to emerge.

Another part of that answer will be based on finding a balance in meeting your child’s growth and development needs while also caring for yourself, your spouse, and other family members.

Give some thought to what the “best care possible” means to you. Over time that meaning may change as the needs of your child, spouse, and other family members change.
Protect Your Ability to Make Good Decisions

Your child needs you to make good decisions, so you need to develop and nurture your ability to do that.

One way to nurture your decision-making abilities is to connect with parents who share your life experiences—to draw on their successes and lessons learned as a way to lighten your load and clear your path while caring for your child. Another way is regularly tending to your well-being through exercise, creative outlets, socializing with friends and family—activities that rejuvenate and refresh your mind and spirit.
Some Facts Every Parent of a Child with a Disability Needs to Know

**Financial Issues.** Health care costs are high and continue to rise. Special health care, medications, and equipment costs are even higher. For some disability-related expenses, you may not be able to recover them through benefit plans: assistive technology, transportation, assistance with activities of daily living, respite care for family members, special home care for the child, home renovations, and loss of work time.

**Health Care Plans.** This is an all-inclusive term used throughout this publication to refer to health care benefits provided in:
- Government health care assistance, such as Medicaid.
- Employer-provided health care plans.
- Health insurance policies provided by private insurance companies

Typically, you will be financially responsible for covering the following health care costs:
- Co-pays for doctor’s visits.
- Deductibles—the amount you must pay before health care benefit payments kick in.
- Co-benefit payments (example: you pay 20 percent of the cost of a service, your provider pays 80 percent).

These cumulative payments can run into many thousands of dollars. Fortunately, the 2010 Health Care Reform legislation removed lifetime dollar maximums—the dollar amount at which a health care plan would stop providing health care coverage. Beginning on September 23, 2010, health care benefit plans cannot:
- Limit the dollar amount of a patient’s lifetime coverage, also referred to as lifetime maximums.
- Limit the dollar amount of an individual service, such as surgery.

For health care benefit plans in place before September 23, 2010, any lifetime maximums specified in the plan will be removed on the anniversary of the plan’s annual renewal date.

**Government Health Care Assistance Programs.** Throughout this publication we point out ways you can help maintain your child’s eligibility for these important programs, such as Medicaid and Supplemental Security Income (SSI), if they are needed on an ongoing basis.

Eligibility for Medicaid and SSI is based on financial need and your child’s disability. “Need” and “disability” are strictly defined by
all government health care agencies. And each agency may define these terms differently. Be sure to keep all information that documents your financial need and your child’s disability. You will need it for two reasons:

1. To establish your child's eligibility for government programs
2. To provide proof of government benefits payments, if necessary.

Next Section: Organizing Your Game Plan
< Prev
Organizing Your Game Plan: Your Vision of Your Child’s Future—Your Peace of Mind

Every parent strives to answer the question “Who will care for my child after I’m gone?” The distress in trying to answer it can feel immobilizing. First, you know best how to care for your child and how to implement that care with the right balance of tenderness and tough love. How, you might think, can my child possibly receive the same level of care from someone else? And second, planning on how to meet your child’s long-term needs after you’re gone forces confronting one’s mortality far earlier than desired.

This publication’s aim is to guide you through these issues with the goal of bringing you to a place of peace about them—to help you create a game plan that incorporates your guiding principles, experience, and quest for balance, all for the sake of providing the best care possible for your child.

So, how do you get started on organizing a game plan? Resources can vary greatly by geographic location, and it may take a while to understand what your child’s long-term needs will be. Your game plan will likely evolve over the years as you learn from your experiences and as your child’s and family’s situation changes. Here is one version on how to get started on developing your game plan:

1. Call your state’s Parent Center, it can help you find resources and information that are relevant at various points in your child’s life. Your Parent Center can also help you connect with a disability-specific organization—there are many—that is right for you.
   To find a Parent Center near you:
   Call 952-838-9000 (Voice) or 952-838-0190 (TTY)
   Visit www.ParentCenterNetwork.org

2. A referral from your Parent Center or information you find from your own research can link you with organizations that can help you get the medical and emotional support your child needs.

3. Begin studying your health care plan. Get to know what is covered and what is not. If you don’t have health care benefits, contact the Family to Family Health Information Center in your state. Also, parents who have children with disabilities similar to those of your own child may be able to direct you to local health care benefits and resources they find helpful.

4. Broaden your circle of connections with specialists, support professionals, friends, disability advocates, and people in your community who can help you.

Caring for your child may be an ongoing and time consuming responsibility, but after your child’s immediate care is in place, at some point you’ll want to regroup and add create a game plan that calls for taking specific actions.

Your game plan is like a journey. Making it takes time. Here are some key actions you can take over time to plan for the long-term well being of you, your spouse, your child with special needs, and other...
family members.
1. Organize your paperwork. See in this chapter.
2. Manage your finances. See Making the Most of What You Have - Managing Your Finances.
5. Create and fund a special needs trust. See Planning Your Children's Future and the section, The Special Needs Trust.
6. Establish a conservatorship (guardianship), if necessary. See Planning Your Children's Future and the section, Conservatorship (Guardianship).
8. Engage your child in creating a vision of his or her future. See Planning Your Child's Future and Your Child's Education and Your Child's Employment.
9. Identify what actions you and your child need to take so the vision becomes a reality.
10. Take the actions that allow the vision to unfold.

Guidelines

Our culture of independence and the complex emotions that surround money issues can keep us from taking the best action—in any situation. Here are a couple things to keep in mind as you create your vision of the future and set out to achieve a peace of mind about it.

- Commit to asking for and receiving help.
- Be willing to manage your finances with eyes wide open and a readiness to make adjustments.

Next Section: Organizing Your Paperwork
Organizing Your Paperwork

# Article Title
1. Organizing Your Paperwork
2. Keep Your Records in One Place
3. Record Keeping Tasks
4. Why Record Keeping Can Help
5. Why Record Keeping Can Help, Part 2
Organizing Your Paperwork: The Engine Behind Your Advocacy

Organizing paperwork related to your finances and child’s disability will help you make the most of your financial resources, and in essence, become the engine behind your advocacy.

When your paperwork is organized, you can quickly find important information. Having the right information nurtures your decision-making abilities, relieves stress, and fosters timely rather than delayed decisions.

For every agency service, doctor’s visit, or school meeting, especially in the early days of your child’s diagnosis, you may find yourself with overwhelming emotions and frustration in response to form after form requesting the same types of information. Having that information organized and accessible can help calm emotions and paperwork-related frustrations, leaving you with more energy to care for your child.

Shorten Your To-Do List

Keeping your child’s care-related documents organized is a way to shorten your to-do list. Information stays at your fingertips—you don’t have to spend time finding it.
Keep Your Records in One Place

When your records are all in one place, you know where to find things. If your records are organized, you can find information fast. The benefits of this are many, but two really big ones are:

1. Having your records in one place reduces clutter. For some, that reduces stress.
2. Your phone conversations and meetings with individuals who provide your child with services and support will be more productive. When all your records about a certain issue are in once place, you can determine an appropriate action plan more quickly, without having to get back to someone about a particular issue.

You'll eventually develop a recordkeeping system that works for you. To get started, pick up some filing supplies. Listed below are some to consider. You can find them at any office supply store, retail superstores, and some drug stores.

Recordkeeping Supplies

- A notebook for recording phone conversations and meetings with professionals and other parents.
- A calendar with room for writing notes.
- A place to file things, such as a filing cabinet—stationary or rolling—or a file box with a lid.
- Hanging file folders.
- Plastic tabs to identify the hanging file folders.
- File folders.
- File labels for the file folders (using labels allows you to reuse the folders).
- Magic markers and highlighters for making notes and drawing attention to important information.
- Rubber bands for grouping contact cards you receive from professionals into categories, such as health care, disability-specific foundations, education, and so on.
- A three-ring binder.
- Tabs for the three-ring binder to divide the binder into sections.
- A three-hole punch.
Recordkeeping Tasks

The key to staying on top of the flood of paper you'll likely accumulate is to break large filing tasks into small ones. So even if you don't have time to actually file things away, you can still keep your paperwork organized and accessible in case you need it. Here are some ideas you might find helpful:

- Keep handy a box or file for items you know are important but don't have time to file. Examples could be bills to pay, health care plan summaries, Explanation of Benefits (EOB), and new contact information for professionals you frequently work with.
- When you open a bill, highlight the due date. Organize your bills in a way that helps you pay them on time, every month. For monthly recurring bills, mark the due dates on your calendar.
- Take a look at the File Categories below. Create large piles of documents for each main category.
- Break large piles into smaller piles for each sub-category.
- Place each small pile of documents in a manila folder, then label it.
- Place each group of folders in a hanging folder file, then label it.

File Categories

Below is a detailed list of file categories that will help you get started in the filing process. Not all file categories listed may apply to your situation, and you might come up with new categories not listed here.

To break down your filing into smaller tasks, begin with the main categories you think you need to be the most organized about, say “Government Health Care Assistance,” “Spending Plan,” and “Transition Planning.” As you come to know what kind of paperwork you reference regularly, you'll likely keep it more organized. This will help you quickly find important papers when you need to enroll your child in schools, see a new doctor, or apply for health care plan reimbursements or benefits.

Ultimately, you'll end up with a file system that helps you do your most important work of all: Be the most effective advocate for your child.

Financial

Your Finances

Spending Plan

- Your Budget
Money Saving Tips

Income
- Pay Stubs
- Alimony
- Child Support
- Public and Private Cash Assistance
- Interest Income
- Investment Income
  - Dividends
  - Rental Income
- Cash Gifts

Checking Account

Debt
- Credit Cards
- Mortgage Loans
- Auto Loans
- School Loans
- Personal Loans

Personal Savings
- Savings Account
- Investments

Living Expenses
- Utilities
- Receipts
- Warranties

Disability-Related Expenses

Tax Returns
- Tax Saving Tips

Source of Funds (examples: Grants, Studies, Foundations)

Retirement
- Employer Plans
- IRA
- Investments
- Social Security

Estate Planning and Will
- Special needs trust
- Guardianship

Your Child’s Finances

Individual Development Account (IDA)

Employment Income

Checking or Savings Accounts

Health Care

Health Care Plans

Government Health Care Assistance
- Medicaid/Medicaid Waiver
- SSI
- SSDI
- Medicare

Private Insurance
- Medical, Hospitalization, Dental, Vision


evelopes. In the days that followed, I spent a little time each day setting up a filing system. When I had finished, I felt such relief. And, no more clutter! We now use that system all the time. It helps in many ways. We know how much we owe and when bills are due. We have information on hand if we need to appeal an insurance decision. Most importantly, we’ve been able to prove my daughter’s eligibility for benefits.

This publication is intended to provide general financial information; it is not intended to substitute for, or supersede, professional or legal advice. The specific needs of every disability or life circumstance have not been covered in this publication. The best course of action must be based on individual circumstances. Note: The content areas in this material are believed to be current as of this publication’s writing, but, over time, legislative and regulatory changes, as well as new developments, may date this material.

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Why Recordkeeping Can Help You Make the Most of What You Have and Become a Better Advocate for Your Child

We mentioned that staying organized and on top of your finances helps you become more effective in advocating for your child. Here’s why. You will frequently need to refer to and provide documentation for a variety of situations in caring for your child. Take a look at the two examples below.

1. **To qualify for medical assistance**, you may have to demonstrate financial need through:
   a. Pay stubs.
   b. Income tax returns.
   c. Receipts for disability-related expenses.

2. **To challenge denial of a health care claim**, you may need to reference your:
   a. Health care plan’s Summary of Benefits.
   b. Your doctor’s visit Explanation of Benefits (EOBs).
   c. Notes from conversations with health care plan representatives.

The more accessible and organized you keep financial and disability-related information, the quicker you can meet your child’s needs. Listed below are other reasons for organizing your records that can have a financial pay-off.

**Why Keep Income Records?** To...

- **Create a Spending Plan**: Through your spending plan, you may be able to identify areas to cut back and make it easier to spend within your means and avoid expensive costs of using credit.
- **Complete Income Tax Returns**: You must declare all of your income on income tax returns. Keeping your income records organized will help you complete your tax returns faster and more accurately. That will help you avoid having to pay penalties that result from filing incomplete, incorrect, or late tax returns.
- **Apply for Benefits**: Many kinds of benefits, not just medical ones, are based on financial need. To demonstrate that, you’ll need quick access to your income through pay-stubs or the prior year’s income tax return. With accurate income records on hand, you may be able to receive benefits that you don’t have to pay for yourself.

**Why Keep Living Expense Receipts and Bill, Loan, and Credit Card Payments?** To...

- **Request Credit**: There are times you may need to request credit, and therefore, demonstrate your history of paying bills. We talk more about credit later, but paying bills on time, every month, is the single most important thing you can do to establish and maintain good credit. Your billing statements help create your payment history.
- **Challenge Items You Did Not Buy but Charged to Your Account**: Occasionally a mistake occurs. You may find you have been incorrectly charged for something, or incorrectly charged a fee. Or, someone may have stolen your credit card. By regularly reviewing your expense documents, you will be able to quickly identify when something isn’t right.
- **Create a Spending Plan**: You will use the amounts of recurring monthly expenses to create your spending plan. Through your spending plan, you will know when it’s time to look for lower costs of credit, find inexpensive alternatives to certain monthly expenditures, or learn to do without non-essential
items you've been spending money on.

Complete Income Tax Returns. You may be able to deduct certain expenses, such as home mortgage interest, on your income tax returns. By reviewing your expense documents, you may find expense items that can lower your income tax liability (the amount you owe). Speak with a financial or tax professional for (1) information on what expenses you might be able to deduct on income tax returns and for (2) an overall tax strategy.

Why Keep Documentation of Special Expenses Related to Your Child’s Disability? To...

Complete Tax Returns: You may be able to also deduct some disability-related expenses on your income tax returns. Again, speak with financial or tax professional about which expenses are allowable. Also, the IRS provides a list of toll free numbers for individuals to ask tax-related questions.

Here is a list of disability-related expense items that might be deductible. Be sure to save and file receipts for these items:

During hospitalization
- Transportation to and from treatment
- Parking while at treatment
- Lodging (if you must be away from home for treatment)
- Child care costs for your other children
- Tutoring

After hospitalization
- Special dietary supplements or food
- Medical equipment
- Assistance with activities of daily living
- Special home care
- Utility costs
- Home modifications

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Why Record Keeping Can Help, Part 2

Why Keep Checking Account Records? To…

*Balance Your Check Book.* Keep track of your checking account balance by recording all deposits, checks written, ATM and debit payments, and cash withdrawals. By doing so, you avoid bouncing checks and paying expensive overdraft fees. And that helps you protect your credit, and ultimately, qualify for lower interest rates on loans.

If you bank or pay your bills online, be sure to compare your online banking and bill-pay transactions with what you've recorded in your check book.

Why Keep Health Care Plan Records? To…

*Understand Your Medical Coverage.* Your health care plan summary that describes your benefits is one of the most important documents you own. You may need to refer to it often to find out if you have coverage for the types of health care benefits and services listed below. By knowing exactly what benefits and services are covered, you may want to consider setting aside funds or investigating alternatives before getting an expensive service or treatment that is not covered by your health care plan.

- Treatments
- Therapies
- Prescriptions
- Clinical services
- Practitioner services
- Home- and community-based services
- Assistive technologies
- Transportation
- Institutional and long-term care

Why Keep Receipts and Warranties? To…

*Get Refunds, Reimbursements, and Rebates or Exchange Items:* Sometimes new items don’t work the way they should or break during their warranty periods. A store may replace or fix an item still under warranty. Sometimes you’re eligible for a reimbursement or rebate if you can show proof of purchase. By keeping receipts and warranties, you avoid having to replace items sooner than you need to, or you get that rebate!

Why Keep Social Security Administration Documents? To…

Keep records of all communication or transactions with the Social Security Administration (SSA), initiated either by you or the SSA:

- Payments received and sent.
- Correspondence received and sent.
- Notes of all telephone and in-person conversations with SSA agents.
- SSA income and retirement benefits statements.

You may need to reference your SSA documents in order to maintain your child’s eligibility for benefits.
or to help avoid possible misunderstandings with the IRS. Also, SSA statements that document your annual income and future retirement benefits can help you determine how much you need to save for the future.

If you make an overpayment based on an obvious math error, the IRS will refund the overpayment only if you don’t owe the IRS other taxes. If you do, the IRS will apply that overpayment to any owed tax (see IRS.gov. “CP 12 - Changes to Tax Return, Overpayment” Retrieved from http://www.irs.gov/individuals/article/0,,id=125360,00.html on October 28, 2010).

Keep SSA documents forever. There is no expiration date for when the government can check on whether the SSA ever overpaid you (by error).

**Why Keep Communication Logs? To…**

Quickly Recall Important Information. Set up some system that makes sense to you so you can quickly recall important conversations and meetings or find important emails, notifications, announcements, and faxes. As an example, if someone doesn’t do what he or she promised to do and it ends up costing you money, you may be able to put together a good case for recovering that cost.

For conversations, keep a special notebook handy for recording just about everything you discuss about your child’s disability. Here is a short check list to help you make sure you record essential pieces of information:

- Date and time
- Name of the person and place of work
- Issue
- Things discussed (try to record these things in the order discussed)
- Types of information you gave
- Action items: who will do what and by when
- Contact information
- Case number (or some identifying code referencing the conversation)

For e-mail, if you use it, create subfolders in your inbox so you can quickly find important pieces of information. Create as many subfolders as you need to stay organized. Decide on a consistent way to file them.

For announcements, notices, and faxes, file these by subject matter or keep them all in a handy box.

**Next Chapter: Managing Your Finances**
Making the Most of What You Have—Managing Your Finances

Knowing where you stand financially will also help you nurture your decision-making abilities, and help you be an effective advocate for your child as well. As an example, when you have a clear idea of what you can afford or not, and how much credit you have available, you can take advantage of introductory offers or short-term sales on higher-priced items your child may need, knowing you can pay them off in full and not incur expensive credit card fees.

So let’s get started on managing your finances. Here is the basic plan we’ll follow:

1. Make a Spending Plan
2. Track Your Spending Leaks
4. Manage Your Debt
5. Protect Your Identity

Next Section: Make a Spending Plan

Finding Financial and Tax Advice

As you manage your finances, you may find areas in which you’d like to seek the advice of a financial or tax professional. Ideally you want to work with a professional knowledgeable about disability-specific financial and tax issues. Here are a few ways to go about finding a professional:

- Some Parent Centers or disability-specific organizations may know of affordable financial or tax professionals.
- Some financial and tax organizations in your area may offer professional services to people with limited resources. These organizations may also offer informative publications or workshops on disability-specific financial and tax issues. For more information, contact the following organizations to find professional financial and tax services in your area:

American Institute of CPAs—Personal Financial Planning Section: an organization for CPAs who provide estate, tax, retirement, risk management and investment planning advice to individuals.

Call 1-888-777-7077
Visit www.aicpa.org

Financial Planning Association (FPA): the largest organization of financial planners who provide financial advice to individuals and are committed to upholding the highest standards of professional competence, ethical conduct, and clear disclosure to the individuals they serve.

Call 1-800-322-4237
Visit www.fpanet.org
# Make a Spending Plan

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<td>Make a Spending Plan</td>
</tr>
<tr>
<td>2</td>
<td>Step 1: List Your Income</td>
</tr>
<tr>
<td>3</td>
<td>Step 2: List Your Expenses</td>
</tr>
<tr>
<td>4</td>
<td>Step 3: Calculate your Cash Flow</td>
</tr>
<tr>
<td>5</td>
<td>Step 4: Find Resources and Make Changes</td>
</tr>
</tbody>
</table>

This publication is intended to provide general financial information; it is not intended to substitute for, or supersede, professional or legal advice. The specific needs of every disability or life circumstance have not been covered in this publication. The best course of action must be based on individual circumstances. Note: The content areas in this material are believed to be current as of this publication’s writing, but, over time, legislative and regulatory changes, as well as new developments, may date this material.

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Make a Spending Plan

Here is where your time spent getting organized really pays off, because you'll use many of your organized documents to create a spending plan. Your spending plan, or budget, shows you exactly where your money comes from and where it goes. It is the best way to get the big picture of your finances. The big pay-off comes through the keen awareness you develop on how you spend your money and how much things cost. With that comes an additional awareness of areas to cut back on or replace with lower-cost alternatives.

You can create your spending plan in four steps:

1. List your income
2. List your expenses
3. Compare your income and expenses
4. List your resources and set priorities

“There are many programs to help meet expenses, but they are not always well-publicized. This means you have to use all the ‘know-how’ and ‘stick-to-it-iveness’ you can muster. You really have to dig to find the help your child needs!”

—Mindy Cheney, mother of Carol Ann

Give Yourself a Raise

Did you know that the average family loses 30 cents of each dollar (or 30 percent of their money) through careless spending? For example, if you earn $600 a week, your spending habits could be robbing you of $180. But if you stop this loss, it's like giving yourself a 30 percent bonus or pay increase.

How to Use the Spending Plan Forms for Steps 1, 2 & 3

The spending plan forms for Steps 1, 2, and 3 have two columns:

- Column 1: “Current Amount”
- Column 2: “Anticipated Amount”

“Current Amount” refers to the income and expense amounts you have today. “Anticipated Amount” refers to income and expense amounts you think you might have in the near future. To get started, just fill out Column 1, “Current Amount.” But you'll want to come back and fill in the “Anticipated Amount” column. Over time, your financial needs may change, health care costs will likely change as your child’s needs change, or your financial situation may change significantly from a loss of income, a job, or a benefit.
Step 1: List Your Income

Using your organized documents and the "Income" form (see links below), enter the amounts of your current monthly income in the first column. Also list all the income or funding you can reasonably expect to receive related to your child’s disability, such as government health care assistance and gifts of money from community, civic, or religious organizations.

How to Handle Reimbursements

You may receive reimbursements for some medical costs from your health care provider. Reimbursements are not a source of income, but a type of payment for medical care. Reimbursements offset actual expenses. This is why any medical reimbursement amounts and the actual expense amounts must both appear in your spending plan. Even though the reimbursements cancel out the actual expenses, including them in your spending plan will help you keep track of how you spend your money.

Take note! If you include a medical reimbursement in the "Income" form and not the actual expense in the "Expense" form, you will overstate your income. Likewise, if you include a medical expense but not its reimbursement, you will overstate your expenses.

How to Handle Periodic or Temporary Income

Some investment income, such as dividends, is paid monthly. Workers compensation is temporary income. Financial assistance from friends or family may be periodic. The purpose of the spending plan is to get a picture of what is happening right now in your financial life. If you do include periodic or temporary income, take into account that your actual monthly income amount may be overstated for some months.
<table>
<thead>
<tr>
<th>Income</th>
<th>Current Amount Per Month</th>
<th>Anticipated Amount Per Month</th>
</tr>
</thead>
<tbody>
<tr>
<td>After-tax wages (your own)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>After-tax wages (others in your household)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bonuses/tips</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gifts</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child support</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Interest on savings</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Investment income (may fluctuate from month-to-month)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unemployment compensation (temporary income)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Government health care assistance</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sources of funding related to your child’s disability:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health care plan reimbursements (doctors, hospital, lab, etc.; see “How to Handle Reimbursements” above)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medicaid income</td>
<td></td>
<td></td>
</tr>
<tr>
<td>State programs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social Security Disability Insurance (SSDI), Supplemental Security Income (SSI), or Social Security Retirement Income</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Assistance from fraternal and civic organizations (may be periodic)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Assistance from family members, friends (may be periodic)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other:</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Total Income:** $ - $
Step 2: List Your Expenses

Using your organized documents and the “Expense” form in the link below, enter the amounts of your current monthly expenses in the first column.

- **For monthly expense amounts that vary every month**, such as utilities, use an average monthly amount.
- **For periodic expenses**, such as auto insurance premiums, spread the expense amount over the service period. For example, if your insurance premium due is $600 every six months, divide $600 by six months for a monthly expense of $100.
- **For items you purchase on credit**, such as a piece of assistive technology equipment for, say, $6,000, adjust your spending plan to reflect how much you’ll spend each month to pay it off. You may have to account for interest expenses on unpaid balances.
- **For items you purchase for cash from your savings account**, such as travel or entertainment items, adjust your spending plan to reflect how much you’ll save each month to build your savings back up.
- **For anticipated expenses** you might incur while caring for your child, there is no easy answer. You may have to purchase or replace assistive technology devices or pay for new services. Consult with professionals, your case worker, and other parents familiar with your child’s disability to get a feel for what types of costs you might incur, their approximate amounts, and any lower-cost alternatives.

List_Your_Expenses_pdf  List_Your_Expenses_Excel File

< Prev  Next >
<table>
<thead>
<tr>
<th>Expense</th>
<th>Current Amount Per Month</th>
<th>Anticipated Amount Per Month</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home mortgage (includes principle, interest, taxes, and insurance [PITI])</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rent</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Renters insurance premiums</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health insurance premiums</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Life insurance premiums</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Natural gas or heating fuel</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Electricity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Water</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Phone—Landline (include local and long distance, plus any special services)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Phone—Cell (include special services such as ring tones and texting)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Computer and Internet services</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cable TV</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Groceries</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Meals eaten out</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transportation (public transportation, car payments, gasoline, insurance, maintenance, repairs, etc.)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dental bills</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pet care</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Union and professional organization dues</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clothing costs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tithing or charitable donations</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Loan payment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Credit card payment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Personal (toiletries, allowances, etc.)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Entertainment</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**Miscellaneous (cable TV, subscriptions, magazines, classes, etc.)**

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

<table>
<thead>
<tr>
<th>Item</th>
<th>Expense 1</th>
<th>Expense 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Special diet for child with a disability</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical costs (doctor bills, hospitalization, lab work paid out of pocket)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical costs that will be reimbursed (be sure you enter the reimbursed amounts in your “Income” form; see)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Co-payment for health care benefits other than Medicaid or Medicare</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Therapy (occupational, physical, etc.)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transportation to/from special care or hospitalization</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lodging and meals during treatment away from home</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Costs for disability related adaptations for a vehicle</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other assistive technology</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disability related home renovation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child care/nursing care</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home health care to assist in day-to-day living</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Legal fees</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Total Expenses:** $ - $ - $
Step 3: Calculate Your Cash Flow—Compare Monthly Income and Expenses

“So many people find it offensive to either seek or accept help. But when you get right down to it, we are a single nation and community. We all pay taxes, and some of those taxes are earmarked for the most vulnerable among us—our kids. When a family has a child with a disability, costs may be way beyond the scope of one family’s ability to pay. We shouldn’t be embarrassed to do the hard work of finding and applying for the help our children need.”

—Diane Hovey, parent advocate, mother of Sonya

Calculate_Your_Cash_Flow_pdf  Calculate_Your_Cash_Flow_Excel File

< Prev  Next >
<table>
<thead>
<tr>
<th>Cash Flow</th>
<th>Current Amount Per Month</th>
<th>Anticipated Amount Per Month</th>
</tr>
</thead>
<tbody>
<tr>
<td>Write down your total monthly income from Step 1.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Write down your total monthly expenses from Step 2.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Calculate your Cash Flow:</td>
<td>$</td>
<td>-</td>
</tr>
<tr>
<td>Subtract your expenses from your income and list the amount here.</td>
<td>$</td>
<td>-</td>
</tr>
</tbody>
</table>
Step 4: Find Resources and Make Changes—Increase Income or Reduce Expenses

Do you have money left over each month—a positive cash flow—after paying your expenses? If so, fantastic. If not, you have a negative cash flow. There are ways to fix that. The most obvious one is to reduce your expenses. You also can increase your income, or do a combination of both. Let’s start with reducing your expenses. Often, that is the easier thing to do.

Strategies for Reducing Your Expenses

Expenses associated with your child’s disability, such as hearing aids, are often not covered by health care plans. As your child’s needs change and these associated expenses increase, you may find that you are unable to continue paying for them.

If your child receives support through a government health care assistance program, contact your case manager to find out what resources might be available to help you pay for these items. You can also:

- Contact your local Parent Center to speak with someone about possible funding sources for these associated costs.
  - To find a Parent Center near you:
    - Call 888-248-0822 (Voice) or 952-838-0190 (TTY)
    - Visit www.ParentCenterNetwork.org
  - Write
    - PACER Center, Inc.
    - 8161 Normandale Blvd.
    - Bloomington, MN 55437

- Contact a disability-specific organization to inquire about funding sources. Examples of disability-specific organizations are Spina Bifida Association, United Cerebral Palsy, or the Autism Society. You might also want to visit www.Disability.gov. The Web site lists many disability-specific organizations, and provides many other disability-related resources.
  - To find a particular disability organization on www.Disability.gov, click “Community Life” and “Disability Organizations.”

Even though we haven’t yet begun talking about planning for your child’s employment, there is a job-related resource that might point you in the right direction for funding sources. The Job Accommodation Network (JAN), a service of the Office of Disability Employment Policy and the U.S. Department of Labor, has a web page that lists possible funding sources for assistive technology and disability-associated expenses. To check out these resources, contact JAN:

- Call 1-800-526-7234 (Voice) or 1-877-781-9403 (TTY)
- Visit www.askjan.org

Here are some other things you can do to lower your expenses:
Network. Contact your local Parent Center to find out how to get connected to parent support groups for families of children with your child’s disability. Other parents may be able to share money-saving ideas for treatments, therapies, services, and assistive technologies.

Look for Funding Sources. Some foundations, government agencies, and financial, academic, and medical institutions offer grants, low-cost loans, or other funding mechanisms for a variety of needs associated with your child’s disability. Contact your disability-specific organization or your local Parent Center for tips on finding potential funding sources.

Compare Rates, Fees, and Premiums. Do a little shopping around for lower mortgage and auto loan rates, credit card rates and fees, bank fees, and auto and health insurance premiums. If you find a lower mortgage interest rate, then apply to refinance your mortgage to a lower interest rate. If you find lower bank fees, then switch banks. If you find lower auto or health insurance premiums, then switch insurance companies. Be sure to ask about any fees you might incur before taking any of these actions.

Examine Your Bills for Errors. Mistakes happen, even with automated billing systems. Sometimes they break down a bit.

Other Cost-Reduction Tips

- Make a grocery list from a preplanned menu and stick to it.
- Buy store brands, compare prices, and look for the weekly store specials.
- Clip coupons and use a store “membership” card.
- Shop the sales and stock up on items you use regularly.
- Learn new recipes that have simple, readily available ingredients.

Strategies for Increasing Your Income

Finding an option for increasing income can be very challenging for parents of children with special needs. Because of the high-level of care your child may require, likely you’ll want to spend more time with your family, not less. Taking on a second job or working over-time might not be practical.

Job searches themselves can be very demanding, and not only because of a competitive job environment. Finding a job with employee health care benefits is a big consideration in any job search, along with finding an employer willing to provide you with flexibility when you need it for emergency care or time off to visit a specialist in another city.

Working with a job-search agency or employment agency may help you find the job and health care benefits you want and need.

Here are some ways you can increase your income:

- Ask for a raise.
- Find a higher paying job.
- Work over-time.
- Get a second or part-time job.
- Start your own business, even if you can only do it on nights and weekends. If you have a special skill, such as accounting or woodworking, sell it to people you know or ask them for referrals to potential customers.
- For help in getting your own business started, take a look at the U.S. Small Business Administration—Small Business Planner. You will find information on how to plan, start, and manage your business.
- Visit www.sba.gov and click “Small Business Planner”
- Provide a needed service in your community for pay. Babysitting, dog walking, snow shoveling, and tutoring are some examples.
- Participate in a research study for pay at hospital or university.
- Sell unused household items at a garage sale or through an online auction.

Beware of Job Scams

Some jobs promise to pay attractive income for simple work, like stuffing envelopes. These jobs might be scams. So might advertised jobs that require you to buy materials before “beginning” the job. For help in identifying job scams, visit the Federal Trade Commission’s Web
Track Your Spending Leaks

Spending money on small stuff—things nice to have but easy to do without—adds up over time. For example, what might you be spending on bottled water, coffee, ATM fees, and extra cell phone services? Take a closer look at where all of your money goes. For about seven days, track how you spend money on “minor” expenses and purchases that don’t seem to add up to much. Don’t worry if you occasionally skip a day. The point is to become keenly aware of how you spend all of your money. After this period, ask yourself what expenditures you can cut back on.

Track_Your_Spending_Leaks_pdf

Track_Your_Spending_Leaks_Excel File

Next Section: Set Smart Financial Goals
### Track Your Spending Leaks

<table>
<thead>
<tr>
<th>Name of Item</th>
<th>Cost of Item</th>
<th>What I spend on this item each:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ATM Fees</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bottled water</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Soft drinks</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Coffee</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alcohol</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Snacks</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cigarettes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fast food</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dining out</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lottery tickets</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Movie tickets</td>
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<td></td>
</tr>
<tr>
<td>Extra cell phone features</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cable TV</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Short-term payday loans</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Books, CDs, DVDs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Subscriptions (print and online)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Online auction purchases</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Recreational shopping</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Total spent each week, month, and year.</strong></td>
<td>$ - $ - $ - $ -</td>
<td></td>
</tr>
</tbody>
</table>

Add amounts of circled items to find out how much money you can save each week, month, and year.
Set S.M.A.R.T. Financial Goals

Consider the times in your life you set a financial goal, such as saving money for a down payment on a car or house. While you knew you were committing to a potentially long period of monthly payments, once you received your set of keys, you materialized a dream and met a financial goal.

Today, you face higher expenses while caring for your child with special needs. Maybe you’ve had to put your career on hold or take on part-time work to help finance these expenses. Even if you face a less-than-desirable cash flow, you can still set goals that help improve your financial well-being.

For example, in the sections Make a Spending Plan and Track Your Spending Leaks we listed ways you can reduce your expenses. Starting with those, let’s set some S.M.A.R.T. goals.

S.M.A.R.T. goals are:

**Specific:** “I’ll go to the coffee shop only twice each week” is more specific than “I won’t go to the coffee shop as much as I used to.”

**Measurable:** “I will call and speak to an advocate at my local Parent Center to get at least one list of organizations that might be able to help pay for assistive technology” is measurable; “I want to find out how other parents pay for assistive technology” is not.

**Achievable:** “I will save $5 a week” is more achievable than “I am going to save $50 a week” if you don’t have the money.

**Realistic:** “I will shop around for a low-rate, low-fee credit card by the end of the month” is realistic only if you set aside the time to do actually do that.

**Time bound:** “I will start contacting funding sources for assistive technology by the end of next week” is a more specific time frame than “I will start looking for funding sources after the holidays.”

When you first learn of your child’s disability it may be difficult to think beyond your family’s immediate needs. At some point, though, you’ll need to think about, plan, and set goals for the future:

- Your future: estate planning and retirement.
- Your child’s future: education, employment, independent living, and transportation to and from places.
- Your family’s travel and entertainment.

**My S.M.A.R.T. Goals**

Setting S.M.A.R.T. goals helps you stay focused on achieving them. Putting your goals in writing makes them seem more real. Use this form to write your goals. Read your goals out loud, and often. That will help make them seem even more real.

My_SMART_Goals.pdf  My_SMART_Goals_Excel File

Next Section: Credit — What You Need to Know
areas in this material are believed to be current as of this publication’s writing, but, over time, legislative and regulatory changes, as well as new developments, may date this material.

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# My S.M.A.R.T Goals

Setting S.M.A.R.T. goals helps you stay focused on achieving them. Putting your goals in writing makes them seem more real. Use this form to write your goals. Read your goals out loud, and often. That will help make them seem even more real.

<table>
<thead>
<tr>
<th>Time Frame</th>
<th>Achievement Date</th>
<th>Amount Needed to Achieve Goal (if applicable)</th>
<th>Monthly Savings Needed to Achieve Goal (if applicable)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Short Term</strong> <em>(goals you want to achieve in 1 to 3 months)</em></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Medium Term</strong> <em>(goals you want to achieve in 3 to 12 months)</em></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Long Term</strong> <em>(goals you want to achieve in one year or more)</em></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## Credit — What You Need to Know

<table>
<thead>
<tr>
<th>#</th>
<th>Article Title</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Credit — What You Need to Know</td>
</tr>
<tr>
<td>2</td>
<td>What is Credit?</td>
</tr>
<tr>
<td>3</td>
<td>Get and Read Your Credit Report</td>
</tr>
<tr>
<td>4</td>
<td>What Does My Credit Score Mean</td>
</tr>
<tr>
<td>5</td>
<td>How Do I Improve My Credit Score?</td>
</tr>
<tr>
<td>6</td>
<td>I Want to Shop Around for a Credit Card</td>
</tr>
<tr>
<td>7</td>
<td>Transferring Credit Card Balances</td>
</tr>
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This publication is intended to provide general financial information; it is not intended to substitute for, or supersede, professional or legal advice. The specific needs of every disability or life circumstance have not been covered in this publication. The best course of action must be based on individual circumstances. Note: The content areas in this material are believed to be current as of this publication’s writing, but, over time, legislative and regulatory changes, as well as new developments, may date this material.

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Credit—What You Need to Know

Credit plays an important role in our lives. Without it, life gets complicated. You might even miss money-saving opportunities. For example, few can afford to buy a home or car with cash; most take out a loan to do that. Some employers run credit checks on potential employees as a way to screen them, especially if they are handling cash or working with sensitive customer information.
What Is Credit and Why Do I Need It?

Credit is buying today and paying later, by a specified date. Lending institutions and credit card companies will consider you credit worthy if you can demonstrate a history of routinely paying back borrowed money on the date it is due; less so, if you occasionally pay back borrowed money on the date it is due. The cost to use credit is in the form of an interest rate charged against the amount of borrowed money you owe the creditor.

How you use credit reflects how you manage your money. You will qualify for the best rates on loans and credit cards when you are considered credit worthy, or considered most likely to pay back borrowed money on time, every month. The opposite is true if you are considered less credit worthy, or less likely to pay back borrowed money on time, every month.

Why Do I Need Credit?

People usually use their good credit to:
- Buy large, expensive items, such as a car or appliance.
- Finance an education.
- Buy a house.
- Purchase items online.

Having credit is important for several other reasons. Employers, landlords, utilities, and insurance companies may want to look at your credit as well. Here is why:

Employers sometimes view job applicants’ credit reports as a screening tool to:
- Confirm a person’s identity.
- Determine a person’s future job performance; employers may consider a person responsible with money likely to also be responsible while on the job.
- Determine if a person’s debt payments would require too much take-home pay and cause financial hardship.
- Take precaution when jobs require employees to use cash or confidential information.

Landlords and utility companies need to know if you will pay your bills on time. Your credit report shows whether or not you routinely pay your bills on time.

Insurance companies may view your credit to help predict if you will file a claim. Sounds odd? Car insurance companies find that people who manage their money well...
This publication is intended to provide general financial information; it is not intended to substitute for, or supersede, professional or legal advice. The specific needs of every disability or life circumstance have not been covered in this publication. The best course of action must be based on individual circumstances. Note: The content areas in this material are believed to be current as of this publication’s writing, but, over time, legislative and regulatory changes, as well as new developments, may date this material.
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Get and Read Your Credit Report Every Year

Your credit report is a snapshot on how you manage your money—how timely you pay your bills and the amount of your debt, if any.

What Kind of Information Is on my Credit Report?

Three national credit-reporting agencies collect your financial information from financial institutions and utility companies to create your credit report. It contains four types of information:

- **Identifying Information**: your name, address, date of birth, and social security number.
- **Credit Information**: all the financial institutions that have approved you for credit, and for how much; and whether you have paid back borrowed money on time, every month.
- **Public Record Information**: charge-offs, foreclosures, and bankruptcies.
- **Inquiries**: a list of financial institutions that have requested your credit report to determine whether or not to approve you for credit.

Like regularly checking the oil in your car as part of maintaining it, you need to regularly check your credit as a way to maintain it. Reading your credit report should become an annual “to-do.” Here are three good reasons to do that:

- Look for errors, such as late payments or a collection notice, that could negatively affect your credit.
- Look for credit activity you didn’t authorize, which could be a sign of identity theft.
- Stay informed on the type of information that creditors can view about you.

How to Correct Credit Report Errors

If errors appear on your credit report, you have the right to have them corrected at no charge to you. The credit report itself will provide information on how to correct errors. Instructions on how to do that may be listed under “How to file a dispute” located at the end of your credit report. You will have to provide evidence, such as a copy of a canceled check as proof of payment, that supports your request to fix an error.

If a credit-reporting agency refuses to correct information you believe is in error, initiate another “dispute.” If the credit card company still does not correct the error, you have the right to...
insert a written explanation of the error into your credit report. You may want to contact your state’s attorney general’s office or the National Foundation for Credit Counseling (NFCC) for assistance. If you believe your identity has been compromised, in that you notice credit activity on your credit report that you know you didn’t authorize, see the section on reporting identity theft.
What Does My Credit Score Mean?

Your credit score is a three-digit number that sums up all the information on your credit report into one tidy number. It follows you around for your entire life, its value moving up and down depending on what's happening in your financial life.

This three-digit score goes by two different names, FICO or VantageScore. The FICO score is named after the company who invented this three-digit scoring system in the mid-1980s, Fair Isaac, Inc. Many lenders use the FICO scoring system.

More recently, the three major credit reporting agencies created their own scoring system, called the VantageScore, designed to produce a more consistent score across all three credit reporting agencies. (Each credit reporting agency collects different financial information on you, and therefore, reports a different credit score.)

So what does a score mean? What's a good credit score? Or a bad one?

**VantageScore**

With a VantageScore, you can determine what kind of rate and terms you’d qualify for. The VantageScore range is 501–990, along with an assigned letter grade.

- **A**: 901–990 (Super Prime; lenders offer their best rates and terms)
- **B**: 801–900 (Prime Plus; lenders offer good rates and terms)
- **C**: 701–800 (Prime; lenders offer reasonable rates and terms)
- **D**: 601–700 (Non-Prime; lenders offer less favorable rates and terms)
- **F**: 501–600 (High Risk; lenders usually do not offer credit)

**FICO Score**

With a FICO Score, what kind of rates and terms you’d qualify for is not really defined. The FICO score range is 300–850. While there is no clear indication of what a good or bad score is, you can generally consider a score of 640–680 the dividing point between good and bad scores—the point at which above you’d get better rates and terms; the point at which below you’d get worse rates and terms.

The VantageScore Compared to the FICO Score

So what are the similarities and differences between the two scores? Because the VantageScore and FICO Score use different scoring systems, a VantageScore of say, 650 (considered “non-prime”) does not equal a FICO Score of 650 (where some lenders might consider that a “prime” score).

If you want to assess whether or not you’d qualify for a loan before you actually apply for it, you’ll want to assess your credit by the same credit score your lender will use. Just ask your lender if it uses VantageScore or FICO.

**Similarities**

Both VantageScore and FICO appear to place high importance on:

- **Payment history**: whether or not bills are paid on time.
- **New credit inquiries**: how often you request new credit for, say, a credit card, a mortgage loan, or an auto loan.

**Differences**
Vantage Score appears to emphasize:

- Credit utilization: how much of your available credit you use.

FICO appears to emphasize:

- Length of credit history: the number of years you’ve been using credit.
- Types of credit you use: credit card, mortgage loan, auto loan, for example.
How Do I Improve My Credit Score?

The single most important thing you can do to improve your score is pay your bills on time, every month. Getting and keeping your paperwork organized can help you improve your credit score. By keeping your monthly bills in a “To Pay” folder with due dates highlighted and marked on your calendar, you become less likely to miss a payment, or even lose track of a bill because it’s hiding in a stack of unorganized papers.

Here is how FICO and VantageScore view your financial behavior and assign percentages to each behavior to determine your credit score. The higher the percentage, the more important that behavior becomes in determining your credit score.

As you can see, both FICO and VantageScore place a high importance on your payment history—whether or not you pay your bills on time, every month.

<table>
<thead>
<tr>
<th>Credit Behavior</th>
<th>VantageScore</th>
<th>FICO Score</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Payment History</strong>: How pay your bills</td>
<td></td>
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<tr>
<td>On time: improves your score</td>
<td>32%</td>
<td>32%</td>
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<tr>
<td>Late: damages your score</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Available Credit</strong>: How much credit you are approved for</td>
<td>7%</td>
<td>not applicable</td>
</tr>
<tr>
<td>The more available credit you have, the better (but the more you use, not so).</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Credit Utilization</strong>: How much of your approved credit you use</td>
<td>23%</td>
<td>not applicable</td>
</tr>
<tr>
<td>Do you use all of the credit you’re approved for (your available credit)?</td>
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<td></td>
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<tr>
<td>Even if you pay off your credit cards each month, try not to use more than 30% of the total amount of credit you’re approved for. If you must carry a balance, limit it to that 30% of total approved credit.</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Credit Balances</strong>: How much money you owe (your debt)</td>
<td>15%</td>
<td>30%</td>
</tr>
<tr>
<td>Low or zero credit card and loan balances: improves your score</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High balances: damages your score</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Depth of Credit</strong>: How long you’ve been using credit</td>
<td>13%</td>
<td>15%</td>
</tr>
<tr>
<td>While the number of years you need to have used credit before they help improve your score rather than damage it is undefined, the longer you’ve used credit, the better.</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Inquires</strong>: How often you request credit</td>
<td>10%</td>
<td>10%</td>
</tr>
<tr>
<td>None to once a year: improves your score</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Many times a year: damages your score</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Exceptions: requesting credit for insurance or mortgage or auto loans—lenders know you shop around for these types of products</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Credit Type</strong>:What kind of credit you have—mortgage, auto, revolving (credit card), personal credit</td>
<td>not applicable</td>
<td>10%</td>
</tr>
<tr>
<td>A combination of loan types: helps your score (having only one type of credit, such as credit cards, doesn’t hurt your score, but having a variety of types helps your score).</td>
<td></td>
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</tr>
</tbody>
</table>
I Want to Shop Around for a Credit Card. Where Do I Begin?

Your local banks and credit unions are a good place to begin shopping for a credit card. Using the form in *Fees Associated with Credit Cards*, you can begin comparing which card might be best for you. If you have a computer, your credit card shopping options increase. At [www.BankRate.com](http://www.bankrate.com), you can shop for a variety of credit cards. For example, you can shop for a card that features:

- Low-interest rates for credit card balances.
- No annual fee to use the card.
- Low fees for transferring credit balances from a high-rate card to a low-rate card.

**Beware of “Teaser Rates”**

There are many credit card companies out there and they all want your business. Offering an introductory or “teaser rate” for charges on unpaid balances is one way credit card companies try to attract your business.

While teaser rates might appear very attractive and well below rates other credit cards offer, teaser rates are good only for a certain period of time, such as six or nine months. After the introductory period ends, you will be charged the credit card company’s normal rate on unpaid balances.

In some cases that normal rate may be in line with what other companies charge. In other cases, it will be a lot higher. If you are interested in a credit card offering a teaser rate, be sure you know what rate you will be charged on unpaid balances after the introductory period ends.
Transferring Credit Card Balances—What You Need to Know

If you want to transfer credit card balances to a lower-rate or lower-cost card, make sure you know:

- The fees charged to transfer the funds—usually three to four percent of the balance. That amount will be added to your existing balance.
- The transfer rules—when does the advertised rate, or “teaser rate,” end? What could trigger the teaser rate to end earlier than advertised, such as a late payment?
- Usually the teaser rate applies only to transfer balances, not on existing balances, or balances for new purchases. What rate will be charged for new purchases? Often the rate for new purchases is higher than the teaser rate.
Fees Associated with Credit Cards

Using credit comes with a price, and in different forms. It literally pays to know what to look for when shopping around for a credit card. Here is a list of fees you need to know about so you can knowledgeably assess which card is right for you.

If you are unable to determine exactly what type of fee might be charged from the credit card company’s brochure or web site, call the credit card company and speak with a representative.

Typical_Fees_Charged_by_Credit_Cards_pdf

Typical_Fees_Charged_by_Credit_Cards_Excel

File
### Typical Fees Charged by Most Credit Card Companies

<table>
<thead>
<tr>
<th>Fee Type</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Annual Fee</td>
<td>The amount you pay each year to use the credit card.</td>
</tr>
<tr>
<td>Annual Percentage Rate (APR)</td>
<td>The interest rate you pay on unpaid balances.</td>
</tr>
<tr>
<td>Balance Transfer APR</td>
<td>The interest rate you pay on balances transferred to your card.</td>
</tr>
<tr>
<td>Balance Transfer Fee</td>
<td>The fee you pay to transfer a balance to your card.</td>
</tr>
<tr>
<td>Cash Advance APR</td>
<td>The interest rate you pay on cash advances.</td>
</tr>
<tr>
<td>Cash Advance Fee</td>
<td>The fee you pay at the time you get the cash advance.</td>
</tr>
<tr>
<td>Credit Limit</td>
<td>This is not a fee or a charge, but the maximum amount of purchases you can charge to a card.</td>
</tr>
<tr>
<td>Grace Period</td>
<td>The length of time from the date of purchase to the date you start accumulating interest.</td>
</tr>
<tr>
<td>Late Fee</td>
<td>The fee you pay if you don’t pay your bill by the due date.</td>
</tr>
<tr>
<td>Over-The-Limit Fee</td>
<td>The fee you pay for purchase amounts that exceed your credit limit.</td>
</tr>
</tbody>
</table>

#### Additional Fees that May be Charged for Cards Issued to High-Risk Users

- Account Set-up Fee
- Activation Fee
- Additional Card Fee
- Application Fee
- Inactivity Fee
Provisions of the Credit CARD Act of 2009

The goal of this legislation that became fully in effect February 22, 2010, is for consumers to easily determine what fees lenders charge, when, and for what amount. Here is a summary of new restrictions imposed on credit card companies.

Interest Rates

Companies cannot raise interest rates on existing balances for the first 12 months after you open an account unless:

- Your card is tied to a rate index, which moves up and down over the course of time.
- The period for an introductory (“teaser”) rate ends (see Beware of Teaser Rates).
- The account is at least 60 days overdue.

However, credit card companies can increase interest rates for new charges, but only after the first 12 months of opening your account.

Fees

- **Over-the-Credit-Limit Fees.** Consumers must agree in advance (opt-in) to pay for purchases that exceed their credit limits. If that advance agreement is not made, credit card companies will deny purchases that exceed credit limits.
- **Caps on High-Fee Cards.** Some credit card companies charge an application fee, or annual fee to use the card. These fees cannot exceed 25 percent of your credit limit. For example, if a card has a $500 credit limit, application or annual fees charged for the first year can’t exceed $125. This provision does not apply to penalty fees, such as a late payment fee.

Payments

- **Companies may not charge consumers a fee to pay by phone, electronic funds transfer, or mail unless the consumer requests to expedite the payment.**
- **For balances charged one APR for purchases and another APR for cash advances (usually a much higher APR), the portion of a credit card payment that exceeds the minimum balance must be applied to the balance with the higher APR.**
- **Consumers must receive statements at least 21 days before the grace period ends—the period where purchases are not subject to interest charges.**

Due Dates

Due dates must be the same every month.

Student Cards

Consumers under the age of 21 are eligible for a credit card only if they can demonstrate independent sources of income or if a parent, guardian, or spouse co-signs the credit card contract.

Gift Cards

Issuers of prepaid cards, gift cards, and gift certificates cannot charge service or inactivity fees unless 12 months have passed. Cards cannot expire within five years of the card’s activation date.


Next Section: Managing Your Debt
# Manage Your Debt

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<th>Article Title</th>
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<td>About Bankruptcy, Foreclosure, and Repossession</td>
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<tr>
<td>5</td>
<td>About Bankruptcy, Foreclosure, and Repossession Part 2</td>
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</table>
Manage Your Debt

Doctor visits, home modifications, medications, therapies—the costs of them add up and stress your finances. In addition, you may have less money if one parent had to cut back on hours or give up a job to care for your child. Perhaps your good credit is keeping you going while you figure out how to manage all of your expenses.

At times it might seem that the only thing you can do is delay paying bills. Don’t. Pay something. If you are having trouble paying your bills, pick up the phone and call the company or person to whom you owe money—the credit card company, the utility company, the doctor’s office, your landlord—and propose a realistic payment plan. Then keep your promise. If at any time you fear that you can’t, call your creditor immediately and be prepared to offer a solution (see below).

Once you’ve made a payment, call the lender to make sure your payment was received and credited to your account. If it hasn’t, wait a couple of days and call again. If you think your check got lost in the mail, you will have to call your bank to stop payment on it and send your lender a new check. Most banks charge a “stop payment” fee.

If you made your payment online, you’ll get immediate confirmation of your payment. Make a note of the confirmation number in case you need to reference it.

What Do I Do if I Miss—or Am About to Miss—A Payment?

If you’ have missed a payment or are coming close to missing one, contact your creditor and work out a payment plan. Doing so can help avoid collection calls and minimize damage to your credit score that could result from paying late (or not at all).

Before you make your call, decide what you will propose—how much you can pay and by what date. Be realistic about exactly what you are able to do.

- Can you pay the amount in full, but after the due date?
- Can you pay a reduced amount? By when?
- Can you pay nothing for the foreseeable future?

Questions to Ask Your Creditor if You’ve Missed Your Payment

Before you make your call try to determine if:

- You’ve been charged a late fee
- Your interest rate got higher
- Your payment terms (fees, due date) have changed.
Begin your phone conversation acknowledging that you missed a payment, then propose your payment plan. Be sure to ask these questions before you end the conversation:

- Can you waive the late fee?
- Can you make one payment that will cover two months—the month you are late on and the current month?
- Can you restore the interest rate to the previous level (if it has gone up)?
- What else will I be charged for on account of the late payment? Can you remove the charge?

Your creditor’s willingness to accommodate your requests will be greater if you have a history of routinely paying your bills on time, every month. However, even if you’ve made late payments or have missed payments, it still is worth trying to negotiate different terms (interest rates, amount due, due date, fees).

Get New Terms from Your Creditor in Writing

If the lender agrees to new terms, request the changes in writing. You’ll want to check your next statement to make sure your lender has honored the new agreement.

Avoid these common mistakes that can delay your payment:

- Mail the payment to the wrong address.
- Make an online payment to the wrong account.
- Write the wrong account number on your check.
- Write a check that is returned (bounced) because there’s not enough money in your checking account to cover it.

To rebuild your payment history with each creditor you contact, honor each renegotiated term (due date, payment amount) and make future payments on time.
I’m Completely Overwhelmed with Debt. I Need Help.

If you feel completely over your head with bills you cannot possibly pay, call the National Foundation for Credit Counseling (NFCC) to get help. NFCC is a national non-profit whose mission is to instill positive financial behavior in consumers and help them get their debt under control.

Making money off of your difficult situation is not on NFCC’s agenda, as it is with many other so-called credit-repair and debt-relief businesses making attractive promises to relieve you of your debt. NFCC helps you protect your credit and guides you toward debt solutions that improve your credit. Credit-repair and debt-relief companies don’t.

Be careful who you work with. Many shady businesses promising to relieve you of your debt operate under the guise of a non-profit. Be assured they have found a way to legally make a profit off of your difficult situation.

Contact the National Foundation for Credit Counseling (NFCC)

NFCC has many offices around the country staffed with credit counselors prepared to help you manage your debt.

National Foundation for Credit Counseling (NFCC)
Call 1-800-388-2227
Visit www.nfcc.org
Write
National Foundation for Credit Counseling
801 Roeder Road, Suite 900
Silver Spring, MD 20910

If you fear you cannot pay all of your bills and you don’t know which to pay first, the NFCC can also help you determine that.
What Are Some Things I Can Do On My Own to Reduce Debt?

Getting the big picture of how much you owe, and to whom, will help you gain a sense of order and focus on what you need to do to reduce your debt. In addition to paying your bills on time every month, and, if necessary, negotiating new terms with your creditors, there are several other things you can do. Get started by creating a debt reduction plan.

Create a Debt Reduction Plan

What you want to try to do is accomplish little victories as you work to reduce your debt. You can do this two ways:

- Pay off the debt with the highest balance(s) first.
- Pay off the debt with the highest APR(s) first.

To help you make that decision, let's first get the big picture of your debt. List all of your debt on the Debt Reduction Plan form that you can download below. Make note of low balance amounts, or balances with high APRs. Decide which balance makes the most sense to pay off first. Then, begin paying as much as you can to pay off that balance. Again, look for victories. Select a debt you think you can pay off in a short amount of time, then move on to pay off another one.

Debt_Reduction_Plan_pdf  Debt_Reduction_Plan_Excel File

Tips for Making the Most of Your Debt Reduction Plan

- Have you tracked your spending for seven days? What items can you do without? Small expenses add up over time. Refer to Track Your Spending Leaks for more guidance.
- Review the list of expenses on your spending plan. Which ones can you do without? What lower-cost alternatives might be available?
- Using your credit card is a quick fix when cash is tight, but it is an expensive one. Try to avoid using your credit card except for emergencies—events that affects life’s basic needs. For example, a basic need is reliable income so you can provide for your family. Let’s say your car breaks down, and it is the only way you can get to work—you’d risk losing your job without your car. This car break down is considered an emergency, and would justify the use of your credit card to get it fixed as soon as possible.
- Work out realistic payment plans with the companies or persons to whom you owe money (hospitals, doctor's office, the landlord, etc.).
- Consider applying for and using a low-rate, low-cost credit card.
- Stay on top of due dates for all of your bills and any collection notices. Pay something on each bill. Again, stay in touch with your creditors and try to work out a realistic payment plan instead of skipping a payment.
<table>
<thead>
<tr>
<th>Creditor</th>
<th>Balance Due</th>
<th>APR</th>
<th>Current Monthly Payment</th>
<th>Accelerated Monthly Payment</th>
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</table>
About Bankruptcy, Foreclosure, and Repossession

If you are suffering a severe financial set-back, you may feel compelled to take drastic measures as a way to relieve yourself of mounting financial stress. Each measure discussed in this section—bankruptcy, foreclosure, and repossession—might be avoided if you reach out for some help and make a plan. In some cases, especially in a poor economy, they can’t be avoided.

Bankruptcy

Health-related bankruptcy is on the rise for all Americans and more so for families of children with special needs. Not only do the bills stack up, but the time it takes to tend to them easily slips away while caring for your child. When you do finally open the mail and add things up, you might find you’re in financial trouble.

What Should I Do if I Think I Am In Serious Financial Trouble?

First, you might find some relief through the 2010 Health Care Reform (Patient Protection and Affordable Care Act). Details of the Act are discussed in more detail here, but you might find three of its provisions helpful in this situation:

1. Health care benefit providers are prohibited from excluding coverage to children based on pre-existing conditions.
2. A standardized annual out-of-pocket spending limit will be established so no family would face bankruptcy due to medical expenses.
3. Annual and lifetime caps (a maximum amount paid on claims) cannot be enforced by private health insurance companies.

Second, avoid turning medical debt into credit card debt, which is one of the most expensive debts of all (high interest, recurring fees on unpaid balances). As a rule of thumb, do not use your credit cards to pay your medical bills.

Third, review the section "Create a Debt Reduction Plan." You might get ideas on how to improve your finances.

Fourth, contact the National Foundation for Credit Counseling and explain your situation. Someone may be able to offer a debt solution that works for you.

National Foundation for Credit Counseling (NFCC)

Call 1-800-388-2227
Visit www.nfcc.org
Write National Foundation for Credit Counseling
801 Roeder Road, Suite 900

Where to Look for a Bankruptcy Lawyer

The American Bar Association (ABA) is a national organization of professional lawyers who specialize in many areas of the law, including bankruptcy. The ABA’s Web site provides many resources to the general public about a variety of legal topics, and a way to search for a lawyer in your area.

To contact the ABA:
Call 1-800-285-2221
Visit www.abanet.org; to search for a lawyer in your area, click "Public Resources" then "Find Legal Help"

Write
American Bar Association
321 North Clark Street
Chicago, IL 60654-7598

You can also look for a bankruptcy lawyer at the National Association of Consumer Bankruptcy Attorneys (NACBA), the only national organization of professional bankruptcy lawyers.

To contact the NACBA to find a bankruptcy lawyer in your area:
Visit www.nacba.org; you can search for a lawyer in your area on the site’s home page.
Call 202-332-8005
Write National Association of Consumer Bankruptcy Attorneys
2300 M Street, Suite 800
Washington, DC 20037

Note! Be sure to ask if you can speak with a bankruptcy lawyer also knowledgeable in disability-related issues. While that knowledge is not necessary for a lawyer to give you legitimate advice on filing for bankruptcy, having the right type of advice can make all the difference in a bankruptcy proceeding.
If none of those provide a workable solution, contact a bankruptcy lawyer for additional advice.

Filing for Bankruptcy

Filing for bankruptcy should always be an absolute last resort—it is a very serious credit decision. Bankruptcy is the most damaging thing you can do to your credit. It can stay on your credit report for seven to 10 years. During that time, you might be able to get a loan or credit card, but you will pay high rates of interest and high fees.

There are two types of bankruptcy. For each one, you must pay a fee to file for bankruptcy and any fees charged by your lawyer. Before considering whether or not to file, ask yourself the question, “What do I need to do differently so I don’t get in the same financial trouble again?”

Chapter 13

This type of bankruptcy is generally a debt repayment plan that you negotiate with your creditors. You may be able to negotiate to have some of your debt reduced. The payment plan stays in effect over a period of three to five years. Chapter 13 bankruptcy stays on your credit report for seven years from the date you make your final payment of the negotiated plan.

**When to Consider Filing Chapter 13 Bankruptcy.** When you think you can pay off your debt—possibly at a reduced amount—in three to five years.

Chapter 7

All of your debts will be erased, and you start your credit life over. This type of bankruptcy stays on your credit report for 10 years from the date of filing.

**When to Consider Filing Chapter 7 Bankruptcy.** When you think you can’t pay off your debt in three to five years, even if the amount of your debt could be reduced.
About Bankruptcy, Foreclosure, and Repossession Part 2

Foreclosure

A mortgage default or delinquency occurs when a mortgage payment is 30 days past due. While each lender handles this situation differently, a foreclosure can occur when a mortgage payment is approximately 90 days past due. At that time, the bank that approved the mortgage loan can issue a Notice of Sale. This means your lender can legally sell your home through a public auction. On the date of the auction, you will be required to move out of your home.

Information related to a foreclosure can stay on your credit report for seven years.

What Should I Do if I Can’t Pay My Mortgage?

If you are in financial distress and think you might be unable to pay your mortgage, or have missed mortgage payments, take action immediately. As tempting as it might be, Do Not Wait. The four most important things to do are:

1. **Call your lender immediately** and explain your situation. Because foreclosures are expensive for banks, they may be inclined to look for alternatives to foreclosure. Be prepared to propose a payment plan. Ultimately, you’ll want to work one out that is acceptable to both you and your lender. Here, too, ask what fees or charges might be waived.

2. **Find a HUD-approved housing counselor** in your area for support and recommendations on how to keep your house. Housing and Urban Development (HUD) Call 800-569-4287 to find a HUD-approved housing counselor near you.

3. Ask your HUD-approved housing counselor about the Home Affordable Modification Program, which is part of the 2009 Financial Stability Plan. The program provides eligible home owners opportunities to modify their mortgages to make them more affordable. For more information about this program, visit www.MakingHomeAffordable.gov.

4. **Stay in touch with your lender** as you implement your payment plan and get back on track with your finances.

5. **Avoid foreclosure prevention companies**. Like credit-repair and debt-relief companies, their aim is to profit off of your difficult situation, not help you keep your home and protect your credit.

Repossession

If you miss payments on your car loan, your lender can legally
take the car from you, or "repossess" it, for the lender really owns (possesses) your car until you pay off the loan in full. If you’ve missed a car loan payment, or think you are about to miss one, take the same type of actions described for missing credit card or mortgage payments: call your lender immediately, explain your situation, propose a payment plan, and ask what fees or charges might be waived.

Next Section: Protect Your Identity

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# Protect Your Identity

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Protect Your Identity

Identity theft occurs when someone uses your name, Social Security number, credit card number, or other personal information without your permission. It is a crime and creates financial chaos in people’s lives. People whose identities have been stolen can spend months or years and a lot of money cleaning up the mess thieves leave behind.

Next >
What Do Identity Thieves Do?

Stealing your personal information is every identity thief’s objective, and for the goal of financial gain at your loss. Thieves steal personal information from wallets, purses, and computers, or through the Internet in a variety of ways (but ways that can be stopped with safe computing).

Here are some of the things thieves do:

- Steal your personal information from your mailbox or purse or wallet, or while you’re working on the internet.
- Change your billing address. They can do this two ways: using a “change of address” form obtained from the post office or enclosed in your credit card bill (that they stole from your mailbox). Then, they charge items to your account. Even though you stop receiving your credit card bill, it might take you a while to notice that. By the time you do, your account could be maxed out.
- Open new credit card accounts in your name using your Social Security number. The accounts rack up charges you don’t know about, go unpaid, and show up as late payments on your credit report.
- Open a bank account in your name and bounce checks.
- File for bankruptcy under your name to avoid paying debts they incurred under your name.
- Buy a car by taking out an auto loan in your name.
- Get identification, such as a driver’s license, issued in your name but with their picture.
- Give your name to the police during an arrest. When you don’t show up for the court date, an arrest warrant is issued in your name.

Fighting Back Against Identity Theft

The U.S. Federal Trade Commission (FTC) has a Web page devoted to many identity theft topics, such as:

- How to detect it.
- What to do if your ATM, debit card, or credit card is stolen.
- What to do if your identity is stolen.

For more information, on FTC resources for identity theft:

**Call** 1-877-438-4338 (Voice) or 1-866-653-4261 (TTY)

**Visit** [www.ftc.gov](http://www.ftc.gov) and click “Consumer Protection,” then “Consumer Information”

**Write** Federal Trade Commission
600 Pennsylvania Avenue, NW
Washington, DC 20580
Types of Personal Information Identity Thieves Steal

You have many types of personal information that thieves use to steal your identity. What are they? Take a look through your wallet or mailbox, for starters. Or, if you use a computer, consider the type of information you use while shopping online.

Each family member should understand why it is important to protect this information. If you think your child with special needs will be unable or find it difficult to understand that, you'll need to protect this information for him or her as well.

### Your Personal Information

- Full name
- Address
- Social Security number
- Date of birth
- Mother's maiden name
- Personal Identification Numbers (PINs) used for ATM, debit, and credit cards
- Passwords or pass-phrases that access online accounts
- Bank and credit card account numbers

### Your Personal Items

- Social Security Number card
- Checkbook
- ATM Card
- Birth certificate
- Passport
- Credit report
- Financial statements: bank, credit card, investment, life insurance, loan
- Information about your child's benefits: Medicaid, SSI
- Estate planning documents: will, special needs trust, powers of attorney, letter of intent
How Thieves Steal Personal Information

Your purse, wallet, mailbox, briefcase, and home are places thieves can steal your personal information. Your computer is also a big target. Not only is the computer itself valuable, but the personal information you've saved on it is valuable as well. The Internet is another place thieves go to steal personal information. It's called hacking—accessing personal information transferred over the internet that is not secured by software and firewalls.

For more information on how to practice safe computing, visit www.OnGuardOnline.gov.
How Do I Avoid Identity Theft?

Don’t ever give out your personal information unless you call a company or person you trust and need to provide it. For example, you might call a lender or your insurance agent to get some information about your account. In that situation you would need to provide some personal information so the representative you’re speaking with can access your account.

Reduce credit card offers by calling the three major credit reporting agencies toll-free numbers and requesting to opt-out of pre-approved credit offers. Ever wonder how you get on those lists? The credit reporting agencies share your contact information with insurance and credit card companies. You can also call:

OPT OUT
1 888-567-8688 (1-888-5OPTOUT); request to be removed from mailing lists for credit card and insurance offers.

Stop telemarketers from calling you by adding your phone number to the federal government’s Do Not Call Registry. You can do that by phone or online. Your phone number stays in the registry for five years. After that time, you can renew your registration. Once you add your phone number to the registry, telemarketers cannot call you (unless you have done business with them in the past).

Do Not Call Registry
Call 1-888-382-1222
Visit www.DoNotCall.gov

If after you register your phone number, telemarketers continue to call you, you can file a complaint by calling the toll-free number listed above.

Reduce junk mail by contacting the Direct Marketing Association. Request to be removed from telemarketing and mailing lists.

Direct Marketing Association (DMA)
Call 1-202-955-5030
Visit www.the-dma.org
Write
Consumer Affairs
1111 19th St., NW, Ste. 1100
Washington, DC 20036
consumer@the-dma.org

Practice safe computing. Install firewalls, anti-spyware, and anti-virus software on your computer. If you purchase items over the internet, be sure you know whether you are on a “secure” site. To find out how to go about all this, visit www.onguardonline.gov.
What Should I Do if I Think My Identity Has Been Stolen?

If you become a victim of identity theft, or even suspect that you might be a victim, take immediate action.

1. **Contact one of the credit reporting agencies’ fraud alert departments** and place a fraud alert on your credit report. This prevents identity thieves from opening accounts in your name. Many credit card companies offer no-cost fraud protection where you would not be held financially responsible for charges made to your account by thieves who steal your personal information. In order to receive the most protection possible, though, it is important you call one of the credit reporting agencies as soon as you possibly can, even if you aren’t 100 percent sure your identity has been stolen, but may only think it has.

   **Tell the agency you think your identity has been stolen.** The agency will ask you to verify your identity with your Social Security number, name, address, and possibly other personal information.

   **One call does it all.** The credit reporting agency you contacted must contact the other two. Each agency will place a fraud alert on their version of your credit report. For the next 90 days, your creditors and other businesses that want to offer you credits will see the alert on your credit report. If anyone asks for credit in your name, the appropriate lender will contact you to verify your identity and find out if you asked for credit.

   Equifax Fraud Department  
   Call 1-800-525-6285  
   Visit www.equifax.com

   Experian Fraud Department  
   Call 1-888-397-3742  
   Visit www.experian.com

   TransUnion Fraud Department  
   Call 1-800-680-7289  
   Visit http://www.transunion.com

2. **Contact your lenders, banks, and insurance companies** and let them know the situation. Ask to close accounts. Open new ones with new personal identification numbers (PINs) and passwords.

3. **Victims of identity theft are entitled to a free credit report.** Wait about a month before you request it. Some activity may take a while to show up on your report. When you get it look for:
   - Personal information that has changed: your name, date of birth, Social Security number, address, and employer
   - Inquiries from companies you didn’t contact
Accounts you didn’t open
Debts on your accounts you can’t explain

4. **File a police report—it is proof of the crime.** If the credit reporting agencies need to investigate fraudulent activity on your report, they will need this police report.

5. **Periodically check your credit reports** over the next year to make sure no new fraudulent activity has occurred.

6. **Work with the credit reporting agencies** to remove fraudulent activities from your credit report.

7. **Work with your credit card companies** to reverse fraudulent charges to your credit card.

Next Chapter: Preparing Your Income Tax
Preparing Your Income Tax—Know Your Tax Benefits

As primary caregiver of your child with special needs, you may be entitled to certain tax benefits, such as tax credits and tax deductions. These tax benefits help offset a portion of expenses incurred while caring for your child. At certain income levels, you may be eligible for other tax benefits as well. To determine eligibility for tax benefits, learn how to apply them, and make the most of the tax benefits you’re entitled to, you may want to seek the advice of a tax professional.

Next Section: Tax Credits

Finding Financial and Tax Advice

Ideally you want to work with a professional knowledgeable about disability-specific financial and tax issues. Here are a few ways to go about finding a professional knowledgeable about what tax credits and tax deductions you might be eligible for.

- The IRS provides toll-free numbers tax filers can call to ask income-tax related questions. To contact the IRS:
  - Call 1-800-829-1040
  - Visit www.irs.gov and search on the name of the tax credit or tax deduction
- Some financial and tax organizations in your area may offer professional services to people with limited resources. These organizations may also offer informative publications or workshops on disability-specific financial and tax issues. For more information, contact the following organizations to find professional financial and tax services in your area:
  - American Institute of CPAs—Personal Financial Planning Section: an organization for CPAs who provide estate, tax, retirement, risk management and investment planning advice to individuals. Call 1-888-777-7077
  - Visit www.aicpa.org
  - Financial Planning Association (FPA): the largest organization of financial planners who provide financial

This publication is intended to provide general financial information; it is not intended to substitute for, or supersede, professional or legal advice. The specific needs of every disability or life circumstance have not been covered in this publication. The best course of action must be based on individual circumstances. Note: The content areas in this material are believed to be current as of this publication’s writing, but, over time, legislative and regulatory changes, as well as new developments, may date this material.

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Tax Credits

A tax credit lowers the dollar amount of income tax you owe (your tax liability). For example, if you owed $1,000 in taxes but qualified for $200 in tax credits, you would owe the federal government $800. Below is a list of some tax credits you might qualify for based on your income, dependents, or medical or education expenses. Each tax credit has its own qualifying terms. Speak with a tax professional for other tax credits you might be eligible to take.

Child and Dependent Care Credit. If you and your spouse (if applicable) have had to hire professional child or dependent care (including home care help you pay for directly) so you could work or look for work, you might qualify for this credit. If you do, you could receive a tax credit for up to 35 percent of your child care expenses.

Child Tax Credit. A child who meets six criteria—age, relationship, support, being claimed as a dependent, citizenship, and place of residence—may be counted for this credit. The maximum credit amount allowed is $1,000. The Child Tax Credit’s purpose is to lower the federal income tax liability for families raising children.

Earned Income Tax Credit (EITC). This credit offsets social security taxes paid through employment wages. Resulting in a tax refund for working families who qualify for the credit, the EITC was enacted (became law) to encourage low-income families to work. One in four (25 percent) eligible taxpayers do not claim their tax credit (See IRS.gov. “IRS Marks EITC Awareness Day; Highlights Expanded Tax Credit.” IR-2010-14, Jan. 29, 2010. Retrieved from http://www.irs.gov/newsroom/article/0,,id=218828,00.html on October 29, 2010). A couple reasons for this are that some people don’t know about the tax credit at all, or they don’t expect a refund. Even if you owe income tax but are eligible to receive the EITC, if the amount of the tax credit is greater than the amount of income tax you owe, the IRS will send you the difference. For more information about the EITC and how to qualify, contact the IRS:

Call 1-800-829-1040 (Voice) or 1-800-829-4059 (TDD)
Visit www.irs.gov and search on “EITC”

Next Section: Tax Deductions
Tax Deductions

A tax deduction lowers the dollar amount of taxable income. For example, if your total income is $50,000 but you have $5,000 in tax deductions, you would calculate your tax liability on $45,000. Listed below are some types of tax deductions. There are others. Speak with a tax professional to find you what other tax deductions you might be eligible to take.

Accommodations. Qualified (IRS-approved) costs associated with installing special equipment or modifying your home.

Lodging. Qualified costs associated with travel away from home to care for your child.

Medical. Qualified costs associated with maintaining and improving your child’s health. These costs must be itemized (listed on the tax return). The total amount of these costs must be greater than seven-and-a-half percent of your adjusted gross income (AGI). Your AGI is the total amount of income reported on your income tax return less certain allowable deductions, such as some business expenses, IRA contributions, student loan interest, and paid alimony.

Example:

If your AGI is $50,000 you would need more than $3,750 in IRS-approved medical expenses in order to take a tax deduction.

Math: $50,000 x .075 (7.5%) = $3,750.

Travel. Qualified costs associated with travel in caring for your child, such as gas and parking expenses incurred while traveling to and from the doctor’s office may be tax deductible. Some restrictions may apply, but generally you may take travel deductions if your child is:

- Under 19 years of age.
- Under 24 years of age if a full-time student.
- Any age if permanently and totally disabled (see Internal Revenue Service. “Publication 502: Medical and Dental Expenses.” November 10, 2009).

For more information on whether you may deduct travel expenses, speak with a tax professional or contact the IRS:

Call 1-800-829-1040 (Voice) or 1-800-829-4059 (TDD)
Visit www.irs.gov and search on “Publication 502”

Next Section: Tax Income Preparation - VITA
Income Tax Preparation Services—

Volunteer Income Tax Assistance (VITA)

Volunteer Income Tax Assistance (VITA) is a government program that provides free tax preparation services for people with certain levels of income. VITA collaborates with the National Disability Institute (NDI), and Real Economic Impact (REI) Tour, and the Disability and Business Technical Assistance Centers (DBTACs) to better serve individuals with disabilities. Two significant efforts being made through these collaborations are:

1. Heighten awareness on the obligations VITA sites have under the American with Disabilities Act (ADA) to provide:
   - Better access to VITA facilities and to the location of the VITA services.
   - Alternative ways to communicate. Examples include audio recordings, text and instant messaging, and Braille and large-print materials.
   - Reasonable modifications and auxiliary aids and services.

2. Heighten awareness of disability etiquette and disability-specific tax issues related to:
   - Income sources for filers with disabilities
   - Tax provisions relevant to filers with disabilities.
   - Tax provisions relevant to parents of children with disabilities.

VITA sites are located in many but not all states. To find out what income level is required to qualify for VITA services and if there is a VITA site located near you:

**Call** 1-800-906-9887

**Visit** www.irs.gov and search on "VITA"

Next Chapter: Family Relationships
every disability or life circumstance have not been covered in this publication. The best course of action must be based on individual circumstances. Note: The content areas in this material are believed to be current as of this publication’s writing, but, over time, legislative and regulatory changes, as well as new developments, may date this material.

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Family Relationships

All family relationships have some degree of tension—it’s natural and to be expected. You, as parents, try to work through those moments and help family members do the same. Because caring for a child with special needs requires more of your attention and financial resources, it is possible that tension among family members can reach an undesirable level. Here are some stressful situations that can lead to conflicts in some families.

- Other family members may feel left out or abandoned because you have to devote so much time and money to caring for your child with special needs.
- You may differ with your spouse on what treatments to pursue and how much money to spend on them.
- Each family member’s emotions around your child’s disability may be expressed in different ways.
- One parent may have had to give up working or put a career on hold in order to care for a child.

Next Section: Keeping the Peace
Keeping the Peace

What are some of the ways you can come together as a family and diffuse the escalation of tension? Establishing some ground rules on how you will handle certain situations might help. Possible areas include:

- The extent you’ll go to care for each family member. Will you do anything it takes, even if it means accumulating debt? For example, will you incur debt for certain situations, such as those that are life-threatening, but not for others? Will you try to stay within your financial means and forego some desirable treatments?

- How will you and your spouse come to agreement on all that? How you will encourage family members to talk about their emotions around your child’s special needs. If and how often you’ll set aside family-only or spouse-only time for fun activities or a vacation.

- How you will share with your spouse the responsibilities of caring for all family members.

- How you can involve other family members in the care of your child with special needs to instill a sense of responsibility while keeping it interesting and rewarding. How you will discipline each family member for inappropriate behavior.

If Things Don’t Work Out Between You and Your Spouse

If you and your spouse have tried several ways to reduce tension only to have it escalate, perhaps you’ve come to the conclusion, after much consideration, that a divorce would be the best thing for your relationship and your family. Should that occur, clearly state in your divorce decree who is

Where to Look for a Divorce Lawyer

The American Bar Association (ABA) is a national organization of professional lawyers who specialize in many areas of the law, including divorce. The ABA’s Web site provides many resources to the general public about a variety of legal topics, and a way to search for a lawyer in your area. You can get the contact of your local bar association through the phone book or the Internet, or you can contact the ABA’s national resources:

Call 1-800-285-2221
Visit www.abanet.org; to search for a lawyer in your area, click “Public Resources” then “Find Legal Help”
Write
American Bar Association
321 North Clark Street
Chicago, IL 60654-7598

Note! Be sure to ask if you can speak with a lawyer also knowledgeable in disability-related issues. While that knowledge is not necessary for a lawyer to give you legitimate advice and service, a lawyer experienced with disability-related matters might be able to provide you with
financially responsible for what expense in the care of all of your children and maintenance of your household.

This includes expenses you have right now and expenses you think you might have in the future. Consideration should also be given to how you’ll handle:

- Current expenses that might become more costly over time.
- New, unanticipated expenses that you incur.

The expenses listed in your spending plan can help you determine who will become financially responsible for family expenses.

If your child receives Medicaid or SSI now or is expected to receive them in the future, give careful consideration to how child support payments on behalf of your child with disabilities should be made. The important issue here is that you don’t want to disqualify your child from benefits. Child support payments should not be paid directly to the child. To help make sure you make the most equitable decisions around your divorce, seek the financial advice of a lawyer experienced in handling divorce for parents of children with special needs. For help on navigating the financial aspects of a divorce, visit www.SmartAboutMoney.org and click "Life Events."

**Next Chapter: Your Health Care**
Your Health Care

Health care plans, policies, and assistance are intended to protect you and your family from catastrophic medical expenses. We define each type of health care coverage below. It is important to be able to distinguish the differences among each type.

Employer-Provided Health Care Plans. For these plans, your employer, not an insurance company, foots the bill for all employees’ medical costs. In some types of employer-provided health care plans, the employer also bears the financial risk of insuring you and your family. These types of employer-provided plans are called “self insured plans.” Your employer pays a health care administrator, a company that specializes in administering health care plans, to process your medical claims.

To participate in an employer-provided health care plan, you pay a monthly amount through paycheck deductions. In addition to these deductions, you are also typically financially responsible for:

- A co-pay: a portion of the cost to visit a health care provider.
- Co-insurance: a portion of the cost of health care services. A typical co-insurance requirement is 80/20. This means that your health care plan would pay for 80 percent of your health care expenses; you would pay for the remaining 20 percent.
- An annual deductible: an amount you pay each year before your health care plan starts paying for your medical services.

HealthCare.gov

HealthCare.gov is a comprehensive Web site for all individuals who need help:

- Finding insurance options.
- Comparing different types of health care.
- Learning about ways to stay healthy.
- Learning about new health reform legislation.

HealthCare.gov has a section devoted to individuals with disabilities.


Family-to-Family Health Information Centers

Figuring out who to contact, what your health care benefits are, and how much they cost is a challenge. Funded by the Health Resources and Services Administration, Maternal Child Health Bureau, Family-to-Family Health Information Centers located in each state offer parents go-to resources for navigating and working effectively with various health care systems. Each state’s center offers parents resources based on what health care services the state provides. The mission of each family center is to help parents make informed health care choices for their children with special needs.

To find the Family-to-Family Health Information Center in your state, contact Family
Insurance Health Care Policies. These are purchased from private insurance companies, usually through your employer or directly through an insurance agent. The insurance company bears the risk of insuring you and your family. You pay for insurance policies with monthly premiums. If your insurance is purchased through your employer, your monthly premium is usually automatically deducted from your paycheck and your employer pays the insurance company for you. Some employers pay for all or a portion of your monthly premium. Whether you or your employer pays your monthly premium, you are typically financially responsible for co-pays, co-insurance, and an annual deductible.

Government Health Care Assistance. This is insurance coverage provided through government agencies, such as Medicaid. It is financed by federal and state governments, but administered by the states. This means each state’s health care assistance program may have a unique name. Contact your county’s Office of Public Assistance or Social Services to find out about your state’s health care assistance program. Also, each state varies in program eligibility requirements, what types of services are covered, and how those services are paid for.

Note! For simplicity, throughout this publication, we collectively refer to the three types of health care coverage explained above as “health care plan.”

Next Section: Your Medical Coverage
Your Medical Coverage

# Article Title
1 Your Medical Coverage
2 Your Summary of Benefits and Explanation of Benefits (EOB)
3 Types of Employer-Provided and Private Insurance Health Care Plans
4 Your Medical Coverage—What You Need to Know
5 Making Your Policy Work for Your Child
6 How Free Are Parents to Change Jobs?
Your Medical Coverage

Your medical expenses may place one of the biggest and most stressful demands on your financial well-being. Whether you receive health care benefits from an employer, an insurance company, or a government health care assistance program, you want to get the very most out of the coverage you have. To do that, it is essential you completely and clearly understand the provisions of your health care plan.
Your Summary of Benefits and Explanation of Benefits (EOB)

These are your most important medical documents. Keep them in one convenient place.

The Summary of Benefits describes in detail what medical conditions and services will be covered, for what amounts, and your financial responsibilities. The Explanation of Benefits (EOB) describes in detail your benefits for a particular service or health care provider’s visit.

Documentation on medical coverage is complex. By breaking it down into chunks of information—it won’t seem so overwhelming. Here are the essential pieces:

- **Your benefits**: what is covered, or not.
- **Your financial responsibilities** for doctor’s visits, prescriptions, hospital care, any special treatments or therapies your family requires, and assistive technologies.
- **Your health care plan’s financial responsibilities**.
- **How your claims are paid**.
- **How to appeal a denied claim**.

Your doctor’s office will usually file medical claims for you (notify your health care plan administrator of the services you received). In some cases, you have to send in your own claims. After your health care plan administrator receives your claim, it will process it. That means your health care plan administrator, based on the service you received and the benefits of your plan, determines:

- The dollar amount of the service it will cover.
- The percentage of that amount it will pay for.
- The percentage of that amount you must pay for.

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How Deductibles Work

This is a very simple explanation of how deductibles work. Other health care plan conditions may affect how deductibles are applied.

Say your annual deductible amount is $500. That means you must pay for the first $500 worth of medical services you receive for any year. So you visit your doctor and it costs $1,000. Let’s also say that (1) you are responsible for a $25 co-pay for each doctor’s visit, and (2) your health care plan will pay for 100 percent of this visit.

When you receive your EOB, the calculation of how much you and your health care plan will each pay might look something like this:

- **Cost of Visit**: $1,000
- **Less: $500 deductible (you pay this)**
- **Subtotal**: $500
- **Less Co-Pay**: $25 (you pay this)
- **Your Benefit**: $475 (your health care plan pays this)

After you’ve paid the bill for this visit, you’ve completely paid your deductible for the year. The next time you have this same type of visit, it will only cost you $25, the co-pay, because your health care plan pays 100 percent for that type of visit.

Every January or on your plan’s anniversary (the day your benefit plan went into effect), the deductible goes back to zero. That means you again pay the first $500 of medical services.
Sample Information on an Explanation of Benefits Document

Say a doctor’s visit for a check-up costs $200. Your health care plan may only cover 80% of that check-up amount, or $160. You would pay the difference of $40.

Of that $160, your health care plan may pay for half of it, or $80. You would pay for the difference, or $80.

Adding those two payments of $40 and $80 together, you would be financially responsible for $120 of that $200 doctor’s visit; your health care plan is responsible for $80.

Your health care plan administrator will summarize all this on an Explanation of Benefits (EOB) statement, indicating the total amount you owe. This statement is not a bill, merely an explanation of your coverage and who is financially responsible for what. Your EOB will also contain information on how to appeal a claim. You will want to appeal a claim, or ask your health care plan administrator to review your claim again, if you were denied coverage you believe you are entitled to.
Types of Employer-Provided and Private Insurance Health Care Plans

Employers and private insurance companies offer a variety of benefit plans. We’ll explain five types of them below, stating for each its typical plan features. Nearly all plans are variations of these five types, though. Use this information as a quick reference. Your health care plan documentation will provide a more accurate description of your health care benefits.

Health Maintenance Organization (HMO)

This type of plan is the most restrictive in what doctors you can see and the type of health care offered. HMOs cover expenses related to an illness and offer preventive care services such as check-ups, well-baby care, and mammograms. Some government health care assistance programs require that plan beneficiaries use specific HMOs for their services. If you have an HMO, you must:

- Use doctors employed by the HMO. Ask an HMO representative about the plan’s policy for seeing doctors not employed by the HMO.
- Use hospitals affiliated with the HMO except for out-of-town emergencies.
- Make co-payments for each doctor’s visit, typically $10–$30.

It is also important to know what your plan’s policy is on seeing both in- and out-of-network specialists. Speak with your primary care physician or an HMO representative about this before seeking a specialist. Your doctor’s office usually submits claims to the HMO for you. The HMO in turn sends you an Explanation of Benefits (EOB).

Preferred Provider Organization (PPO)

This type of plan offers a wider access to doctors and may offer some coverage to alternative types of health care, such as acupuncture. PPOs cover expenses related to an illness and typically offer some preventive care services. Under this plan you:

- Use doctors who are members of the PPO’s network.
- Make co-payments for each doctor’s visit, typically $25–$45.
- May need permission from your primary care physician to see a specialist who is a member of the network.
- Have the option to see out-of-network providers (doctor’s and specialists who are not members of the PPO). Permission to see them is usually not required, but you will pay an additional cost to see out-of-network providers.

Your doctor’s office usually submits your claims to the PPO for you. The PPO in turn sends you an EOB.
Point-of-Service Plan (POS)

This type of plan is the most flexible of all. Its features are similar to those of the HMOs and PPOs just described. The name of this plan says it all—the point, or place, where you receive the service affects your out-of-pocket cost. Under this plan you:

- May use specific doctors who are members of the network and pay the low co-pay (similar in cost to an HMO).
- May select from a list of doctors outside of the network, but who are affiliated with the plan, and pay a higher co-pay (similar in cost to a PPO).
- May select a doctor not affiliated with the plan at all and pay the highest co-pay and possibly a deductible (an amount you pay before your health care plan starts paying your health care claims).

Your doctor’s office usually submits your claims to the POS for you. The POS in turn sends you an EOB.

Indemnity Plan

This is a fee-for-service plan. You can go to any doctor you choose, including a specialist—no permission required. These plans, though, are often more expensive than plans described above. And, they typically only cover medical expenses related to illness and accident, not preventive care. Under this plan you:

- Pay an annual deductible.
- Pay a co-pay for doctor’s visits.
- Pay a portion of each medical expense. Often you’ll see an 80/20 split, which means your health care plan would pay 80 percent of the cost of your service; you’d pay the remaining 20 percent.
- May be required to pay for services up front and then submit the bill to your health care plan administrator for reimbursement.

Exclusive Provider Organization (EPO)

There are two types of EPOs. The first operates like an HMO, but EPO health care providers are not employees of the organization. An insurance company generally manages an EPO while an HMO is a business unto itself. The second type of EPO, which operates like a PPO, is used by employers. Each employer has a unique EPO. The name of the insurance company providing the benefits is displayed on health care plan documentation (not the name of the employer). An EPO may be insured or self-funded by an employer.
We already mentioned how important it is to understand your health care plan. As you’ve probably discovered over the years, it is the types of services that are not covered by your health care plan that can cause financial stress.

By now you might be aware of the types of services and medical needs your child requires now, and may require in the future. If you aren’t, though, speak with:

- Your doctor
- Other health care professionals you work with
- Disability-specific organizations
- Other parents

Try to get a feel for what types of medical services your child may need in the future so you can determine whether or not your health care plan covers them. Knowing this will help you adjust the “Anticipated Amount” on your spending plan. For whatever medical needs your health care plan does not cover, consult with your Parent Center and your disability-specific organization for what assistance might be available to help you pay for them.

It might also be helpful to speak directly with the following people, depending on your plan, to get absolutely clear on the services your plan covers and what your financial responsibilities are:

- A Human Resource Department employee who oversees your employer-provided health care plan or group health insurance policy.
- A health care plan customer service representative.
- Your insurance agent.

When you have this conversation, have the following information available in case you need to refer to it.

- Your Summary of Benefits.
- Any Explanation of Benefits (EOB) that you think will be helpful during the conversation.
- A list of your child’s medicines.
- A list of the types of specialists who care for your child.
- The types of procedures and therapies your child needs.
- A list of anticipated services or medicines your child might need.

During your conversation, use the following linked form to document some of the details of your health care plan’s benefits.

Health_care_plan_review_pdf  Health_care_plan_review_Excel File
As you get to know your health care plan and its benefits, the Medical Plan Features chart linked below will help you further analyze them. The chart includes questions you can ask your health care plan representative to help you learn more about your health care plan.

You might also want to keep handy the Key Provisions of the 2010 Health Care Reform Legislation of this chapter for further reference.

“There is an art to navigating the health care system, and it is one you can learn. Ask for case managers in the hospital and with the insurance company, and then work at developing a good rapport and working relationship. You have to be willing to ask questions and keep on asking questions until you understand. That is your right. It is what you have to do.” —Carolyn Allshouse, parent advocate, mother of Jack

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<td>□ Deductible</td>
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<td>□ Limits on the dollar amount of coverage</td>
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<tr>
<td>□ Limits on the number of visits</td>
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<tr>
<td>□ Co-insurance</td>
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<td>□ Co-payments</td>
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<tr>
<th>Questions to Ask</th>
<th>Notes</th>
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<tr>
<td>□ Does my plan allow me to seek out and use the specialists my child needs?</td>
<td>Does my plan allow me to seek out and use the specialists my child needs? Examples: cardiologist; ear, nose, and throat; neurologist</td>
</tr>
<tr>
<td>□ Which hospitals can we use?</td>
<td>Does my plan allow me to seek out and use the specialists my child needs? Examples: cardiologist; ear, nose, and throat; neurologist</td>
</tr>
<tr>
<td>□ Does my plan cover the type of medicines my child needs?</td>
<td>Does my plan cover the type of medicines my child needs? Examples: medication, medications used to treat cystic fibrosis, grown hormone deficiency, intermittent seizure activity, or pediatric AIDS. Examples of treatments that are typically not covered include homeopathic medication, vitamins and food supplements, O2 therapy, and special diets</td>
</tr>
<tr>
<td>□ Does my plan cover the specific procedures and therapies my child needs?</td>
<td>Does my plan cover the specific procedures and therapies my child needs? Examples: physical therapy, occupational therapy, speech therapy, botox treatments, orthotics, hippotheray, alternative therapies for autism</td>
</tr>
<tr>
<td>□ Does my plan limit the number of times I can collect per year for a certain item or procedure?</td>
<td>Does my plan limit the number of times I can collect per year for a certain item or procedure?</td>
</tr>
<tr>
<td>□ Does my plan cover assistive technology?</td>
<td>Does my plan cover assistive technology? Examples: audio books and publications, augmentative communication devices, speech recognition programs, talking calculators, word-prediction programs</td>
</tr>
<tr>
<td>□ Does my plan cover durable medical equipment?</td>
<td>Does my plan cover durable medical equipment? Examples: manual or power wheelchair, hospital bed, commode, stander</td>
</tr>
<tr>
<td>□ If my child has a long-term condition, are there any limitations to benefits?</td>
<td>If my child has a long-term condition, are there any limitations to benefits?</td>
</tr>
<tr>
<td>□ What is the procedure for appealing a denied claim (the process you go through if you think a benefit should be covered but was denied)?</td>
<td>What is the procedure for appealing a denied claim (the process you go through if you think a benefit should be covered but was denied)?</td>
</tr>
<tr>
<td>□ What is the maximum out-of-pocket expense I will be financially responsible for?</td>
<td>What is the maximum out-of-pocket expense I will be financially responsible for?</td>
</tr>
<tr>
<td>Medical Plan Features</td>
<td>Good to Above-Average Plans</td>
</tr>
<tr>
<td>-----------------------------------------------------------</td>
<td>----------------------------</td>
</tr>
<tr>
<td>Specific treatments excluded or limited. Are there any treatments, such as kidney dialysis, that the policy will not cover?</td>
<td>Few or none</td>
</tr>
<tr>
<td>Hospital costs covered. What share of hospital costs will the policy cover?</td>
<td>All (after deductible, co-insurance and/or co-payment)</td>
</tr>
<tr>
<td>Days of hospital coverage in a year. If your child needs to be hospitalized, how many days will the plan pay for each year?</td>
<td>All</td>
</tr>
<tr>
<td>Does the policy cover major medical devices? If your child needs life support systems, does the policy pay for it?</td>
<td>All (after deductible, co-insurance and/or co-payment)</td>
</tr>
<tr>
<td>Does the policy cover assistive devices? If the quality of your child’s life can be significantly improved with assistive technology, does the policy pay for it?</td>
<td>All (after deductible, co-insurance and/or co-payment)</td>
</tr>
<tr>
<td>Lifetime maximum payment. If your child needs continuing treatment, what is the cap on total payments the policy will make? (With the 2010 Health Care Reform, insurance plans can no longer impose maximum dollar amounts for essential services, such as hospitalization.)</td>
<td>$2 million or unlimited</td>
</tr>
<tr>
<td>Home nursing care. If your child requires frequent or continual nursing care, how much will the policy pay? Is there an exemption for custodial care if the child’s condition is chronic?</td>
<td>As often or as much as needed (unlimited)</td>
</tr>
<tr>
<td>Yearly deductible. How much of your own money must you spend on doctor bills before the plan begins to pay?</td>
<td>$200 to $500 per person</td>
</tr>
<tr>
<td>Annual co-insurance limit. Find out what percentage of a claim your health care plan will pay for, and what percentage you must pay for. For example, a typical arrangement is 80/20. This means your health care plan would pay for 80 percent of a claim and you must pay 20 percent of the claim—in addition to the co-pay.</td>
<td>80/20</td>
</tr>
<tr>
<td>Co-payment. How much will you pay each time you visit an HMO’s or PPO’s health care provider?</td>
<td>$20 to $50 per visit</td>
</tr>
<tr>
<td>Choice of medical service provider. Can you pick your own doctor, or must you use someone who belongs to the plan’s group?</td>
<td>Any provider or a wide choice within a network</td>
</tr>
<tr>
<td>Personal care assistance and home- and community-based services. What kind of personal or home-based care do you provide? Are there any limitations? Will I need to share the costs?</td>
<td>As often or as much as needed (unlimited)</td>
</tr>
<tr>
<td>Preexisting condition exclusion period. If this is a new policy, will there be a waiting period before the policy pays for your child’s treatment?</td>
<td>HIPAA rules apply</td>
</tr>
<tr>
<td>Prescription drugs. How much do you have to pay for prescription drugs?</td>
<td>Usually $10 or $50 co-payment or plan covers 80 percent of cost (after deductible)</td>
</tr>
<tr>
<td>Mental health counseling. How many outpatient mental health visits will the policy cover in a year?</td>
<td>As many as needed (unlimited)</td>
</tr>
<tr>
<td>Drug/alcohol treatment. What kind of drug and alcohol treatment will the policy pay for?</td>
<td>Rehabilitation (usually limited to in-patient)</td>
</tr>
<tr>
<td>Does the policy cover physical, speech, and occupational therapy? If the quality of your child’s life can be significantly improved with the above therapies, does the policy pay for it? Is there a difference in coverage between habilitative and rehabilitative care?</td>
<td>All (after deductible, co-insurance, and/or co-payment)</td>
</tr>
<tr>
<td>Does the policy cover care related to mental health issues? If your child has an emotional or behavioral disorder, obsessive-compulsive disorder, or any other mental disability, are therapy, hospitalization, and prescriptions covered?</td>
<td>Limited; may have maximum number of visits and higher co-payment or co-insurance</td>
</tr>
<tr>
<td>Covered expenses. Are your plan’s “covered expenses” equal to actual charges?</td>
<td>Covered expenses are usual, customary, and reasonable</td>
</tr>
</tbody>
</table>
Making Your Policy Work for Your Child

Obviously, the more services your health care plan pays for, the less you pay. But if you’re in a situation where you’re maxed out on medical bills, it may seem that you don’t have any control over your coverage. Actually, the opposite is true.

Insurance claims processing is complex. To try to simplify the process, insurance claims processors attempt to align your claim with a general rule. Mistakes happen. Your processor may inaccurately assess your claim. And because automation is such a big part of claims processing, an error in your claim may occur if automated systems are not working efficiently. As a result, misunderstandings occur. It is up to you to make your child’s case clear so the processor’s needs are met.

Guidelines for Successful Interactions with Insurance Claims Processors

Working with any large organization can be frustrating. Sometimes it is hard to get a hold of the person you need to speak with the most. At other times you may get conflicting information, or perhaps the customer service representative is new and not as informed as you need him or her to be. Insurance companies are large organizations, but there are ways you can make your phone experiences positive for both you and the person you speak with.

Before you make another call to a health care plan representative, take a look at the following suggestions. You might find one that changes the course of all future phone calls to health care representative for the better.

**Ask for one insurance case manager.** This will save you time and help you avoid the frustrating experience of explaining your child’s needs over and over again. Get a number that goes directly to this case manager’s phone. Send him or her a picture of your child with a disability. This personalizes your situation and makes your child more than a “case.”

**If you are denied coverage for a therapy, treatment, or an assistive device that you know your child needs, don’t take “no” for an answer.** Kindly insist on the exact reason for the denial. Collect all documentation that explains the “need for treatment” along with the reason for the denial. Your Explanation of Benefits (EOB) will explain how to appeal your claim. Insist that your health care plan administrator supplies all information relating to a claim.
denial in writing.

**Keep detailed, written records of everything related to your child’s condition.** Keep all medical bills and insurance claims. You will use these records to calculate tax deductions and appeal denied claims through your health care plan’s administrative channels or the court system. You have the right to copies of your child’s medical records and test results, so ask for them! These records may also be helpful for gaining a better understanding of your child’s health issues.

**Know how to appeal a claim.** If you are denied a claim and appeal it, your health care plan administrator will put the claim through its appeals process. Ask your health care plan representative to send you a copy of its process, then use it! Get letters supporting your claim from primary doctors and other professionals who are familiar with your child’s needs.

**Appeal decisions that are not in your favor.** For example, one mother saw that her child’s lab work costing hundreds of dollars a week was reimbursed at 80 percent by an outside laboratory, but at 100 percent by an in-hospital lab. Since a nurse was drawing and submitting the samples and could submit them to the hospital lab, these costs could be covered 100 percent. The health care plan review committee decided to cover the samples previously submitted to a non-hospital lab at 100 percent.

**Ask your employer to change the benefits in your company’s self-insured plan if the current benefits exclude what you need covered.** Self-insured employers are financially responsible to pay employees’ insurance claims out of their pockets. These employers design their own plans, which means that, to a certain extent, they decide exactly what the covered benefits will be under the plan.

Employers who purchase insurance, on the other hand, do not have quite as much flexibility as self-insured employers do, but they do have choices in the plans they purchase. In the past, some parents were successful in having their employers change their health care plans to include a previously excluded benefit.

Make this request only if you feel comfortable disclosing medical information to your employer. For example, one father negotiated with his employer to provide excellent health coverage for his daughter with Down syndrome. The employer was willing to make the adjustment, even though the company group policy did not originally specify coverage for Down syndrome and related health problems.

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### Americans with Disabilities Act (ADA)

In July 2010, the Americans with Disabilities Act celebrated its 20th anniversary. The ADA is a civil rights law that protects people with disabilities from disability-based discrimination. The Act’s provisions in four areas—employment, public transportation, public accommodations, and telecommunications—heighen public awareness that people with disabilities want to and are able to be productive members of society.

As a parent and an employee caring for your child with disabilities, the ADA protects your ability to financially provide for your family.

- If you obtain group insurance with a new employer, it cannot charge you higher than standard prices, even if your child has a long-term health problem.
- The ADA makes it illegal for an employer to fire or otherwise discriminate an employee who is the parent of a child with a disability based on a presumption

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**The August 2010 update to the Family Medical Leave Act accommodates non-traditional parenting relationships common in today’s world. New definitions of “son or daughter” now allow employees not biologically or legally related to the child, but who provide day-to-day care and financial support in place of the parents, to be covered under this Act.**

**A “Son or Daughter”**

- Biological child
- Adopted child
- Foster child
- Step child
- Legal ward
- A child of individuals who have day-to-day responsibilities to care for and financially support a child in place of the parents, such as an aunt and uncle.

For more information on the Family Medical Leave Act contact the U.S. Department of Labor:

**Call** 1-866-487-2365 (Voice) or 1-877-889-5627 (TTY)

**Visit** www.dol.gov and search on “Family Medical Leave Act”

**Write**

U.S. Department of Labor
200 Constitution Ave., NW
Washington, DC 20210
possibilities: a financial resource guide for parents of children with disabilities

this publication is intended to provide general financial information; it is not intended to substitute for, or supersede, professional or legal advice. the specific needs of every disability or life circumstance have not been covered in this publication. the best course of action must be based on individual circumstances. note: the content areas in this material are believed to be current as of this publication’s writing, but, over time, legislative and regulatory changes, as well as new developments, may date this material.

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How Free Are Parents to Change Jobs?

If you have had medical coverage with an employer, under the Consolidated Omnibus Budget Reconciliation Act (COBRA) you may be able to maintain your insurance coverage with that employer if either you end or your employer terminates your employment for reasons other than gross misconduct, such as stealing or workplace violence.

COBRA is a federal law that serves two purposes:

1. Extend your health care coverage for 18 months from the date ending your employment.
2. Help you qualify for a private health care plan.

**Example**

If you maintain your insurance coverage under COBRA until it runs out, a private insurance company cannot deny you coverage, as long as you purchase a new policy within 180 days from the date COBRA runs out. It is possible that your new policy will cost more than your COBRA plan and not offer the same level of coverage. But the insurance company cannot make you prove insurability. And under a provision of the 2010 Health Reform Act, which goes into effect in 2014, you cannot be denied coverage due to a pre-existing condition.

In addition, some states provide special insurance coverage for children while their parents seek insurance coverage after changing jobs. Such a program could provide the flexibility you need, making it possible for you to accept a position at a company that does not provide health care benefits. For information on these programs, see State Programs in this chapter. For more information on COBRA contact the U.S. Department of Labor:

- **Call** 1-866-487-2365 (Voice) or 1-877-889-5627 (TTY)
- **Visit** [www.dol.gov](http://www.dol.gov) and search on “COBRA Employee FAQ” (FAQ stands for Frequently Asked Questions)
- **Write**
  
  U.S. Department of Labor
  200 Constitution Ave., NW
  Washington, DC 20210.

Next Section: Government Health Care Assistance Programs
# Government Health Care Assistance Programs

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Government Health Care Assistance Programs for People Who Have Inadequate or No Medical Coverage

“It may not seem possible at first, but it is important to start saving money. It makes life a lot easier, a lot smoother, and a lot freer. And there are goals, like higher education or opportunities within the community, that are not automatically covered by government programs.”

—Deborah Leuchovius, parent advocate, mother of Frederick

Government-provided health care assistance programs offer health care to a variety of groups of people:

- Families who have children with disabilities and special health care needs.
- Low- to middle-income families who:
  - Do not have employer-provided health care.
  - Cannot afford private health care.
  - Cannot afford the co-payments.

Government health care assistance programs such as Medicaid provide coverage for these groups of people.

HealthCare.gov is a comprehensive health care Web site and has a section devoted to people with disabilities. The Web site provides help for individuals who need to:

- Find insurance options.
- Compare different types of health care.
- Learn ways to stay healthy
- Learn about new health reform legislation.

Types of Health Care Assistance Programs, Part 1: CYSHCN and CHIP

Exploring government health care assistance options can be a daunting task. States and local governments run these programs, often under a variety of names and departments. And program eligibility requirements and health care services differ from state-to-state as well.

If you are just beginning to find out about government health care assistance programs, contact your county’s Office of Public Assistance or Social Services. A case worker will describe what programs are available, and the eligibility requirements and health care services offered for each one.

Children and Youth with Special Health Care Needs (CYSHCN)

Families of children with disabilities who don’t qualify for Medicaid and have little or no health insurance can obtain the following health care assistance through Children and Youth with Special Health Care Needs (CYSHCN) programs:

- Health insurance
- Income
- Health and medical care

CYSHCN program eligibility is usually based on the child’s age and health condition, the family’s income, and place of residence. “Special needs” refers to serious and long lasting conditions such as these types of disabilities:

- Physical
- Intellectual
- Developmental
- Behavioral
- Emotional

Examples of CYSHCN Program Services (each state’s program will be different)

- Assistive technology
- Case management
- Early intervention and screening for health risks
- Family support services
- Immunization
- Nutrition counseling
- Special education support services
To get more information about your state’s CYSHCN program:

Call your state’s Department of Public Health & Human Services, or your county’s Office of Public Assistance or Social Services. Each state or county may assign a unique name to its CYSHCN program.

Also contact the Family-to-Family Health Information Center in your state:

Family Voices, Inc
Call 1-888.835-5669
Visit www.FamilyVoices.org and click “State FV” to find the family center in your state
Write
2340 Alamo SE, Suite 102
Albuquerque, NM 87106

Children’s Health Insurance Program (CHIP)

This program, formerly known as State Children’s Health Insurance Program (SCHIP), is designed to provide health insurance to children of families who cannot afford private insurance but whose incomes are modest enough that it exceeds Medicaid’s income limitations. The Children’s Health Insurance Reauthorization Act of 2009 authorized additional funding to help make CHIP available to more families.

CHIP’s Minimum Level of Medical Services Offered

Each state’s program differs, but all must offer at least these services:

- Routine check-ups
- Immunizations
- Dental and vision care
- Inpatient and outpatient hospital care
- Laboratory and X-ray services

To get more information about your state’s CHIP:

Call your state’s Department of Public Health & Human Services or your county’s Office of Public Assistance or Social Services.
Visit http://finder.healthcare.gov/ to locate your local office.
Speak with the nurse at your child’s school; in some states, you can apply for CHIP benefits through the public school system.
Medicaid

Medicaid is a federal program run by the states that covers the cost of some medical care for millions of low-income families and people with disabilities. It is the foundation of the CYSHCN and CHIP health care assistance programs. An important role Medicaid plays is in providing medical services to people with disabilities that many health care plans are typically not designed to provide.

Who Qualifies for Medicaid

To become eligible for Medicaid, individuals must meet two conditions based on:

- **Category type**, such as pregnant women, children, and individuals with disabilities.

Children under six years of age are eligible for Medicaid if their families’ income, as of 2010, is under $29,326.50 (133 percent of FPL). Children from six through 18 years of age qualify if their families’ income is below the FPL. Again, that level in 2010 is $22,050 per year for a family of four.

The 2010 Health Care Reform Act will broaden Medicaid eligibility to anyone under age 65 whose income is under $29,326.50 (133 percent of FPL) at some time during the first five years of the Act. This broadened eligibility will remove the “category type” condition explained above, thereby basing Medicaid eligibility solely on income.

Each state may apply its own Medicaid eligibility requirements that are less strict than the federal standards. For example, a state may allow families with higher incomes to participate in its

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**How to Locate Your Local Medicaid Office**

Call either your state’s Department of Health and Human Services or your county’s Office of Public Assistance or Social Services to find out how to contact your local Medicaid office. You may also visit [www.HealthCare.gov](http://www.HealthCare.gov) to find your local office online.

**Medicaid and Supplemental Security Income (SSI)**

Many children enter the Medicaid system through the Supplemental Security Income program. Each state sets its own eligibility requirements based on income level and types of assets owned. In most states, children receiving SSI automatically qualify for Medicaid, yet enrollment into Medicaid is not always automatic. Check with your county’s Office of Public Assistance or Social Services for Medicaid enrollment information.

**What Medicaid Covers**

Medicaid covers a diverse range of conditions that many health care plans, such as an employer-paid plan, have typically not covered. In addition to providing traditional medical care, such as doctor’s visits, Medicaid also covers:

- Inpatient and outpatient hospital services.
- Dental and vision care; depends on the state—fewer states are offering this type of coverage.
- Laboratory and x-ray services.
- Early screening.
- Transportation and translation services.
- Long-term care; includes home- and community-based services (HCBS) and acute (emergency room) care.

Each state has the option of providing additional health care services, such as personal care, prescription drugs, and rehabilitation services.
Types of Health Care Assistance Programs, Part 3

Medicaid, Continued

Medicaid Options

Through the provisions of the Deficit Reduction Act (DRA) of 2005, states acquired greater flexibility in qualifying individuals for Medicaid and offering expanded levels of medical services. For example, states may offer optional health care assistance programs that have less restrictive income requirements. The difference in these optional programs is that, unlike Medicaid, individuals may have to go on a waiting list to receive health care service, and the services themselves may be limited.

Buy-In to Medicaid. Through the Family Opportunity Act (FOA) Medicaid Program, families with incomes, as of 2010, up to $66,150 for a family of four (300 percent of Federal Poverty Level) are eligible to purchase Medicaid coverage for their children with disabilities through monthly Medicaid premiums. A child may be covered by private medical insurance and still be covered by the FOA Medicaid Program.

Medicaid Waivers. States can request waivers from federal Medicaid regulations. This means states can expand Medicaid coverage by covering more people and expanding the level of services offered. Presently, waivers allow states to cover “optional” groups that include (see Kaiser Commission on Medicaid and the Uninsured. Medicaid: A Primer 2010. The Henry J. Kaiser Family Foundation. June 2010. Page 9):

- Working individuals with disabilities earning up to, as of 2010, $55,125 (250 percent of Federal Poverty Level).
- Individuals who receive home- and community-based (HCBS) services.
- Individuals who live in nursing homes with incomes up to 300 percent of SSI requirements (each state sets its own SSI income limits).
- The “medically needy” who don’t meet federal low-income requirements but spend a high proportion of their income on medical expenses.
**Home- and Community-Based Services (HCBS).** Since the mid-twentieth century, people with severe disabilities obtained long-term care in nursing home facilities, sometimes located far from the individual’s home and supportive network of professionals, friends, and family. In 1999, the *Olmstead* decision, a Supreme Court ruling, determined that the practice of only providing health care and other supports to individuals with disabilities in nursing home facilities (as opposed to in their own home, apartment or other community setting) was in violation of the Americans with Disabilities Act (ADA). Today, states are increasingly providing supports for HCBS services, a trend that helps individuals with disabilities live independently and greatly improve the quality of their lives.

*2010 Health Care Reform update:* Some states are offering the HCBS Medicaid state plan option called Community First Choice Option. Through this option, states would not have to limit eligibility or the amount of services provided. This option is being offered to people with disabilities who have incomes, as of 2010, up to $33,075 (150 percent of the Federal Poverty Level; see The Henry J. Kaiser Family Foundation. “Focus on Healthcare Reform.” June 2010).

**Tax Equity and Fiscal Responsibility Act of 1982 (TEFRA) State Plan Option.** When a child receives extended care in an institutional setting, family income is disregarded as a qualification for Medicaid. The TEFRA State Plan Option makes it possible to do the same for a family whose child requires care at the level provided in an institution, but who choose to care for their child at home. (see Catalyst Center. “TEFRA & TEFRA Look-alike Programs.” Retrieved from http://www.hdwg.org/catalyst/covers-more-kids/tefra on November 12, 2010).

Not all states offer the TEFRA state plan option. Contact your state’s Department of Public Health & Human Services or your county’s Office of Public Assistance or Social Services to find out if your state offers this Medicaid state plan option.

**Money Follows the Person.** This is an incentive program for states to move people with disabilities from nursing home facilities into home- and community-based services.

*2010 Health Care Reform update:* States received more funding to facilitate transferring individuals with disabilities from nursing home facilities to home- and community-based services. The eligibility requirement that a person be in a nursing home for six months has been reduced to 90 days.
Medicare

This government program is available to children with certain disabilities and to dependent adult children whose parents are currently receiving Medicare. Who qualifies for Medicare:

- Children with amyotrophic lateral sclerosis (ALS or Lou Gehrig’s disease) and end-stage renal disease (ESRD or kidney failure) can qualify for Medicare coverage soon after they have been determined to have a permanent disability.

- Dependent adult children who developed a permanent and severe disability before the age of 22 and whose parents currently receive Medicare are eligible to also receive Medicare benefits. A two-year waiting period for these benefits begins when the child turns 18 years of age. If the parent receiving Medicare benefits dies, the child will continue to receive benefits.

To get more information on Medicare eligibility and benefits, contact Medicare:

Call 1-800-633-4227
Visit www.medicare.gov

If You Do Not Qualify for Health Care Assistance And Cannot Afford Insurance

Perhaps you are unable to meet the eligibility requirements for government health care assistance programs. You find the monthly cost of private insurance too expensive, but you want it and need it. A possible solution is to consider ways to create financial capacity to pay the insurance premiums.

As an option, speak with a financial professional or counselor to find out how you might modify your lifestyle or increase your income to afford monthly insurance payments. Also, take a look at the money management tools presented in Managing Your Finances, such as creating a spending plan and tracking how you spend your money.

Non-Medical Benefits

Two federal benefit programs provide non-medical assistance income to children and young adults with disabilities: Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI).

Determining your child’s eligibility for SSI and SSDI and applying for benefits can be lengthy processes. You will be asked many questions about your child’s disability, which you will have to support with medical records and written statements from teachers and others who have known your child over a period of time.

For a more detailed presentation on who is eligible and how to apply for benefits for each of these...
Supplemental Security Income (SSI)

This federal program provides people with disabilities who have little or no income with cash assistance for basic needs such as food and shelter. Eligibility for SSI can begin at birth and last until 18 years of age (or, if a student, until the age of 22). Eligibility is also based on:

- **Financial need.**
- **The Social Security Administration’s definition of “disability for children.”**

To continue coverage beyond 18 years of age, your child must meet the Social Security Administration’s requirements for need and definition of “disability for adults.” Individuals who receive SSI may not have more than $2,000 in assets such as cash, investments, vehicles, and personal property. Some states have stricter asset requirements, meaning individuals may own less than $2,000 in assets.

Anyone who qualifies for SSI automatically qualifies for Medicaid; however, Medicaid enrollment is not automatic in all states. Check with your county’s Office of Public Assistance or Social Services for information on SSI enrollment.

Social Security Disability Insurance (SSDI)

This federal program provides income to people with disabilities who are unable to work. Your child may be eligible if your child:

- **Is over the age of 18 and:**
  - You, the parents, have paid into the Social Security System though payroll taxes.
  - Your child meets the Social Security Administration’s “definition of disability.”
  - Your child’s disability occurred before the age of 22.

- Paid into the Social Security System through payroll taxes.

The SSDI benefit amount is based on the length of the work period, either yours or your child’s, and the total amount of income earned.

State Mandated Insurance Programs

As part of the 2010 Health Care Reform, states are now able to offer subsidized premiums to individuals previously denied insurance because of pre-existing conditions. These programs are called high-risk insurance pools. As of this publication’s writing, states are in the process of ramping up on this program, which will be offered until 2014 (National Conference of State Legislatures, “Coverage of Uninsurable Pre-existing Conditions: State and Federal High-Risk Pools” November 5, 2010.) Individuals are responsible for paying part of the monthly premium.

For more information on the high-risk insurance pool offered in your state, visit www.StateHealthFacts.org and search on “high risk pool eligibility.”

“You learn a lot over the years. Back when my daughter was first diagnosed, I thought we should pay for everything because we could. I thought ‘programs’ were for truly needy people. I simply had no idea of the costs we would incur. I wish we had applied for programs we were eligible for in the very beginning.”

—Carol Bakies, mother of Sarah
The Issue of Medical Privacy — The Health Insurance Portability and Accountability Act (HIPAA) of 1996

What prompted the passage of this federal Act were situations where people were using patient medical records in ways that had nothing to do with their health care. For a hypothetical example, consider a banker who has access to the medical records of his customers. The banker looks for customers with serious health conditions assuming they wouldn’t be able to pay off the mortgage, and forecloses on their homes. That used to be legal. Now it is not, thanks to the HIPAA Act.

Imagine all the people who have access to your child’s medical information—people such as claims processors, visiting doctors, people studying in medical and health care programs. HIPAA provides patients and employees who have health care plans with several privacy protections. Health care providers that must comply to HIPAA:

- Hospitals and clinics
- Nursing homes
- Home health agencies
- Most physicians, pharmacists, and dentists
- Ambulance services
- Managed care organizations
- Some local health and social services departments
- Laboratories
- State Medicaid programs

Key Provisions

Access to Your Medical Records. At any time you can request to see your medical records, which must be sent to you within 30 days of the date you request them. You might have to pay for copying and postage costs.

Notice of Privacy Practices. You must be informed on how your health and medical information will be used. You’ll typically receive a notice of this information the first time you visit or use one of the health care providers listed above, and be requested to read and sign the notice.

Limits on How Your Health and Medical Information is Used. The health care providers listed above need certain information to provide you with the best possible care. However, your information may not be used in ways

Privacy and Your Child’s School Health Records

The Family Educational Rights and Privacy Act (FERPA) of 1974 is designed to protect students’ educational records, which include their health records. This protection applies to students attending federally funded (public) schools, kindergarten through senior year of high school. Until students turns 18, parents have the right to inspect and modify their children’s educational records, and control (with some exceptions) how those records are released to other individuals. After the age of 18, those rights transfer to students who attend any federally funded educational intuition, such as public colleges and universities (see U.S. Department of Education. “Family Educational Rights and Privacy Act (FERPA).” Retrieved from http://www2.ed.gov/policy/gen/guid/fpco/ferpa/index.html on November 14, 2010).

For more information on FERPA, visit www.ed.gov and search on “Family
unrelated to your health care (like the example given in the introduction to this section). This means that if you share your personal information with a health care provider, it must first get your permission before sharing that information with marketers and advertisers.

**Stronger State Laws.** States may apply greater protective measures than what the federal HIPAA law requires.

**Requests for Confidentiality.** You may request that individuals of the health care providers listed above keep confidential any communications you have with them: verbal, electronic, written, or typed. Those individuals must take reasonable steps to meet your request for confidentiality.

**Complaints.** You may file a formal complaint if you think your or your child’s health and medical information is being used in ways unrelated to health care.

**How to File a Complaint:**

You may file a complaint through the U.S. Department of Health and Human Services or your regional Office of Civil Rights (OCR).

The U.S. Department of Health and Human Services

**Call** 1-877-696-6775 (ask for your regional Office of Civil Rights (OCR) office)

**Visit** www.hhs.gov and click “Regulations”

**Write**

200 Independence Avenue, S.W.
Washington, D.C. 20201

Next Chapter: Life and Disability Insurance
Your Life & Disability Insurance

Life and disability insurance play important roles for your entire family. It’s hard to think about or plan for, but if you were to experience a fatal or debilitating accident or illness damaging your ability to provide your family with income, life and disability insurance could help maintain your family’s financial well-being.

Next Section: Your Life Insurance
# Your Life Insurance

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This publication is intended to provide general financial information; it is not intended to substitute for, or supersede, professional or legal advice. The specific needs of every disability or life circumstance have not been covered in this publication. The best course of action must be based on individual circumstances. Note: The content areas in this material are believed to be current as of this publication’s writing, but, over time, legislative and regulatory changes, as well as new developments, may date this material.
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Your Life Insurance

An obvious role life insurance plays is its ability to provide income for a surviving family's ongoing living expenses and financial goals around education, career, and retirement. Yet for families of children with special needs, the role of life insurance takes on an even greater role. It becomes part of the answer to, “Who will care for my child after I’m gone?”
The Role Life Insurance Plays in Families of Children with Special Needs

Depending on the type you get, a life insurance policy can provide your child with special needs with these long-term benefits:

- Funding for the day-to-day costs of caring for your child.
- Funding for special needs trust.
- A way to leave funds to a special needs trust (where the trust, not your child, is a beneficiary of the life insurance policy) after the second parent dies, while maintaining your child's eligibility for government benefits.
- Funding for the costs of a caregiver if your child needs long-term or part-time care.

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Calculate Your Life Insurance Needs

How much life insurance do you need? You can begin determining that by reviewing the current expenses listed on your spending plan, then move on to determining expenses you think you might have in the future. And because the cost of things generally go up (inflation), you’ll need to calculate how much the cost of something at today’s prices will cost many years from now.

For help in determining how much life insurance you need, speak with a life insurance agent or financial advisor, preferably one with experience in working with families of children with disabilities. To learn more about life insurance and the issues related to it, visit the Insurance Information Institute at www.iii.org.

Areas to Consider When Calculating Insurance Needs

- How much money your family needs to live on now—the day-to-day expenses you listed in your spending plan.
- How much money you will need to finance your family’s future expenses, such as college, the long-term care of your child with special needs, career training, and the long-term care for you and your spouse.
- How much you owe now. If you created a Debt Reduction Plan, use the total debt amount you listed. Consider future debt you might incur for other financial goals around education, career, and retirement.
- Medical expenses that are not covered by your health care plan.
- Funeral expenses and final estate-settlement costs.
Life Insurance and Your Social Security Benefits

By taking into account your Social Security benefits, the amount of life insurance you actually need is reduced. Social Security legislation may change over the years, but at the time of this publication, surviving family members of the deceased may receive the following benefits.

- A surviving spouse can collect:
  - The deceased’s *full monthly* Social Security benefit beginning at age 65 to 67, depending on her or his year of birth.
  - A *permanently reduced monthly benefit* as early as age 62. The benefit is reduced permanently because of the earlier age compared to the full benefit age listed in the bullet above.

- A surviving spouse caring for a child who also receives Social Security benefits can collect the deceased’s *full monthly* Social Security benefits at any age until the child reaches age 16.

- A disabled widow or widower can collect benefits as early as age 50, or at any age if a child under the age of 16 lives at home. Those benefits are in addition to the benefits children themselves receive.

- Unmarried children may collect benefits if they are:
  - under age 18
  - under 19, but still in school
  - over 18, but severely disabled and the disability occurred before age 22.

- Social Security may also pay a small death benefit to the surviving spouse or children.

For more information on life insurance and your Social Security Benefits, contact the Social Security Administration:

**Call** 1-800-772-1213 (Voice) or 1-800-325-0778 (TTY)

**Visit** [www.socialsecurity.gov](http://www.socialsecurity.gov) and search on “Survivors Benefits Publication 05-10084”

**Write**

Social Security Administration
Office of Public Inquiries
Windsor Park Building
6401 Security Blvd.
Baltimore, MD 21235
Your Disability Insurance

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Your Disability Insurance

Disability insurance is designed to protect a wage earner’s income stream on account of a disabling accident or illness. There are two types of disability insurance: short-term and long-term. While both types will typically replace from 50 to 70 percent of pre-tax income lost on account of a disability, short-term disability insurance will often pay up to a specified amount.

**Short-term disability insurance** typically lasts 90 days to two years. Coverage usually begins one to 14 days after the onset of a disability.

**Long-term disability insurance** usually starts 30 to 180 days after the onset of a disability. How long it lasts depends on the policy, but usually up to two years.

If a person is covered by short- and long-term disability insurance, the short-term plan usually stops when the long-term plan starts. Also, employees may have to use sick days to take time off of work (due to the disability) before disability insurance benefits begin.
Sources of Disability Insurance

The majority of disability insurance is provided by employers, yet other sources are available. Before you consider purchasing your own disability insurance policy, consider the following sources of disability insurance and how you can qualify for them.

Be aware that even though you may be eligible for disability insurance from multiple sources, receiving benefits from one source may reduce your benefits or disqualify you from receiving them from another. Generally, the sum of all disability payments received will not exceed 80 percent of your average lifetime earnings (rather than your current earnings) before the accident or illness. Disability benefits you receive from an employer are taxable; benefits received from a disability insurance policy you’ve purchased are not.

Your Employer

Employer benefits packages vary when it comes to taking care of employees who become sick or disabled. One thing that doesn’t vary, however, is this: All employers are required to pay into Worker’s Compensation, a form of insurance for employees injured while on the job.

Disability Insurance

Many employers provide employees who become disabled and unable to work with short- and long-term disability insurance. Employees may have to pay for this insurance through payroll deductions. Some employers offer baseline coverage (a monthly benefit amount) with the option to add to it. Other employers don’t offer employees the actual coverage but the option to purchase it from a group plan.

Speak with your Human Resource representative for information about your company’s disability insurance program or options to purchase coverage from a group plan.

Worker’s Compensation

If you become disabled from working while on the job, your employer will provide you with Worker’s Compensation Insurance to replace about 60 percent of your income. All states require employers to provide this type of disability coverage.

Sick Leave

Some employers provide employees who become ill or disabled with paid sick leave for a few days or up to one year. How much payment you receive and for how long depends on your company’s sick leave policy and how long you’ve been employed.
Your State

Some states provide short-term disability coverage, usually up to six months. Employees pay for it through a payroll deduction. Speak with your Human Resource representative to find out if your state provides this type of coverage.

Your state’s Vocational Rehabilitation (VR) Agency offers programs to help people with disabilities become employed. Again, your Human Resource representative may be able to provide you with resources to find out about your local VR program.

To find a VR office near you—there might be more than one if you live in a large city—contact the Job Accommodation Network (JAN):

Call 1-800-526-7324 (Voice) or 1-877-781-9403 (TTY)
Visit www.askjan.org

The Federal Government

Social Security Disability Insurance (SSDI) is a disability benefits program paid through the Social Security Administration. SSDI may replace only a limited amount of income. Eligibility requirements are very strict. To receive benefits, you must meet all of the following conditions:

- You have been disabled for five full calendar months.
- Your disability is expected to last at least 12 months or end in death.
- You are unable to be employed at any occupation.

Other Sources of Income Should You Become Disabled

- Special disability programs are available for:
  - Veterans injured in war
  - Federal and state government workers
  - Railroad employees
  - Miners who develop black lung disease
- Automobile insurance benefits for a disability resulting from a car accident.
- A spouse’s income.
- Your savings, such as an emergency savings account, that can support income needs during a short-term disability.

A Private Disability Insurance Provider

If after considering the sources listed above you think you need to purchase disability insurance, take a look at the Consumer Federation of America’s “Long-Term Disability Insurance: Financial Protection for You and Your Family.” This is a 12-page report on what you need to look for in disability insurance. It contains a checklist to help you get the policy that is right for you. To order the report, contact the Consumer Federation of America:

Call 1-202-387-6121
Visit www.consumerfed.org
Write
This publication is intended to provide general financial information; it is not intended to substitute for, or supersede, professional or legal advice. The specific needs of every disability or life circumstance have not been covered in this publication. The best course of action must be based on individual circumstances. Note: The content areas in this material are believed to be current as of this publication’s writing, but, over time, legislative and regulatory changes, as well as new developments, may date this material.
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Planning Your Future

Should the air pressure in a plane drop, making it difficult to breathe, airline staff instruct you to place an oxygen mask around your own nose and mouth before you do the same for your child. That is, care for yourself first so you can care for your child.

The same concept holds true when it comes to your financial future—plan for yourself first so you can plan for your child.

Through saving in special accounts designed to provide income during your retirement years and tending to some legal matters, you can create your own income stream during retirement, and then later, for your child.

Borrowing Against the Future

In some cases, you can use your retirement savings as a safety net for present financial needs. Certain conditions apply, but if necessary, you may be able to borrow money from certain retirement accounts. Some types of accounts allow you to borrow or withdraw money for medical purposes.

But borrow very cautiously, for two reasons.

1. You must pay borrowed money back. If you don’t, you pay heavy fees and income tax on the borrowed money.

2. Not paying borrowed money back can seriously jeopardize your retirement income.

Before you borrow from any retirement account, be sure you understand what fees you’ll incur, if any, and the consequences, in dollar amounts, for not paying borrowed money back: fees, taxes, and lost retirement income.

Next Section: Types of Retirement and Savings Programs

Learn More About Retirement Planning

A lot of decisions go into making a retirement plan, saving for it, then actually retiring. The types of decisions you make about your house, work, investments, insurance, social security, and debt all affect your retirement income, or the amount of your monthly “retirement paycheck” after you retire. The resources listed below provide information to help you:

- Identify what decisions you need to make around retirement.
- Learn about the types of retirement plans available.
- Understand how each type of retirement plan works.
- Understand the rules that govern each plan.

IRS.gov
Call 1-800-829-1040 (Voice) or 1-800-829-4059 (TDD)
Visit www.IRS.gov and search on the
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### Types of Retirement and Savings Programs

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Types of Retirement and Savings Programs

You have several options for saving for retirement. From Social Security Benefits to employer-provided 401(k) plans to your own investments, a lot of ground is covered in this section. Yet understanding all of your retirement savings and retirement income options may inspire you to either start saving or save even more.

Next >
Social Security

If you pay into the Social Security system as a wage earner, you will receive a portion of the money you need to retire. Social Security is not intended to provide all of your retirement income needs. How much of a retirement benefit you receive from Social Security depends on how much and how long you paid into the system through payroll deductions or, if self-employed, through quarterly tax payments.

Your Social Security Statement

If you are 25 years of age or older, and have paid into the Social Security system as a wage earner, you should receive a Social Security statement every year. Your statement should arrive about three months before your birth month. It will list your retirement benefits, your earnings record, and information on how your benefits are estimated. This information can help you plan for the future.

How Your Retirement Age Affects Your Retirement Income

Make special note in your Social Security Statement in the difference in your monthly income should you retire at the earliest possible age of 62, compared to retiring at age 66 or 67 (depending on when you were born), or even later.

This is an important distinction.

Note that if you begin collecting benefits at age 62, you permanently reduce your monthly income. That means you will never be able to collect the full monthly income benefit you are entitled to collect. You can only collect that full income benefit if you retire at age 66 or 67, or later.

How to Request Your Social Security Statement

If you are over 25 years of age or older, and have paid into the Social Security System but are not receiving a statement of benefits every year, contact the Social Security Administration and request a copy of Your Social Security Statement, Form SSA-7004-SM:

Call 1-800-772-1213 (Voice) or 1-800-325-0778 (TTY)
Visit www.socialsecurity.gov/mystatement
Write
Social Security Administration
Office of Earnings Operations
P.O. Box 33026
Baltimore, MD 21290-3026

Information You Will Need to Request Your Social Security Statement

- Have ready the following information to complete a request for Your Social Security Statement:
  - Your name as shown on your Social Security Card
  - Your Social Security Number
  - Your date of birth
  - Your place of birth
  - Your mother’s maiden name (last name only; to help identify you)
If You Need to Correct Information on Your Social Security Statement

If any of your personal information or income listed in your earnings record is incorrect, contact Social Security using the information above and request Form 8822. Complete the form and mail it back to the address specified on the form. You can also correct your information online at www.socialsecurity.gov/mystatement.
As part of your employment benefits package, some employers provide a way for you to save for and invest in your retirement. The money you save or invest in employer retirement plans accumulates tax-free until you retire and begin withdrawing money from the plan.

For some employer plans, saving and investing in them can lower your taxable income. Each type of employer plan is presented below.

### Defined Benefits Plans

In years past, many companies paid the costs of pension plans for their workers under a program called a “defined benefit plan.” This retirement plan pays you a fixed amount (the defined benefit) each month during retirement. How much you receive depends on how long you worked for the company and how much you earned before you retired.

Although defined benefit plans are not as common in the private sector any more, many employees who work in the public sector (federal, state, or local governments) still receive “defined benefits” at retirement. However, even those plans are changing for some public sector employees, including newer ones who are being enrolled in defined contribution plans.

### Defined Contribution Plans

Today, as part of an employee’s benefit package, many companies offer a “defined contribution” plan instead. For this type of retirement plan, you contribute a fixed amount (the defined contribution), usually a percentage of your income. Employers typically offer retirement plan workshops for employees so they can learn:

- How the plans work.
- The tax benefits they offer.
- How to transfer funds after a change of jobs.
- How to begin withdrawing the funds at retirement.

Employers will also inform employees on the types of investments they can make in their defined contribution plans, and the level of risk associated with each investment. Which investment(s) employees choose in their defined contribution plans is left to each employee. That way, employees can choose investments with risk levels they are comfortable with.

### Types of Defined Contribution Plans

Three common types of defined contribution plans you may hear references to are:

- **401(k)** (For-profit companies)
- **403(b)** (Non-profit organizations)
- **SIMPLE** (Savings Incentive Match Plan for Employees)

### Contribution Amounts
Employees may choose what amount they want to contribute to their retirement plans, usually one to six percent of their income. For example, if you earn $60,000 and contribute five percent of your income to a defined contribution plan, you will save $3,000 each year. There are limits to the amount you can contribute each year. For example, with SIMPLE, you can contribute up to $6,000 each year.

Matching Contributions

Some employers provide the employee benefit of matching your retirement plan contributions. While employer matching contributions are regulated by the Employee Retirement Income Security Act of 1974 (ERISA), each employer is able to decide by how much it will match employee retirement plan contributions. Typically, employers base their matching contributions on a certain percentage of your:

- **Income.** For example, your employer may base matching contributions on 50 percent of your income. From the income example above of $60,000, this means your employer’s matching contributions would be based on $30,000.
- **Contributions.** For example, your employer may base matching contributions on one percent of your contributions. From the contribution percentage example above of five percent, or $3,000, this means your employer’s matching contribution would be based on one percent, or $600.

If you take into account that your employer’s matching is based on only 50 percent of your income, this means your employer’s matching contribution would be $300, or one percent of $30,000.


Employers are also able at their discretion to suspend or reduce matching employee retirement plan contributions, for example, in challenging economic times. But for any matching your employer does provide, at any level, consider it a valuable employee benefit. It is like getting free money.

Vesting

When it comes to your retirement plan, vesting means “ownership.” Your contributions to an employee retirement plan are always vested (see IRS.gov. “Retirement Topics—Vesting.” Page last reviewed August 5, 2010. Retrieved from http://www.irs.gov/retirement/participant/article/0,,id=211024,00.html on November 19, 2010.), meaning that you always “own” them—you never have to give them back. Should you change jobs, you can transfer the amount of your contributions from your “old” retirement plan to a new one or directly to a rollover IRA.

Sometimes employers’ contributions may become immediately vested. This means that you own them as soon as you start receiving them. In other cases, employer contributions may follow a phased-in vesting period based on your years of service. For example, you may own, or become vested in, a certain percentage of your employer contributions after one year of work, a higher percentage after two years of work, and so on until you own, or become fully vested in, all of your employer’s matching contributions.

Vesting periods for employer contributions vary at each company, but they generally last three to six years (see IRS.gov. “The Fix Is In: Common Plan Mistakes - Vesting Errors in Defined Contribution Plans” Retrieved http://www.irs.gov/retirement/sponsor/article/0,,id=144502,00.html from on November 19, 2010.) and have a phased-in ownership schedule. If you were to change jobs before the full vesting period is over, you would be able to transfer only the vested employer contributions (the amount you “own”) to a new retirement plan. Check with your employee benefits staff to find out how long your company’s vesting period is.
How Retirement Plan Contributions Affect Your Take-Home Pay

When you contribute to your employee retirement plan, you divert a portion of your income into retirement savings, away from your take-home pay. From the example above, still assuming your annual income is $60,000, your $3,000 contribution to your retirement plan would reduce your gross (before taxes) take-home pay to $57,000.

The Tax Benefits

Lowering your take-home pay may not sound all that appealing, but you get two tax benefits for making the sacrifice:

1. **Tax-deferred earnings.** The money you contribute to and invest in your defined contribution plan grows tax free until you retire and begin withdrawing money from the plan. At that point, you begin paying income tax on the withdrawals. In other words, your taxes are “deferred” to a later time, when your income tax rate might be lower than when you were working.

2. **A lower taxable income.** Because your contributions are not taxed now, but later, your taxable income is lowered by the amount of your contributions. For example, if you earn $60,000 and contribute five percent, or $3,000, to your defined contribution plan, your taxable income is $57,000. In other words, you would calculate your annual income tax on $57,000, not $60,000.

Investment Choice

Your employer will provide you with a choice of investments you can make in your defined contribution plan, usually money market, mutual funds, stocks, and bonds.

Penalty for Early Withdrawals

If you withdraw money from your defined contribution plan before 59 years of age, the earliest age you may withdraw, you will pay a 10 percent penalty fee on the amount of the early withdrawal in addition to income tax on the withdrawn amount.

Exceptions: Hardship Withdrawals

Some employer retirement plans allow for hardship withdrawals, penalty-free, for medical expenses not covered by your health care plan. Check with your employer on whether this is the case with your retirement plan. Some pretty strict requirements usually have to me met to qualify for a hardship withdrawal. To avoid a potentially costly error, be clear on what your financial responsibilities are before you make an actual withdrawal. Employers may also allow the hardship withdrawals listed below (see GuideTo401kHardships.com. “Information on 401(k) Hardship Withdrawals.” Retrieved from http://www.guideto401khardships.com/ on September 7, 2010). Again, be clear on what requirements you must meet before you make any withdrawals from your employer retirement plan.

1. Un-reimbursed medical expenses.
2. The purchase of your first home (the one you would live in; not a rental or investment home).
3. Payment of college tuition and some related costs, such as room and board.
4. Payments on your primary residence (not rental or investment property) to prevent eviction or

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5. Funeral expenses.
6. The repair of your primary residence.

Important Considerations for Hardship Withdrawals


1. You will have to pay income tax on the amount withdrawn from your employee retirement plan.
2. You reduce the amount of your retirement savings by the amount withdrawn.
3. You may withdraw only your contributions, not your employer’s matched contributions.
4. The withdrawal may not be higher than the hardship expense. For example, it may not be more than the actual unreimbursed medical expenses.

If you’re strapped for cash, a hardship withdrawal might seem like the answer to your financial hardship. But consider the long-term consequences.

First, do you want to potentially reduce your retirement income? And second, do you expect your financial situation to improve? If you don’t think it will, what is the possibility of finding yourself strapped for cash again?

If you think your financial situation might improve and you are not contributing the maximum amount allowable to your retirement plan, you may have the opportunity to “pay yourself back” by making higher contributions in the future.

Catch-Up Contributions

The IRS allows individuals age 50 and over to make annual “catch-up” contributions to their employee retirement plans. The IRS limits the amount of catch-up contributions. As of 2010, the annual limit is $5,500. Other restrictions to making catch-up contributions apply. For more information on catch up contributions, take a look at the IRS article Retirement Topics—Catch-Up Contributions. It is very important you fully understand every financial consequence to a hardship withdrawal. If you are considering one, speak to someone at your company knowledgeable about them. Also, visit the IRS Web site and take a look at the article, Retirement Topics—Hardship Distributions.
Profit-Sharing Plans

Your employer may offer to share its profits, often by contributing company stock or cash into a profit sharing account, in your name. The contributions grow tax-deferred, and you don’t pay income tax on the contributions until you withdraw them at retirement.

If you receive company stock, the value of your profit sharing plan will rise and fall as the price of the company stock fluctuates over time. Remember to keep in mind the importance of diversifying your investments—do not invest too heavily in any one type of investment or particular stock. You might have heard this rule of thumb referred to as “Don’t put all of your eggs in one basket.”

In addition, your employer does not have to share its profits year after year. Think of your profit-sharing plan as a bonus rather than as a resource for your retirement or for your child’s needs.

For more information on profit sharing plans, visit the Profit Sharing/401k Council of America at www.401k.org or call 312-419-1863.
Individual Retirement Accounts (IRAs)—Self-Funded Retirement Plans

You might find saving through an employer easy and convenient. If you never see the money you save in your paycheck, you don’t miss it! Saving on your own takes a bit of discipline, but even small amounts saved add up over time.

Individual Retirement Accounts (IRAs) are a type of self-funded retirement plan. Here, you open the account on your own through a bank, credit union, or investment firm. You fund the plan with your “after tax” savings, rather than the “pre-tax” income from your earnings or from your employer’s matched funds.

IRA Contributions

The IRS regulates how much you may contribute to an IRA each year. Allowable amounts will change over time. At the time this publication was written (2010), the maximum allowable contribution amounts:

- If you are under 50 years of age, is $5,000 per year.
- If you are over 50 years of age, is $6,000 per year.

Each year, you can contribute any amount up to the maximum amount. And, you can contribute at any time during the year. Because of the IRA tax benefits (see next section), the deadline for making contributions is tied to the date by which your income tax returns must be filed. For example, IRA contributions for 2011 must be made by April 15, 2012.

Types of IRAs

Special Needs—Special Consideration for the Roth IRA

For parents of children with special needs, the Roth IRA may provide a needed benefit. If you plan on making your child’s special needs trust the beneficiary of your IRA, the funds distributed to the special needs trust upon your death are not taxed. This could be one way to make the most of your money for the benefit of your child. The trade-off is that you don’t get a tax benefit when you make the contribution, as you do with the traditional IRA.

Learn More About Early Withdrawals from Retirement Plans

In addition to speaking to a representative at your bank or credit union, or to your trusted financial advisor about IRS rules for early withdrawals from retirement plans, you can explore the IRS Web site directly.

Call 1-800-829-1040 (Voice) or 1-800-829-4059 (TDD)
Visit www.IRS.gov and search on “hardship distributions” or “IRA, early withdrawals”.

Types of Retirement and Savings
There are two types of IRAs you need to know about, the Traditional IRA and the Roth IRA. Rules about these plans change over time. Before you open an IRA, speak with someone knowledgeable about these plans, such as a bank or credit union representative or trusted financial advisor, to find out what rules apply.

- **Traditional Individual Retirement Account (IRA).** The Traditional IRA was the first type of IRA to be established. Contributions you make to these types of plans:
  - Can lower your taxable income by the amount of your contribution, if your income doesn’t exceed a certain amount. If it does, you may still be able to lower your taxable income, but only by a portion of the amount you contribute. Contact your bank or credit union representative or trusted financial advisor to find out what the current income limitations are, as they change over time. You can also find out that information on the IRS Publication 590. Visit [www.irs.gov](http://www.irs.gov) and search for “Publication 590.”
  - Will grow tax free until you begin withdrawing from the plan at retirement. The earliest you may withdraw funds without penalty is at age fifty-nine and one half.
  - Will be taxed at when you withdraw the funds at retirement, and at the then current income tax rate.

- **Roth IRA.** This IRA is named after the last name of the Senator who introduced it in 1997. Contributions you make to these types of plans:
  - Will not lower your taxable income.
  - Will grow tax free.
  - Will not be taxed when you withdraw the funds at retirement. With very limited exceptions, the earliest you may withdraw funds without penalty is at age fifty-nine and one half.

**Penalty for Early Withdrawals**

If you make a withdrawal before the
age of fifty-nine and one half, you will pay twice: once with a 10 percent early withdrawal penalty and then again with federal and state income taxes on the amount withdrawn.

Exceptions to the Penalty

The IRS allows you to make an early withdrawal from your IRA account without penalty for these situations:

You have unreimbursed medical expenses that are more than seven-and-a-half percent of your adjusted gross income.

- You are disabled.
- You are the beneficiary of a deceased IRA owner.
- You use the withdrawal to buy, build, or rebuild a first home.
- You use the withdrawal to finance a college education.

The IRS places strict conditions on these exceptions. For example, withdrawal amounts cannot be more than the costs of your medical insurance or college education (if applicable).

If you think you might need to withdraw funds from your IRA account before you turn fifty-nine and one half, speak with someone knowledgeable about these exceptions to early IRA withdrawals, such as a bank or credit union representative or trusted financial advisor, to find out how they might apply to you. Also take a look at the considerations for hardship withdrawals from employee benefit plans they apply here, too.
Personal Investments and Savings

The more you can save for the future, the more financially secure it will be for you and your child. Many financial advisors suggest investing your personal savings in stocks, bonds, or mutual funds for long-term financial goals, such as retirement. What you decide to invest in depends on an assessment of what your financial needs will be at retirement and your tolerance for risk. Speak with a trusted financial advisor for help in selecting appropriate investments for the personal savings you’d like to use for retirement.

Next Section: Your Long-Term Care
Predicting how much assistance you'll need with day-to-day living activities in your elderly years and how much it will cost is difficult—there are many unknowns. Planning to pay for any long-term care you might need out-of-pocket can be risky—its cost may turn out to be far more expensive than you anticipated. Should that occur, you risk the future of your own well-being along with your ability to care for an adult child with ongoing special care needs.

Long-term care insurance policies offer a variety of benefits that assist the elderly with activities of daily living (ADL). Long-term care options include coverage for in-home care, assisted living, hospice care, and nursing home care. Speak with a trusted financial advisor on whether purchasing long-term care insurance is right for you.

Why Purchase Long-Term Care Insurance?

Did you know that Medicare does not pay long-term care expenses associated with day-to-day living activities? Medicare is a form of government health care assistance that covers some hospital, medical, and prescription drug expenses, but not expenses associated with long-term daily living activities. Long-term care insurance does.

Another consideration is whether a child of yours without disabilities may take on the role of caregiver of your child with special needs. If that occurs, your child-caregiver may not be available to tend to your needs during your elder years.

Along with protecting your and, potentially, your child’s well being, long-term care insurance helps you also protect and retain your assets that you need to support yourself, your spouse (if applicable), and your child’s additional needs. What assets remain after you die can be passed on to heirs and your child’s special needs trust.

Choosing a Long-Term Care Insurance Product

Many factors need special consideration when selecting long-term care policy options and evaluating their costs. People are living longer than in the past, which might have some bearing on the level of benefits you ultimately receive. Take extra care in...
choosing a long-term care product. Ideally, seek the advice of a trusted financial professional experienced in issues related to children with disabilities.

How Much Does Long-Term Care Insurance Cost?

Health care costs rise over time (you may know that all too well). At the time of this publication’s writing (2010), one year in a nursing home can cost $60,000. (see "Talking About Medicare: Your Guide to Understanding the Program, 2009—Long Term Care." The Henry J. Kaiser Family Foundation. Retrieved from http://www.kff.org/medicare/7067/med_longterm.cfm August 30, 2010). The average hourly rate for an in-home health aid is $21 per hour. If you figure an aid’s assistance for five hours a day, your monthly cost for in-home care would be about $3,150 per month (see The 2009 MetLife Market Survey of Nursing Home, Assisted Living, Adult Day Services, and Home Care Costs." MetLife Mature Market Institute. 2009. Retrieved from www.metlife.com on September 26, 2010.).

Your actual cost to purchase long-term care insurance depends on your age, what benefits you want or need, how long you think you’ll need to receive them, and the length of time you are willing to wait until benefits begin. You can receive long-term care in an assisted living center, through adult day care and in-home services, or in a nursing home.

As with any type of insurance, carefully read the policy and compare it to long-term care insurance policies before purchasing. In certain circumstances, you may be able use the premium amounts as a deduction on your income tax return.

Next Section: Estate Planning for Your Family

Medicare.gov
Get more information on what Medicare is and the benefits it offers. Visit www.Medicare.gov.
# Article Title
1 Estate Planning for Your Family
2 The Two Basic Categories of Assets
3 Why Estate Planning is So Important
4 What You Do When you Make an Estate Plan, Part 1
5 What You Do When you Make an Estate Plan, Part 2
6 What You Do When you Make an Estate Plan, Part 3
Estate Planning for Your Family

Your estate is the sum total of your property and possessions, also referred to as your assets. They include investments, furniture, household items, real estate, jewelry, and any other items of value. Estate planning involves how you want those items distributed after your death, as well as any action you’d like to occur at that time, such as a specific level of care for your child with special needs.

Estate planning also involves protecting your ability to make wise decisions for yourself and your family while you are still alive to make them. Going through the estate planning process may be awkward and uncomfortable. It is hard to fast-forward though your life and plan for a time when you will no longer be here.

Next >
The Two Basic Categories of Assets

The two categories of assets to consider when planning your estate are:

- **Probate assets**, or the assets listed in and controlled by your will. Probate assets transfer to your heirs according to the instructions you made in your will.

- **Non-probate assets**, such as life insurance or proceeds from an Individual Retirement Account (IRA) among others, transfer to your beneficiaries according to the terms of the contract, not by the instructions you made in your will.

How to Legally Transfer Assets to Your Child Without Jeopardizing Government Benefits

In order for your child to remain eligible for government benefits, as of 2010, he or she may never own more than $2,000 in assets. And that is the federal requirement. States are allowed to impose a stricter requirement. That means states can require an asset amount less than $2,000 (see Social Security Online. “Understanding Supplemental Security Income: SSI Resources.” 2010 Edition. Retrieved from http://www.ssa.gov/ssi/text-resources-ussi.htm on November 20, 2010.).

Advocates for the disability community are working to raise the asset limitation amounts, arguing that it keeps people in poverty rather than helping them become financially independent.

To maintain your child’s eligibility for government benefits, do not name your child with special needs as an heir in your will, or as a beneficiary of a financial contract (such as a life insurance policy or an IRA). Rather, name your child’s special needs trust as an heir in your will, or as a beneficiary in your financial contracts.
This publication is intended to provide general financial information; it is not intended to substitute for, or supersede, professional or legal advice. The specific needs of every disability or life circumstance have not been covered in this publication. The best course of action must be based on individual circumstances. Note: The content areas in this material are believed to be current as of this publication’s writing, but, over time, legislative and regulatory changes, as well as new developments, may date this material.

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Why Estate Planning is So Important

The crush of day-to-day activities in caring for your family may make estate planning seem like one of those things you know you need to do but will get to later. Think again before putting it off for too long:

- If you were to suddenly become unable to care for your child with special needs, who could step in and care for your child the way you do?
- If your savings had to be spent on your own sudden illness, how would that affect the long-term financial well-being of your child?
- What if you weren’t able to prevent someone from naming your child as a beneficiary of an investment (rather than your child’s special needs trust), potentially disqualifying your child from government benefits?

The steps you take for estate planning will help you find answers to the question “Who will take care of my child when I can’t?”
As you’re about to see, making an estate plan involves doing several things. The end result from all this planning is protection of:

- Your child’s long-term ability to receive important government benefits.
- Your ability to make important decisions about the future for you, your family, and your child with special needs.
- The way your estate—your property and possessions—is distributed among your family members in ways that provide them with the greatest benefits.

The majority of your work in estate planning is preparing legal documents that will provide the protections noted above. You’ll also select the people who will help you prepare those documents and carry out (execute) the plans you’ve stated in them.

### Steps You’ll Take to Create an Estate Plan

The types of estate planning documents you’ll create and people you’ll need to work with in creating them are listed below. The order in which they are listed is a mere suggestion. The attorney you select to help you create the special needs trust will guide you through these steps.

<table>
<thead>
<tr>
<th>Step</th>
<th>Documentation</th>
<th>People</th>
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<tbody>
<tr>
<td>Write a Letter of Intent</td>
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<td>x</td>
</tr>
<tr>
<td>Select a Special Needs Trust Attorney</td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>Select a Trustee for the Special Needs Trust</td>
<td></td>
<td>x</td>
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<tr>
<td>Prepare a Special Needs Trust</td>
<td></td>
<td>x</td>
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<tr>
<td>Select a Guardian</td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>Prepare Guardianship Papers</td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>Prepare a Living Will</td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>Select a Trustee for Your Will</td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>Prepare a Will</td>
<td></td>
<td>x</td>
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<tr>
<td>Select a Power of Attorney</td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>Prepare Durable Power of Attorney Papers</td>
<td>(for financial decisions)</td>
<td>x</td>
</tr>
<tr>
<td>Prepare a Health Care Proxy (for medical decisions; also known as “health care surrogate” or “durable medical power of attorney”)</td>
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</tbody>
</table>
What You Do When you Make an Estate Plan, Part 2

Here are descriptions of the elements that make up your estate plan.

Letter of Intent

This document becomes part of the special needs trust. It is not a legal document. You write it to the person who will care for your child when you are unable to or after your death. Its purpose is to explain in detail the care you lovingly give now to your child so the caregiver can later walk in your shoes as best as possible. Since the nature of your child’s care changes over the years, you need to update your letter of intent each year.

What to Include in the Letter of Intent

In a way this letter is the story of your child’s life. It covers the range of care you provide your child day after day: personal (includes emotional, intellectual, spiritual), medical, financial, educational, career, and legal. Here are some categories to think about as a way to get you started in writing your letter of intent.

Personal
- Name, date of birth, social security number,
- and address (if different than your own).
- Your child’s abilities and talents.
- The things that make your child happy,
- or sad.
- What causes bad behavior.
- How to correct it.
- The people your child loves.
- The people who love and care for your child the most.
- Your child’s dreams and hopes for the future.
- Your dreams and hopes for your child’s future.
- A detailed description of how you care for your child’s emotional and spiritual health.

Health & Medical
- A detailed description of:
  - Your child’s disability.
  - How you care for your child’s physical health.
  - Your child’s mental health care needs.
- A list of:
  - Medications your child takes and contact information for the pharmacy you work with.
  - Your child’s doctors, specialists, and other health care providers and their contact information.
  - The treatments your child needs.
- Lab, x-ray, MRI, etc. results.
- Your child’s vital information: weight, blood type, blood pressure.
- The types of health care plans that cover your child’s medical expenses.
- Assistive technology used now and anticipated to use in the future.
<table>
<thead>
<tr>
<th>Financial</th>
<th>Educational</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information on your child’s government benefits that affect his or her financial well-being.</td>
<td>Academic strengths and weaknesses.</td>
</tr>
<tr>
<td>Your financial advisor or trusted friend who handles your child’s financial matters.</td>
<td>Details about your child’s Individual Education Plan (IEP)</td>
</tr>
<tr>
<td>Professionals who help handle your child’s affairs: financial advisor, attorney, trustee, power of attorney, accountant.</td>
<td>The level of your child’s involvement in developing the IEP.</td>
</tr>
<tr>
<td>The aspects of your estate plan that involve your child.</td>
<td>The level of your child’s involvement that you know your child needs take responsibility for.</td>
</tr>
<tr>
<td>A vision of your child’s financial care</td>
<td>How you encourage your child’s progress through school.</td>
</tr>
</tbody>
</table>

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<tr>
<th>Career</th>
<th>Legal</th>
</tr>
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<tbody>
<tr>
<td>Your child’s career aspirations or dreams on what he or she wants to be upon “growing up.”</td>
<td>Any legal paperwork that is not part of the categories above.</td>
</tr>
<tr>
<td>How far along your child is in meeting career goals.</td>
<td></td>
</tr>
<tr>
<td>Challenges to be met in getting to and from work.</td>
<td></td>
</tr>
<tr>
<td>On-the-job challenges.</td>
<td></td>
</tr>
<tr>
<td>Who your child consults for career advice.</td>
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</tbody>
</table>

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What You Do When you Make an Estate Plan, Part 3

Special Needs Trust

This is covered in the section Planning for Your Child’s Future.

Trustee

This is the person who is responsible for making financial decisions for the special needs trust or your will after your death. The trustee may be someone from your bank or credit union, a financial advisor, an attorney, your child’s guardian, or someone you trust and who you think will savvy managing your money. You want to select a trustee whom you completely trust—one who is aligned with your money values and inspired to carry out your wishes as you would yourself.

Guardian

This is covered in the section Planning for Your Child’s Future.

Living Will

This is a legal document that instructs family members, caregivers, and medical professionals on what type of medical treatment you want should you be unable to request it yourself. Often living wills come into play when one becomes terminally ill or permanently unconscious and does not care to have advanced, life-saving treatments to prolong these conditions. The living will includes a power of attorney—the person you select to make medical decisions on your behalf should you be unable to. Similar in selecting a trustee, you want to select a power of attorney whom you completely trust—one who is aligned with your values and life philosophy.

Will

A will is a legal document that specifies how you want your property and possessions distributed, and to whom (your beneficiaries) after your death. Without a will, the courts would decide who gets what. Parents of children with disabilities who need government services should not name their children as an heir. Doing so may disqualify them from receiving government benefits.

Durable Power of Attorney (for financial decisions)

A legal document where you designate someone (an agent) to act on your behalf should you be unable to. The durable power of attorney remains effective should you become physically or mentally unable to make decisions. Take care in drafting this document by:

- Being specific about what financial responsibilities it includes, or not.
- Appointing an agent you would completely trust with your financial matters.

Health Care Proxy (for medical decisions)

This is a legal document that designates someone of your choice to make medical decisions for you
should you be unable to; also known as "health care surrogate" or "durable medical power of attorney."

Next Chapter: Planning Your Child's Future

< Prev
Planning Your Child’s Future

Before we begin this chapter, let’s reflect a moment. Consider everything you’ve accomplished thus far, on all fronts of your life, and in your child’s life, too. Even though you might feel a lot of things are left undone simply because you don’t have the time to do everything you’d like, you have covered a lot of ground while caring for your child. From the moment you learned of your child’s diagnosis up until this moment, you’ve learned and applied a lot of skills.

It’s time to take some inventory of those skills:

- Creativity: You’ve found creative solutions to complicated problems.
- Zest for Knowledge: You’ve learned about many topics presented in this publication and beyond.
- Decision Making: You’ve analyzed situations, considered the pros and cons, assessed consequences for certain decisions, then made the actual decisions.
- Self-Motivation: On days you’re beyond exhausted, you’ve answered the call of caring for your child, other family members, and, hopefully, yourself.
- Verve: You’ve dug deep to be persistent, tenacious, and resilient.

These are incredibly valuable life skills. Let your child experience you putting those skills into action. As much as your child’s health will allow, include the skills you develop and work on every day as part of your child’s learning process—as part of your plan for your child’s future.

Next Section: Person-Centered Planning
Person-Centered Planning—The Path to Your Child’s Happiness

Person-centered planning brings together a community of support that can help your child set and accomplish specific goals. You can involve anyone you want in person-centered planning. You can do it at any time in your child’s life and make changes along the way. If started before a major transition, such as from high school to a vocation, job, or post-secondary education, person-centered planning can help make for a smoother transition.

Setting the planning process into motion begins with exploring your child’s world, as he or she lives and breathes it—laying test results aside and noticing pure ability, effort, and desire. Person-centered planning helps lay the tracks of your child’s path to the future. It is part of the answer to “Who will care for my child when I’m gone?” because along this path your child will learn to become his or her own best advocate, determined to accomplish dreams and goals.

When Person-Centered Planning Occurs

You will engage in person-centered planning throughout your child’s life. It can become the cornerstone of every effort you make to either advocate for your child or encourage him or her to become a self-advocate. You can use it during day-to-day interactions with professionals of all walks of your child’s life: health care, education, government agencies, life transitions, career, independent living.

A Strategy for Person-Centered Planning

So what do you actually do to make a person-centered plan? Step into your child’s world. Ask what he or she is thinking about when elated, happy, sad, or completely agitated. Ask what your child longs to be or do and how he or she envisions making that happen. Take that information and begin forming a plan that will help your child forge a path toward personal fulfillment, self-advocacy, and independence.

Involving others in the person-centered plan builds a wider net of support. They can be family members;

The expression, “It takes a village to raise a child,” is never more true than when talking about a child with a disability. Young people with disabilities need a support system that recognizes their individual strengths, interests, fears, and dreams and allows them to take charge of their future. Parents, teachers, family members, and friends in the community who offer informal guidance, support, and love can create the “village” for every child.

friends; neighbors; and school, social services, and health professionals.

To help your child develop a person-centered plan, you’ll first develop your child’s profile based on you and your child’s input and that of other individuals you involve in the planning process. Then, you’ll conduct a planning meeting. You may wish to do that at your home or at a place where someone might help facilitate the meeting. Examples include your child’s school, your Parent Center, or social services agencies.

Here are some specific things you can do to create your child’s person-centered plan (see “Person Centered Planning.” PACER Center. Retrieved from http://www.pacer.org/tatra/resources/personal.asp on August 30, 2010).

Develop Your Child’s Profile

- Think of who might like to be involved in your child’s person-centered plan. Invite them to a convenient place, such as your home, house of worship, or Parent Center. These people will be considered your child’s person-centered planning team.
- Ask someone to record the conversation.
- Ask everyone to share experiences with your child’s development, critical life events, and medical issues.
- Ask everyone to describe how they perceive the quality of your child’s life. Ask them to consider your child’s community connections; dreams and goals; choices made; and expressions of confidence, strength, and weakness.
- Ask everyone to describe the things your child loves to do, and the things that bring frustration or angst.
- Create a profile of your child from the conversation notes.

Conduct a Planning Meeting

- Pass out your child’s profile and give everybody a chance to review it.
- Talk about what future events might affect your child’s development.
- Share what future opportunities and obstacles your child might face in these future events.
- Identify strategies for dealing with these events that will help your child reach dreams and goals.
- Describe action steps that can help make dreams and goals become realities.

Person-Centered Planning: Desired Results

By taking the actions described in your child’s person-centered plan, you and the members of your child’s person-centered planning team can help your child embark on a journey toward long-term happiness. You may feel a sense of relief and peace of mind as the plan unfolds. Here are some end results you may see occur for your child:

- Greater control over his or her life.
- Increased opportunities to participate in the community.
- A deeper awareness and appreciation for desires, interests, and dreams.
- A willingness to set goals, and with the help from you and anyone else you involve in your child’s person-centered planning, turn dreams into reality.

**Learn More about Person-Centered Planning**

Cornell University's Employment and Disabilities has developed a Person Centered Planning Education Site, a rich online resource for individuals interested in learning more about the basic concepts of person-centered planning and a variety of tools used in person-centered planning.

Visit [www.ilr.cornell.edu/edi/pcp/](http://www.ilr.cornell.edu/edi/pcp/)

Next Section: Saving for Your Child's Future Needs: Part1
The Special Needs Trust

The special needs trust can be your primary savings tool for your child’s future. It allows you to properly transfer savings to your child without jeopardizing his or her ability to receive government benefits. Several ways to fund the trust are presented below.

Also referred to as a “supplemental care trust” the special needs trust provides a way for you to supplement government benefits such as Medicaid and Supplemental Security Income (SSI). The trust can be set up so it functions while you’re alive, or begins to function after your death.

Here’s the way it works. First you select a trustee—someone you completely trust and who can properly manage money. If the trust is to function while you are alive, the trustee distributes money from the trust to your child in ways that don’t disqualify your child from government benefits. If the trust is to function after your death, the trustee facilitates the transfer of money from your estate into the trust, then helps manage and distribute the money according to your wishes.

The most important benefits of the trust are maintaining your child’s financial well-being and his or her long-term eligibility for government assistance. It has another benefit, though. Through this trust, friends and family can make gifts of money, also contributing to the financial well-being of your child.

“I feel better knowing that my family will have enough money to take care of themselves in case something should happen to me. Saving for my retirement and for my family’s future is just as important to me as budgeting for the mortgage, groceries, and medication. I contribute to an employee retirement plan and have an annuity for my own security. For my family, I have a term life insurance policy and a pre-paid college fund for both my children. Also, I take every opportunity I get to teach my daughter about spending within her means. I plan to continue that with my son as soon as he gets old enough to spend a dime.”

—Chris Stevens, father of Ali and Jacob

How to Fund Your Special Needs Trust

The most important thing to remember in funding your special needs trust is this: The special needs trust, not your child, must be the heir or beneficiary of any funds you or anyone else wants to transfer to your child.

Remember, always, if your child ever accumulates more than $2,000 in assets, he or she may become ineligible for receiving government benefits. Some states have stricter requirements, meaning that asset requirement may be below $2,000 (see Social Security Online. “Understanding Supplemental Security Income: SSI Resources.” 2010 Edition. Retrieved from http://www.ssa.gov/ssi/text-resources-ussi.htm on November 20, 2010).

Here are some ways to fund your special needs trust (see News Digest—Estate Planning. National Information Center for Children and Youth with Disabilities. Washington, D.C. Volume 2, Number 1, 1992. Pages 6–8):

- Life insurance; it is one of the few ways to arrange for future funds after your death. Life insurance will be more affordable if you purchase it while you are young and healthy.
- Standard government benefits, such as Social Security survivor benefits.
- Savings and investments, including money in retirement funds (that can be distributed at an older age or transferred after death).
- Gifts, assistance, and inheritances from friends and family members.
- Property, such as the family home.
- Military benefits.

**How Funds From a Special Needs Trust Can Be Used**

Each state has a different set of limitations on how money in special needs trusts can or can’t be used, but generally it can be used for supplemental needs—those needs not met by government benefits such as Medicaid and SSI. Typical uses of money in special needs trusts (see Insure.com. "Life insurance planning for parents of children with special needs." May 19, 2009. Retrieved from [http://www.insure.com/articles/lifeinsurance/special-needs-children.html on September 9, 2010]):

- Transportation
- Home health aids
- Education
- Rehabilitation
- Computer equipment
- Medical and dental care not provided by government benefits

**How Funds From a Special Needs Trust Cannot Be Used**

Again, each state sets its own limitations on how funds can or cannot be used, but generally the trustee of your special needs trust cannot use funds for (see Insure.com. "Life insurance planning for parents of children with special needs." May 19, 2009. Retrieved from [http://www.insure.com/articles/lifeinsurance/special-needs-children.html on September 9, 2010]):

- Food
- Housing
- Property taxes
- Home insurance
- Utilities
- Transferring cash to your child with special needs

**How to Set Up Your Special Needs Trust**

Select an attorney experienced in working with families of children with special needs to set up your trust. This is a must; the trust has to be properly set up. Your attorney will also properly establish the responsibilities of the trustee who can be a person or financial institution, such as a bank. The trustee's most important job is to make sure your child always stays eligible to receive government benefits. Your attorney will also determine, with your input, what limitations the trustee has in managing and distributing the trust’s funds.

**How Much it Costs to Set Up a Special Needs Trust**

Your cost to set up this trust will vary, depending on your attorney’s fees and the complexity of the trust. Set up fees generally run a few thousands of dollars. Also, the trustee of your special needs trust may charge a small percentage of funds in the trust to manage and distribute them.

“Sometimes, you just have to talk to friends and family members who want to help out financially. You have to be sure they understand how to contribute without endangering your child’s eligibility for benefits. (Even birthday and holiday gifts of money, if saved over time, can add up and be counted as assets that belong to your child.) I’ve learned to suggest other ways for family and friends to carry out their kind intentions.”

—Donna Halcomb, mother of John and Patrick

Next Section: Saving for Your Child's Future Needs: Part 2
Individual Development Account (IDA)

A special type of savings account is available for employed individuals with disabilities. These accounts allow your child to save on his or her own without jeopardizing eligibility of government benefits. The savings account limits how the savings can be used, yet it may open up financial options your child might need to achieve dreams and goals.

Individuals who work but have limited income may be eligible for Individual Development Accounts. These are savings accounts offered by financial institutions, community- and faith-based organizations, and state and local governments. Each IDA program is different, but most require that an individual have a job and that his or her income does not exceed a certain level.

Specific IDA Programs for Individuals with Disabilities

A special federally funded IDA program allows your child to participate in an IDA program and still receive Supplemental Security Income (SSI) benefits. These special IDA programs are funded by the Assets for Independence Act (AIFA) or Temporary Assistance for Needy Families (TANF). Before your child enrolls in an IDA, it is very important that he or she ask the entity that is offering the IDA if it is funded by one of these federal programs. If it is not, assets in the IDA may affect your child’s eligibility for government benefits. Federal laws change. Always double check with a professional knowledgeable about IDAs, such as an IDA administrator at The Corporation for Enterprise Development (CFED) or a staff member at or Real Economic Impact.

Matched Savings Contributions

IDAs can really help your child build a savings. For every dollar your child saves, the entity providing the IDA will match that, at a rate of $1 to $4 for every dollar saved. For example, if your child saves $100 and the matched amount is $2 for every $1 saved (a 2:1 matching ratio), your child would receive $200 in matched funds for a total savings of $300.

Additional Financial Services Offered

Entities that offer IDAs usually provide other financial services, such as financial education, free income tax preparation services, and credit counseling.

What IDA Savings Can Be Used For

The Corporation for Enterprise Development (CFED) is a national non-profit based in Washington D.C. It provides information on the basics of IDAs and how to find a program near you. To get this information, contact CFED:

Call 1-202-408-9788
Visit www.cfed.org and click “Programs”
Write CFED
1200 G Street NW
Suite 400
Washington DC 20005

Real Economic Impact, a vision of the National Disability Institute, offers resources for individuals with disabilities to help them achieve financial stability and independence.

Call 1-202-296-2040
Visit www.RealEconomicImpact.org and search on “IDA”
Write National Disability Institute
1667 K Street, NW Suite 640
Washington, DC 20006

The World Institute on Disability has an informative publication on IDAs: “Individual Development Account Question and Answer Sheet: A Guide for IDA Consumers with Disabilities.” To get this publication, contact the World Institute on Disability:

Call 1-510-251-4341 (Voice) or 1-510-208-9493 (TTY)
Visit www.wid.org
Write World Institute on Disability
510 16th Street, Suite 100
Oakland, CA 94612
Some programs offer additional uses of savings, but generally IDA account holders can use the money to:

- Continue their education beyond high school.
- Buy a home.
- Start a business.
- Save money for the future.

**Where to Find an IDA Program Near You**

Staff at a Volunteer Income Tax Assistance (VITA) site close to your home can let you know if a local entity offers IDAs designed for people with disabilities. To contact a local VITA site near you:

**Call** 800-829-1040  
**Visit** [www.irs.gov](http://www.irs.gov) and search on “Volunteer Income Tax Assistance” to get a nationwide list of VITA sites.

Next Section: Conservatorship (Guardianship)
Conservatorship (Guardianship)

When your child reaches the age of majority (18 years, in most states), you are no longer his or her legal guardian. This is true even if your child lives at home and is unable to make informed decisions. Conservatorship is a legal arrangement in which you or a trusted adult you select is given the right to make decisions for your child. Conservatorship is a court-appointed and -managed role. In legal terms, your child would be considered a “ward” of the guardian.

Types of Conservatorship

A conservatorship may be “of the person” or “of the estate.”

A conservatorship of the person enables the guardian to make all necessary decisions in areas such as shelter, clothing, medical care, food, contracts the ward may wish to make, and so on.

A conservatorship of the estate enables the guardian to manage your child’s financial affairs and all the records associated with them, such as statements and reports. You may find using a special needs trust preferable to accomplishing this function.

Alternatives to Conservatorship

Your child may have some abilities in making decisions but need guidance at times. Because it adds to your child’s confidence, self-esteem, and life skills, you may want to continue letting your child make certain decisions but provide guidance when needed.

Listed below are alternatives to conservatorships, briefly described, that you might find more appropriate. (see Tuberous Sclerosis Alliance. “Guardianship.” Retrieved from http://www.tsalliance.org/pages.aspx?content=62 on September 10, 2010. Consult with an attorney to help you make the best decisions about a guardianship or one of the alternatives listed below.

A joint bank account held by you and your child to prevent your child from bouncing checks.

A Representative Payee who would receive certain checks, such as Supplemental Security Income (SSI), spend the money on behalf of your child, and manage related financial records. This might be helpful in ensuring that certain types of checks, such as SSI, are properly spent on food, shelter, and clothing. Your child can still make personal choices on how the money gets spent. You can appoint yourself as a representative payee through your financial institution.

A Durable Power of Attorney who would make financial or legal decisions on behalf of your child should he or she become unable to do so.

A Health Care Proxy that designates someone of your choice to make medical decisions for you should you be unable to; also known as "health care surrogate" or "durable medical power of attorney."

An Appointment of Advocate and Authorization, made by the individual with a disability him- or
herself, who advocates for your child while working with administrative agencies your child uses, such as Medicaid and the local Department of Human Services.

**Strategies for Selecting a Guardian**

You might find it awkward to engage someone in a conversation about caring for your child if and when you become unable to. The reasons might seem obvious to you, but we’ll articulate them as a way to help you gain clarity through any emotions you might have about selecting a guardian for your child.

**First**, you are well-aware of what goes in to caring for your child on all emotional and logistical fronts. Tending to that level of care is a lot to ask or expect of anyone. Yet by being persistent in developing your child’s self-advocacy skills, a potential guardian may come to notice and appreciate them. As a result, he or she may develop an interest in caring for your child.

**Second**, you might be uneasy about the notion of letting someone try to achieve your level of care. Welcoming people you know and trust into the care of your child may help ease the transition of care to someone who might express an interest in guardianship.

**Next Section: Your Child's Education**
Your Child’s Education—A Life of Learning

# Article Title
1. Your Child’s Education—A Life of Learning
2. Your Child’s Education and the Law
3. Planning and Funding Your Child’s Education—Elementary and Secondary School
4. Planning and Funding Your Child’s Education—Elementary and Secondary School Part 2
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7. Planning and Funding Your Child’s Education—Post-Secondary Schools Part 1
8. Planning and Funding Your Child’s Education—Post-Secondary Schools Part 2
9. Planning and Funding Your Child’s Education—Post-Secondary Schools Part 3
Your Child’s Education—A Life of Learning

Your child begins learning as an infant, responding as you read, speak, and listen to him or her. And then there are the educational milestones your child crosses: the transitions into elementary school, middle school, high school, and beyond. As time passes, your child develops a deeper awareness of the talents, strengths, and desires that drive him or her further along the path to a fulfilling and happy life. The learning never stops!
Your Child’s Education and the Law—A Summary of Your Rights

The purpose of special education during the elementary and secondary education years is to support your child with special needs in ways that put him or her on par with the rest of the student body—to provide equal opportunities to learn and to ultimately become a productive and independent adult. The laws that support this purpose are described below.

K–12 Education—Individuals with Disabilities Education Act (IDEA)

The Individuals with Disabilities Education Act (IDEA) first passed in 1975. It has been updated over the years with the most recent occurring in 2004. IDEA gives your child with disabilities the right to attend public school and receive a free and appropriate education.

In the context of special education, “appropriate” means that your child is entitled to an education in the least restricted environment, that is, your child is to be included in the general education classroom with his or her peers, and is to be taught the general education curriculum in a way that addresses your child’s unique learning needs (see Ellen M. Chambers. “What does ‘FAPE’ Really Mean?” February 2008. SPEDWatch—Special Education Activism. Retrieved from www.spedwatch.org/files/FAPE.pdf on September 11, 2010).

Your child’s right to a Free, Appropriate Public Education, or FAPE, is protected by the IDEA law.

To help bring about this appropriate education, a team that includes you and your child’s teachers will develop his or her Individualized Education Program (IEP). This is a legal document that contains the plan your child needs to make academic progress, and to the best extent possible, become a productive and independent adult. Your child’s school will involve you at every step of this special education plan—it is the law! You have the right to:

- Attend all IEP meetings and invite someone else if you wish.
Have someone explain your child’s evaluation report.
- Receive all meeting and legal notices about your child’s IEP.
- Agree or disagree with proposed actions by the school.

If your child is 16 or older, he or she must be invited to all IEP meetings as well. By becoming part of the IEP process, your child gains the opportunity to shape the IEP and take steps toward self-advocacy.

**Post-Secondary Education—Your Child’s Right to Accommodations**

From the time your child began kindergarten to the time of high school graduation, the school district was required by law to provide learning accommodations specified in your child’s Individual Education Program (IEP). The Individuals with Disabilities Education Act (IDEA) and Section 504 of the Rehabilitation Act of 1973 protected your child’s right to these accommodations. During college, your child still has a right to learning and testing accommodations, but that right is protected in different ways.

The American with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act of 1973 protect your child’s access to an education if he or she is otherwise qualified to attend (accepted into a college program based on test scores and other required prerequisites). In a post-secondary environment, it is your child’s responsibility to ask for accommodations that will provide this access.

Most post-secondary schools offer Disability Support Services (DSS) that help students with disabilities get needed accommodations. It is important your child request accommodations as soon as possible. In the event equipment needs to be ordered, a classroom must be moved to a wheelchair accessible building, or an interpreter is needed, a school may need advance notice.

For information on your child’s responsibilities in requesting learning accommodations, see Social Stigmas - To Ask or Not Ask for Accommodations.

**Comprehensive Transition and Post-Secondary Education—Higher Education Opportunity Act (HEOA) of 2008**

This exciting piece of legislation established a grant program for post-secondary schools to develop programs and coursework designed specifically for students with intellectual disabilities (ID), who very likely will not meet standard academic admission requirements. This Act also allows your child with ID to qualify for grants and Work Study Programs (earning college tuition through on-campus jobs).

**Special Education: What Do I Need to Know?**

This publication is available on the PACER Center’s Web site. It is an excellent overview of special education that will help you understand:
- What it is.
- How your child might get into special education.
- How to resolve disagreements with school staff on your child’s special education.
- What role you play in the special education process.

To get a copy of *Special Education: What Do I Need to Know?* visit [www.pacer.org](http://www.pacer.org) and search on the name of this publication.
Post-Secondary Education—
If Your Child Feels Subject to Discrimination While At College

Every post-secondary school has a person who must deal with compliance issues for Section 504 of the Rehabilitation Act of 1973 and the Americans with Disabilities Act (ADA). Your child should bring discriminatory practices to the attention of the this person. If the school's ADA compliance coordinator is unwilling to change policies or practices that discriminate against students with disabilities, you can assist your child in filing a formal complaint with the Department of Education Office of Civil Rights (DOE OCR) Your parent center may be able to help you frame your argument or direct you to legal resources that can assist you in this process.
Planning and Funding Your Child’s Education—Elementary and Secondary School, Part 1

It is the change of routine, supports, and educators as your child transitions from grade to grade that can present some of the greatest challenges. Positive transition experiences through the elementary and secondary school years may provide your child with the right mix of academic achievement and self-esteem for success.

As provided by the Individuals with Disabilities Education Act (IDEA), parents bear no tuition expense to send their children through the public education system from kindergarten to senior year in high school. Private schools charge tuition and some fees. Both the public and private education systems provide traditional classroom education as well as specialized programs that support your child’s disability learning and developmental needs.

Types of Schools

Your community may provide educational options beyond those provided by your local public school. The alternative schools funded with public monies listed below are required to offer special educational services, and may also have an approach that works more effectively with your child’s learning style.

Magnet Schools

These schools provide a particular focus on a type of coursework, such as science, technology, or fine arts. Coursework in magnet schools is tied to state standards and overseen by the public school district.

Charter Schools

These schools are tailored to meet the specific needs of a geographic area or student body. Charter schools are funded by the public education system but overseen by a school board elected by parents, teachers, and school staff. This board, along with input from community members, determines how the school will teach a standards based curriculum to students. Students must still meet state standards to graduate.

Online Schools

Also known as distance learning schools, online schools offer coursework through the Internet. Licensed teachers provide online instruction that must meet state standards. Your child might find that learning through online coursework is more comforting and suitable to his or her learning style. For example, coursework can be presented in video and audio formats. If you think your child might be more successful learning online than through the face-to-face method used at traditional schools, discuss this option with your child’s IEP team.

The coursework and testing provided by publicly-funded online schools must be accessible to students with disabilities, and specific accommodations outlined in a student IEP must be provided.

Alternative Schools
The coursework for public and private alternative schools is designed to help students perform better—students who haven’t been able to improve their performance in traditional school environments.

Examples of programs offered at alternative schools include:

- Emotional growth programs
- Programs for youth at risk (of dropping out)
- Special-needs programs
- Therapeutic wilderness programs

(See Dore Frances, IEC, founder of Horizon Family Solutions, LLC. “What is an "Alternative School"? Internet Special Education Resources (ISER). Retrieved from http://www.iser.com/resources/alternative-schools.html on September 12, 2009.)

Alternative schools that operate within the public school structure are offered at no expense to families. Private alternative schools may charge a monthly tuition.

Speak with a representative at your disability-specific organization or network at your local Parent Center for information about alternative schools that can serve your child. Remember to discuss the matter with your child’s IEP team.

Private Schools

Private schools with coursework designed around specific disabilities exist in many states. Families are required to pay tuition. Some schools offer scholarships or financial aid. Speak with a representative at your disability-specific organization for information about private schools that can serve your child. Also, consult your IEP team.

The National Association of Private Special Education Centers (NAPSEC) represents private educational institutions serving individuals with disabilities. NAPSEC has information about these private schools located across the country, and information on how to apply for financial assistance as well. To find out if your state has private schools that can serve your child, contact NAPSEC:

**Call** 1-202.434.8225  
**Visit** [www.napsec.org](http://www.napsec.org)  
**Write**  
601 Pennsylvania Avenue, NW  
Suite 900 - South Building  
Washington, DC 20004

A Public or Private School of Your Choice

Some states offer school choice programs open to children with and without disabilities. Under these programs, you aren’t limited to the public school system—you choose which education program you’d like to send your child to. Types of school choice programs include vouchers, charter schools, and online education. Not all states offer school choice programs.

Some of these school choice programs are called Tax-Credit Scholarship Programs. If you qualify for the tax credit, you would take it when you file your state income tax. Not all states allow this credit, which can offset additional expenses, such as books, school supplies, and transportation that you normally wouldn’t have to pay for if your child attended your local public school. In other school choice programs, individuals or companies offer scholarships directly to the student. To find out if your state offers school choice programs for children with disabilities, contact The Foundation for Educational Choice.

**Call** 1-317-681-0745  
**Visit** [www.edchoice.org/](http://www.edchoice.org/)  
**Write**  
The Foundation for Educational Choice  
One American Square, Suite 2420  
Indianapolis, Indiana 46282
Transitions—changes in routines—are a part of life. They occur when you get a new job, get married, start a business, have children, and retire. Changes to routine bring stress. For your child with special needs, they might bring on stress difficult to bear. Your child may experience many changes in routine over time, but three significant ones addressed by transition planning occur as your child moves from:

- Early childhood intervention to elementary school.
- Elementary school to middle school.
- Middle school to high school.

From your child’s early intervention program through high school graduation, you will attend many meetings with education professionals to create transition plans that help your child adjust to these significant changes in environment, academic expectations, and relationships. Transition services at the high school level are intended to prepare youth to for further education, to reach their career goals, and to actively participate in their community, and are based on your child’s strengths, needs, and vision for the future. They include:

- Instruction
- Community participation
- Developing employment skills
- Developing daily living skills
- Prepare for post-secondary education

Your child can become part of transition planning at any time, both formally at school and informally during discussions about it at home. By encouraging your child’s involvement in transition planning early on, he or she can get a jump on developing self-advocacy and self-determination skills. When your child turns 16 years of age, public schools must invite students to attend meetings and, by law, make transition planning part of your child’s Individualized Education Program (IEP).

The ultimate goal of transition planning is to provide your child with choices that will lead him or her to a productive, fulfilling, and independent adult life, to the greatest extent possible.

Transition Planning—Elementary School

Making your child’s experiences in elementary school as positive as possible might ease change-related stress. Positive school experiences will also provide your child with a strong foundation for overall school success. Here are some things you can do help create positive school experiences for your child in elementary school.
Develop a positive and productive relationship with school staff and teachers.

Stay connected to your child’s progress in school; try to know when the time is right to push, or the time to let your child just be.

Expect the best. Your child may become inspired to rise to it.

Take care that your child has accommodations that will best support their academic and developmental achievement. Proper accommodations will also ensure your child’s knowledge is accurately measured.


Transition Planning—Middle School and High School: Creating a Path to Self-Advocacy

The Individuals with Disabilities Education Act (IDEA) requires that your child’s IEP team assemble a formal transition plan when he or she turns 16. The transition plan includes what instruction, skills, services, and accommodations your child needs to accomplish personal, academic, vocational, and career goals after graduating from high school.

Letting Go

By engaging your child early on in decision-making for a variety of life situations—vacations, purchases, accommodations, medical care, his or her IEP—you help ensure that by the time your child reaches the age of majority, he or she will be making decisions that improve the well-being of his or her life. Of course you’ll be there to provide support and guidance as you always have, but by gently letting go of your decision-making authority and allowing your child the opportunity to make decisions, your child gets to learn the value of making informed decisions (or not!). Some of life’s most lasting lessons are learned from making mistakes.

Creating a Vision for the Future

Upon turning 16, your child will need to communicate a vision for the future to his or her IEP team. This vision will help form the basis of your child’s transition plan for the remainder of high school and beyond. To help your child develop a vision for the future, the IEP team may ask your child questions similar to these:

- What skills do you think are your best?
- What skills do you think need some improvement?
- What do you want to do after you graduate from high school?
- Where do you want to live?
- Do you want to live alone or with roommates?
- Do you know what accommodations you’ll need to live independently?
- What kind of work would you like to do?
- Do you know how much additional education that would require?
- What are some of your dreams outside of your employment, such as travel, friendships, or community involvement?

Your child’s answers to these questions help define what supports and skills your child needs for a successful and fulfilling life beyond high school. Encouraging your child to begin creating a vision for the future upon entering the 8th grade might ease transitions into high school and then beyond.

The more he or she participates in transition planning, the more likely your child’s expectations of the future will be met. The more likely, too, your child will have opportunities to gain experience in making decisions and taking action. For example, an IEP specifying that your child spend time making trips to and from a job or post-secondary school using public transportation may demonstrate to your child what skills he or she needs to develop to confidently use public transportation.

What You Need to Know—The Age of Majority

We know from our own experiences that life beyond high school is quite different. Legally, the biggest differentiator is that when your child reaches the age of 18, he or she reaches the age of majority in most states. Likely, this will be a liberating time for your child. It’s also a time your child becomes responsible for making his or her own informed decisions in all areas of life, including the IEP. In order for your child to remain eligible for the transition services that are part of his or her IEP, your child must stay in school through graduation.

Legal Rights. When students reach the age of majority and are deemed competent, they have the legal right to make their own decisions about their IEP. When your child acquires this right, he or she becomes responsible for:

- Attending IEP meetings.
If necessary, approving (or consenting to) re-evaluations and changes in placement.

- Requesting mediation or a legal hearing to resolve disputes over IEPs, re-evaluations, and placement.

Speak with your child’s IEP team to find out what your state’s laws are around the age of majority.

In the PACER Parent Brief, “Age of Majority,” the risk in transferring to your child the decision-making rights over Individual Education Plans (IEPs) is conveyed with this question: Will your child decide to drop out of high school or accept a quick diploma and become ineligible for much-needed transition services? Keeping your child legally eligible for transition services should be part of your estate plan because transition services can play a big role in moving your child toward a fulfilling and independent life beyond high school. To learn more about your child’s responsibilities upon reaching the age of majority and how to help your child stay on-track for high school graduation and decision-making success, request a copy of the PACER Parent Brief, “Age of Majority”:

- **Call** 1-888-248-0822 (Voice) or 1-952-838-0190 (TTY)
- **Visit** [www.pacer.org](http://www.pacer.org) and search on the name of the publication
- **Write**
  - PACER Center, Inc. 8161 Normandale Blvd.
  - Bloomington, MN 55437
Planning and Funding Your Child’s Education

—

Elementary and Secondary School

Part 3

How to Make the Most of the IEP and Transition Plan—The Path Toward High School Graduation and Beyond

Here are some ideas you can share with your child on how to make the most of his or her IEP transition plan (see “College or Training Programs: How to Decide.” PACER Center Action Information Sheets. PACER Center. 2006.). Each action item listed below might help your child further develop a vision for the future and focus on specific goals.

- Take an evening or weekend course at a post-secondary school to get the feel for getting there and back, managing time, and a new learning environment.
- Take high school courses that will help improve eligibility for post-secondary programs. Examples include foreign languages, computer programming, and advanced math and science.
- Look for internships, part-time jobs, or volunteer work in the community.
- Enroll in pre-college courses specifically designed for high school students the summer before or after the senior year.
- Work on communication skills, such as writing, speaking, and presenting. These are practical skills to have and can create opportunities in any endeavor.
- Research and apply for financial aid (scholarships, grants, and loans).

Know the Differences between High School and Post-Secondary School

Your child’s post-secondary school options include:

- One- or two-year programs offered by vocational schools and community colleges.
- Four-year programs offered by colleges and universities.

If your child would like to pursue post-secondary education, you can help your child gain greater confidence of what lies ahead by knowing the differences between high school and post-secondary educational experiences.

In a nutshell, while your child attends public school, his or her IEP team determines the individual support and services your child needs for school success. When your child attends post-secondary school, he or she becomes responsible for requesting supports and services needed to succeed.

Here are additional differences between high school and post-secondary school

<table>
<thead>
<tr>
<th>High School</th>
<th>Area</th>
<th>Post-Secondary Education</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under the Individuals with Disabilities Act (IDEA), your child is entitled to a free and appropriate education (FAPE).</td>
<td>Cost</td>
<td>our child must demonstrate eligibility for a post-secondary education.</td>
</tr>
<tr>
<td>Often you will advocate for the most appropriate IEP for your child by keeping in close contact with your child’s teachers.</td>
<td>Supports/Accommodations</td>
<td>There is no IEP. Your child must be his or her own self-advocate and ask for supports and</td>
</tr>
</tbody>
</table>
Your child’s IEP is created by a team of people who provide supports and accommodations so your child can achieve school success.

You have access to all information contained in your child’s IEP, and to his or her teachers as well.

Teachers adapt all coursework to your child’s needs and are usually available after class to help students. Changes to your child’s coursework are made during mandatory IEP meetings.

You often provide structures at home to help ensure academic success, such as set hours to complete homework and go to bed. The school provides a set routine for the start and end of school, classes, and after-school activities.

Your child’s education rights are legally protected under IDEA and FAPE. These laws are about helping your child achieve success in school.


What You Need to Know—It Pays to Learn

Even though individuals without disabilities tend to earn more than individuals who don’t, the numbers tell it all—the more you learn, the more you earn. The table below compares median incomes of individuals with and without disabilities by level of education attained. While viewing this information, keep in mind that the actual income attained by any individual with disabilities may be influenced by one’s:

- Ability to attain a desired productivity level required by certain jobs.
- Attainment of marketable skills.

Also keep in mind the economic health of a region, the overall job market, employment rate, and industries in your area.

**Median** Income by Educational Attainment and Disability Status for Full-time, Full-Year Workers**

<table>
<thead>
<tr>
<th>Educational Attainment</th>
<th>Without a Disability</th>
<th>With a Disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than a high school diploma</td>
<td>$25,459</td>
<td>$24,441</td>
</tr>
<tr>
<td>High school diploma</td>
<td>$32,588</td>
<td>$30,551</td>
</tr>
<tr>
<td>Some college</td>
<td>$39,714</td>
<td>$35,643</td>
</tr>
</tbody>
</table>
A college graduate with a disability can expect to earn $20,000 more per year than someone with just a high school diploma, and about $29,000 more than someone who didn’t earn one. The median annual income for individuals with disabilities in 2008, the most up-to-date data available at the time of this publication’s writing, is $35,600 (see U.S. Census Bureau. 2008. American Community Survey (ACS)).

*Median means “the middle”; for example if you made a list of nine people’s income from lowest to highest, the median income would be the income of the fifth, or “middle,” person.

** Non-institutionalized population, ages 21-64. Source: Analysis of the 2008 American Community Survey (ACS) data, William Erickson, Employment and Disability Institute, Cornell University

This publication is intended to provide general financial information; it is not intended to substitute for, or supersede, professional or legal advice. The specific needs of every disability or life circumstance have not been covered in this publication. The best course of action must be based on individual circumstances. Note: The content areas in this material are believed to be current as of this publication’s writing, but, over time, legislative and regulatory changes, as well as new developments, may date this material.

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### Planning and Funding Your Child’s Education—Elementary and Secondary School Part 4

High School Graduation Rates for Students with Disabilities


What Can I Do to Improve My Child’s Chances of Graduating from High School?

Students with disabilities who stay on-track with their courses during their freshman year of high school have higher graduation rates than their peers who become passive about their education. The exception is students with behavioral or emotional disabilities, suggesting that other supports are necessary to improve their graduation rates (see Julia Gwynne, Joy Lesnick, Holly M. Hart, Elaine M. Allensworth. *What Matters for Staying On-Track and Graduating in Chicago Public Schools: A Focus on Students with Disabilities*. Consortium on Chicago School Research at the University of Chicago. December 2009).

Just by getting and staying involved in your child’s coursework and activities, he or she has a better chance of doing well in school, and that includes graduating from high school. The three key areas that will increase your child’s chances of graduating from high school are (see Julia Gwynne, Joy Lesnick, Holly M. Hart, Elaine M. Allensworth. *What Matters for Staying On-Track and Graduating in Chicago Public Schools: A Focus on Students with Disabilities*. Consortium on Chicago School Research at the University of Chicago. December 2009):

- Regularly attending school
- Passing all coursework
- Improving grades

You can help in these areas by:

**Communicating**. The teen-age years are when your child becomes more interested in looking beyond boundaries you might have set for his or her well-being. That curiosity might result in your child not communicating with you as openly as you’d like. For example, your child might not bring home school notices about meetings he or she would rather you not attend. Try to encourage communication by asking open-ended questions—questions that can’t be answered with a yes or no. An example: “What school meetings have been announced?” Or you can simply ask “Did you receive any school notices you might have misplaced or forgotten to bring home?”

**Helping with Homework and Setting Boundaries**. Even if you don’t have a lot of knowledge in your child’s coursework, you can help your child regularly complete homework.

- Set a regular time and place to do homework.
Help provide access to learning resources such as the Internet, calculators, a librarian, and a friend or family member knowledgeable in a certain area.

**Encouraging Your Child to Participate in Developing Individual Education Plans (IEPs).** The sooner you encourage your child to create a vision of the future, the greater the chances of your child’s success during high school. Consider involving your child in IEP development when he or she enters the eighth grade. That way, your child has more time to gain a deeper awareness of what it takes to turn dreams and goals into realities. Participating in IEPs early on will also help develop your child’s decision-making skills and provide the time to test and improve them.

**Encouraging Your Child to Take Standardized Tests.** Many post-secondary schools require pre-college test scores, such as the ACT (formerly known American College Testing) and SAT (Scholastic Aptitude Test), to be considered eligible for admission. By encouraging your child to take these standardized tests, new academic opportunities may become available. Students with disabilities may request testing accommodations that will allow them to demonstrate what they know without being limited by their disability. For example, a student with cerebral palsy may need extra time or use assistive technology to show what they know.

**Joining School Committees and Networking with Parents.** You’ll stay in-the-know about school activities and potential problem areas your child might be facing by connecting with your child’s teachers and parents of your child’s classmates.

**Building Positive Relationships with Teachers.** On occasion, you and your child’s teachers may disagree on the direction of your child’s Individual Education Plan (IEP). Because your child might behave differently in school than at home, what you clearly see as an ability of your child might not be seen by your child’s teachers. Should conflict around IEPs arise, present in positive ways stories or “evidence” of your child’s abilities, and discuss what supports the school might provide to replicate that ability during school with the teacher and the child’s IEP team.

**Transition Planning—Resources**

**Center for Early Literacy Learning (CELL)**

The Center for Early Literacy Learning (CELL) guides parents to create building blocks of literacy for their children. Encouraging parents to begin engaging their children in literacy activities as early as possible, CELL offers video, audio, and library resources for infants, toddlers, and preschoolers.

Developing your child’s literacy skills early on may provide later payoffs. The self-esteem your child gains through strong literacy skills can help ease transitions through early childhood education, elementary school, middle school, and high school. To find out what resources you can use to begin building your child’s literacy, contact the Center for Early Literacy Learning:

**Call** 1-800-824-1182
**Visit** www.earlyliteracylearning.org
**Write**
Orelena Hawks Puckett Institute—Asheville, NC Office
8 Elk Mountain Rd.
Asheville, NC 28804

**PACER’s Technical Assistance on Transition and Rehabilitation Act (TATRA)**

This PACER program provides information to help parents guide children with special needs through their life’s transitions: in and out of elementary, middle school, and high school; and on to rehabilitation, vocation, post-secondary education, jobs, and careers.

Through publications, training programs, and special events and workshops, PACER provides many resources that strengthen your child’s ability to achieve education, employment, and independent living goals.

The TATRA Web resources are available to all. Visit www.pacer.org/tatra.

**PACER’s Simon Technology Center**

In a collaborative effort with parents, professionals, and consumers, PACER’s Simon Technology Center (STC) provides publications, training programs, technology consultations, and workshops on assistive technology (AT) to help Minnesota families and children with special needs achieve greater independence in school and work.

Although this is a Minnesota program, the STC’s web resources are available to all. Visit www.pacer.org/stc.

**Federally Funded Resources**

**National Secondary Transition Technical Assistance Center.**

**National Center on Secondary Education and Transition (NCSET).**
Because the Individuals with Disabilities Education Act (IDEA) gives your child the right to attend public school for free, during your child’s years in kindergarten through the completion of high school you bear no public education tuition expense. The public education system is extensive and well-established throughout the United States.

Your community may offer private education choices that include special needs programs and coursework. Private schools typically charge tuition.

Financing Options

By working with your local Parent Center and disability-specific organization, you may be able to find out financing options for private schools in your area. Scholarships and grants are available for some private elementary and secondary schools. They are usually based on merit (academic achievement or community service) and financial need. You don’t have to pay scholarships and grants back.

FinAid! provides information on financing options for private elementary and secondary education. Contact FinAid! to get the specifics:

Call 1-724-538-4500
Visit www.FinAid.org (click “Other Types of Aid” and look for the link: “Aid for Elementary and Secondary School”
Write
FinAid Page, LLCPO
Box 2056
Cranberry Township, PA
16066-1056

The National Association of Private Special Education Centers (NAPSEC) has information about financial aid opportunities offered by private schools serving students with disabilities. To contact NAPSEC:

Call 1-202.434.8225
Visit www.napsec.org
Write
601 Pennsylvania Avenue, NW
Suite 900 - South Building
Washington, DC 20004
Planning and Funding Your Child’s Education —Post-Secondary Schools Part 1

Post-secondary school is an all-encompassing term for a variety of education programs one attends after graduating from high school. Close to 30 percent of Americans with disabilities, compared to about 38 percent for all Americans, acquire some post-secondary education, usually through vocational schools or two-year programs. Only 12 percent (see Disability Statistics: Online Resource for U.S. Disability Statistics (2008 American Community Survey Data Set). Cornell University, graduate from a college or university, compared to over 17 percent for all Americans.

Your advocacy efforts and the self-determination of your child in pursuit of a post-secondary education will help your child become the person he or she aspires to be.

Planning—Creating Paths to Income

In 2000, Jim Langevin, a quadriplegic, became the first individual with a disability to be elected to the U.S. House of Representatives. Since the Americans with Disabilities Act (ADA) became law in 1990, employers have come to know the unique talents of individuals with disabilities, and the value they bring to a working environment.

Even though approximately half of disabled workers are unemployed (as of this writing: see Barbara T. Mates. "Twenty Years of Assistive Technologies" American Libraries: The Magazine of the American Library Association. September 14, 2010. Retrieved from http://americanlibrariesmagazine.org/features/09142010/twenty-years-assistive-technologies on September 26, 2010), if you consider the advocacy efforts over the last 20 years of many organizations for improving workplace conditions, career opportunities for individuals with disabilities are likely to continue to broaden.

Your child can choose from several paths to income, depending on his or her abilities and career goals.

Vocational or Technical School

These schools offer great flexibility in the pursuit of an education or career. A great starting point for students not yet prepared to work towards a four-year degree, vocational and technical schools prepare students for specific job skills. Coursework is usually completed over an 18-month or two-year period. Programs can be offered by stand-alone vocational or technical schools or offered by community colleges. Upon successful
completion, students earn certificates that may qualify them for jobs. Certificate options include:

- Information technology
- Accounting
- Medical coding
- Construction management
- Plumbing
- Electrical engineering
- Air conditioning and refrigeration
- Auto mechanics
- Interior, fashion, or graphic design
- Cosmetology
- Hospitality and tourism

College Programs

These programs offer undergraduate-level coursework at colleges and universities. Students may earn a college degree, also referred to as a Bachelor's Degree, typically a four-year program, or an Associate's Degree, typically a two-year program.

Social Stigmas—To Ask or Not Ask for Accommodations

This can be a sticky point with your child, who might be happy to be rid of “special education” labels upon graduation from high school. Yet having proper learning academic and test accommodations can become an important element in post-secondary education success, and ultimately, in work and independent living.

In any post-secondary learning environment, it is up to your child to request needed accommodations. Those requests can be made through a school’s Disability Support Services (DSS). It is also your child’s responsibility to:

- Find out what procedure must be followed to request or order an accommodation.
- Provide documentation of the disability and the need for an accommodation. Each school has its own documentation requirements.

Should your child hesitate to disclose his or her disability in order to request needed accommodations, you might suggest that doing so is part of self-advocacy and self-determination in getting supports necessary for success in school and beyond.

For more information on your child’s rights to accommodations in post-secondary schools, see Post Secondary Education.

Students with Intellectual Disabilities—Why College?

One reason for pursuing post-secondary education that remains the same across all groups of individuals: qualify for higher paying jobs. In 2009 Think College!, stated in its Fast Facts publication that individuals with intellectual disabilities (ID) who completed a post-secondary program earned 73 percent higher weekly income than their peers who did not complete such a program (see Alberto Migliore, John Butterworth, and Debra Hart. “Fast Facts.” Think College! No.1, 2009. Retrieved from http://www.thinkcollege.net/publications on November 22, 2010.).

Your child with ID may have many reasons to attend college. Beyond the ability to qualify for higher paying jobs, attending a post-secondary education program can help improve other areas of your child’s well-being: independence, community involvement, confidence and self-esteem, and the ability to solve problems without mom or dad’s assistance.

Through the Higher Education Opportunity Act (HEOA), a growing number of post-secondary programs are available to students with intellectual disabilities:

Find Post-Secondary Programs for Students with Intellectual Disabilities

Think College!, a project of the Institute for Community Inclusion at the University of Massachusetts Boston, provides resources for students with intellectual disabilities (ID) who want to attend college. They include information on:

- Entrance requirements.
- Academic and learning programs suited for students with intellectual and developmental disabilities.
- Types of instruction for ID groups only.
- Specialized degrees or certificates.
Find out what post-secondary programs are available for your child with ID. Contact Think College!

**Call** 1-617-287-4300 (Voice) or 1-617-287-4350 (TTY)

**Visit** [www.ThinkCollege.net](http://www.ThinkCollege.net) (Search through the Think College! database to find post-secondary programs for students with intellectual disabilities)

**Write**

Institute for Community Inclusion
University of Massachusetts Boston
100 Morrissey Boulevard
Boston, MA 02125

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Planning and Funding Your Child’s Education—Post-Secondary Schools, Part 2

Funding Your Child’s Education—Post-Secondary Schools

If your plans to save for your child’s post-secondary education got derailed because of disability-related health care expenses, you might not feel financially prepared to even consider post-secondary options for your child. A variety of post-secondary financial aid programs are available to help you finance tuition and other costs related to post-secondary education. These programs include:

- Scholarships
- Grants
- Federal Work Study (FWS) programs
- Federal student loans
- State Vocational Rehabilitation (VR) programs
- Social Security Administration Work Incentives—Plan for Achieving Self-Support (PASS)
- Community Service Programs (example: AmeriCorps)
- Financial Aid for Students with Intellectual Disabilities

Your child must apply for each of these types of student aid programs. Eligibility is based on a variety of factors such as financial need, academic achievement, a special talent, community service, and disability.

Making Your Way through the Financial Aid Maze

Trying to sort through the seemingly endless lists of resources on student financial aid can be pretty overwhelming—there is so much information out there. The following resources might be able to direct you to the best places to look for financial aid:

- Your child’s Individual Education Plan (IEP) team.
- Your child’s disability-specific organization.
- Your local Parent Center.
- Your state’s agency for Vocational Rehabilitation.

Free Application for Federal Student Aid (FAFSA)

To qualify for federal student aid, your child must complete (with your help if you wish) a Free Application for Federal Student Aid (FAFSA). The FAFSA process determines how much federal aid your family needs to cover education costs. Depending on your financial need, you may be expected to pay a portion of education costs. That amount will be defined as the “Expected Family Contribution” in the Student Aid Report (SAR) you receive after
completing the FAFSA.

The FAFSA requests detailed information about:

- Your child
- Your child’s dependency status
- Your child’s finances (income and assets)
- You, the parent
- Your finances (income and assets)
- What schools should receive the results of the FAFSA


Information you’ll need to have handy as you complete the FAFSA:

- Income tax returns, yours and your child’s (if applicable).
- Your current financial statements: savings and checking account, investment.
- Records of any untaxed income you may have received, such as Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI).
- Your Driver’s License (if you have one).
- Your and your child’s Social Security Number.
- If you are not a U.S. citizen, your alien registration or permanent resident card.


How to Apply for FAFSA

The fastest way to complete the FAFSA is online at www.fafsa.gov. The FAFSA online form includes supports for completing the form correctly, and it automatically checks for errors. Your child will save time, and maybe some frustration, by completing the FAFSA online. The online process provides an option for printing a worksheet ahead of time so your child can get familiar with the application.

To learn more about the FAFSA online application process and to apply online, visit www.fafsa.gov.

If you wish to complete the application process by mail, your child’s IEP team can get you a FAFSA form, or you can request one by calling 800-433-3243 (800-4FED-AID). Processing the FAFSA by mail can take three to five weeks longer to find out what aid your child is eligible for.

Getting Help with the FAFSA Form

Seek help on filling out the FAFSA form only through your school or the U.S. Department of Education offices or Web sites. Those Web site addresses have the ending .gov. For example, the official site for filling out the FAFSA form is www.fafsa.gov. You can also attend a College Goal Sunday event. College Goal Sunday is a national initiative that brings together financial aid professionals and families for the purpose of completing the FAFSA. For more information on event sites and locations in your state, visit www.CollegeGoalSundayUSA.org.

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Scholarships and Grants

This type of aid is based on merit (academic achievement or community service) or financial need. When your child gets a scholarship or grant, it is like receiving free money—you don’t have to pay it back. There are all sorts of scholarships and grants available from schools, disability-specific organizations, individuals, and faith- and community-based organizations.

Federal Pell Grants are based on need and are awarded through the FAFSA application. The amount of any other student aid you might receive does not affect the amount of a Pell grant.

The following resources offer helpful information on how to find scholarships and grants and prepare your child for college.

Council for Opportunities in Education
COE advocates and supports federally-funded programs that assist underrepresented students, including students with disabilities, in pursuing and completing post-secondary education. They publish a complete directory of these federally funded programs called TRIO and GEAR UP, where you can locate a program in or near your city and state.

Visit http://www.coenet.us/ecm/AM/Template.cfm?
Section=Council_Products&Template=/CM/ContentDisplay.cfm&ContentID=5703

Student Aid on the Web
Call 1-800-433-3243 (Voice) or 1-800-730-8913 (TTY)
Visit www.studentaid.ed.gov

FastWeb
Visit www.fastweb.com
Write
FastWeb, LLC
444 N. Michigan Avenue, Suite 3000
Chicago, IL 60611

FinAid! (includes information on student aid for students with disabilities)
Call 1-724-538-4500
Visit www.finaid.org
Write
PO Box 2056
Cranberry Township, PA 16066-1056

College Board
Call 1-212-713-8000
Visit www.collegeboard.com
Write
Disability-Specific Scholarships and Grants

Various organizations offer financial aid specifically to students with disabilities. Your child’s Individual Education Plan (IEP) team, your local Parent Center, and disability-specific organization may be able to direct you to sources of financial aid.

If you’d like to investigate some online financial aid options on your own, here a couple of places to look:

**Disaboom.** This is an online resource center that covers many topics specifically for individuals with disabilities. A comprehensive list of disability-related scholarships is available on this site. Check out this list at www.disaboom.com.

**The HEATH Resource Center.** This is an online clearinghouse of information on post-secondary education for students with disabilities. The site provides teaching modules on a variety of topics related to post-secondary education and life beyond education. They include: financial aid, awareness of post-secondary options, college application process, financial literacy, and self-advocacy.

**HEATH Resource Center**  
Visit www.heath.gwu.edu  
Write  
2134 G Street, NW  
Washington, DC 20052-0001

Federal Work Study (FWS) Programs

These federally funded programs are based on financial need, providing part-time, on-campus jobs to your child. Money earned can be used for educational expenses. Not all post-secondary schools participate in this program. Students are considered for federal work study awards through the FAFSA application.

Often times, working while attending school helps students appreciate their education even more. If your child has an opportunity to become part of a work study program, you’ll want to talk about ways your child will juggle school assignments and job responsibilities. Potential employers will appreciate your child’s efforts and hard work in properly managing time.

Federal Student Loans

Should scholarships, grants, and work study not be able to provide the post-secondary funding you need, you may want to apply for a federal student loan. They are low-interest and deferred-interest government loans that must be paid back. Deferred-interest loans are based on financial need. All federal student loans don’t have to be paid back until your child graduates from or leaves college. Also know that you are not required to borrow the full amount of the loan your child qualifies for. Be certain to borrow only what you need. Student loans can be used in combination with other forms of aid. For example, if your child qualifies for a scholarship, grant, or work-study program, it may not be enough to cover all college costs. He or she could also qualify for federal financial aid.

**A special note to parents of children with intellectual disabilities (ID):** Although the HEOA provides students with Intellectual Disabilities access to Federal Pell Grants, Federal Supplemental Educational Opportunity Grants (FSEOG), and Federal Work Study, it did not extend that eligibility to Federal student loan programs. For more information, see Financial Aid for Students with Intellectual Disabilities.

Types of Federal Student Loans

**Federal Stafford (Direct) Loans—Subsidized and Unsubsidized.** Based on financial need (subsidized) and unmet educational costs (unsubsidized), these loans are available for undergraduate and graduate programs. As of 2010, all Federal Stafford Loans are administered by the Department of Education’s Direct Loan Servicer. The loan amount varies each year, and they must be paid back to the federal government beginning six months after the student ceases enrollment.

**Federal Perkins Loans.** These federal loans are also based on financial need but made available through the post-secondary school. The loans must be paid back to that school beginning nine months after the student ceases enrollment.

**Federal Parent Loan for Undergraduate Students (PLUS).** Allows parents with good credit histories to borrow money on behalf of their children.
Learn More About Federal Student Loans

For more information on the types of federal student loans available, loan terms, and how to apply for them, visit www.StudentAid.ed.gov.

State Vocational Rehabilitation Programs

Your state Vocational Rehabilitation agency may offer student financial aid to individuals with disabilities who qualify for VR services. Before your child can qualify for this aid, he or she must first be found eligible for VR services. You also can explore financial aid through other sources, as the VR agency will require you to use that aid before it provides any of its own. A key factor that VR counselors consider is how closely linked the post-secondary course of study is to a student's specific career goals, as identified in their VR Plan for Employment. Note: not all state VR programs provide funds for tuition. In addition, because of limited funding, many states have waiting lists of eligible individuals waiting to receive VR services.

Social Security Administration Work Incentives—Plan for Achieving Self-Support (PASS)

Your child can set aside part of his or her Supplemental Security Income (SSI) to offset college expenses under the Plan for Achieving Self-Support (PASS). To get a PASS, your child must have a clearly defined work goal and know what post-secondary program is needed to achieve the goal.

The PASS program is not just for setting aside money for post-secondary expenses. Your child could use the program to set aside money for any training, supports, or services needed to achieve a work goal, including starting his or her own business.

Speak with your local Social Security Administration office to get more information about PASS and to fill out an application.

Other Student Aid Sources

Your child may be able to fund some education expenses through community service programs such as AmeriCorps. In these programs, your child would perform community service work for a certain period of time. Upon completion, your child would receive an award that can be applied to education expenses. Depending on the program, your child might earn a small stipend during the service period. AmeriCorps is committed to actively recruit individuals with disabilities.

AmeriCorps
Call 1-202-606-5000 (Voice) or 1-202-606-3472 (TTY)
Visit www.americorps.gov
Write
AmeriCorps
1201 New York Avenue, NW
Washington, DC 20525

Financial Aid for Students with Intellectual Disabilities

The Higher Education Opportunity Act (HEOA) provides opportunities for students with intellectual disabilities (ID) to apply for federal financial aid for comprehensive transition and for post-secondary education. Federal financial aid is based on need, which is mostly based on income. Families interested in applying for financial aid can do so through the Free Application for Federal Student Aid.

The types of financial aid opportunities for students with ID that are available through the FAFSA application are:

- Pell Grants. A federal program that provides need-based grants to low-income students.
- Federal Supplemental Educational Opportunity Grants (FSEOG). A federal student aid program that provides assistance to the neediest students with priority given to those students eligible for the Pell grant.
- Work Study Programs. Students finance their education through work at on-campus jobs.

Next Section: Your Child's Employment
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Your Child’s Employment—a Growing List of Options

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Your Child’s Employment—A Growing List of Options and Support

As of this publication’s writing, individuals with disabilities are two and a half times more likely to be unemployed or underemployed than their non-disabled peers (see “Getting and Keeping the First Job” (PPT). A curriculum created by the National Family Advocacy Support and Training (FAST) Project. PACER Center. 2010.). Yet a growing list of advocacy organizations and government programs are committed to forging new employment pathways so individuals with disabilities can find meaningful work and become as self-sufficient possible. Available work options allow your child with special needs to work and either continue receiving government benefits or become completely financially independent and self-sufficient.

“Every youth has some skill that, if nurtured, will provide them the opportunity to make money for the rest of their life.”

Larry Kortering, Ph.D., Co-Principal Investigator for National Secondary Transition Technical Assistant Center (NSTTAC).
Prepare Your Child for Employment


The point here is this. Transitions services provided to your child as part of his or her Individual Education Plan (IEP) can play an important role in preparing your child for employment, should that occur during or after high school, or after post-secondary education. Your child’s post-secondary coursework and experiences play a similar role. They all give your child opportunities to develop career skills such as gaining knowledge in a specialized area, interviewing practice, and asking for accommodations. But they are not the only stepping stones to employment.

Consider the employment skills your child can develop in volunteer experiences, unpaid internships, and paid employment while still in high school and post-secondary school. Consider also the input from members of your child’s person-centered planning team. They may be able to provide opportunities for work-related experiences, or simple advice about life while on the job.

Know thyself, the famous philosopher Socrates advised. As your child comes to know personal strengths and weaknesses, he or she can use that knowledge to form career and life goals. Offering a supportive environment to get to that point will help your child develop self-determination and self-advocacy skills. Here are some suggestions for creating that environment:

- Encourage your child to set and meet goals.
- Allow your child to take risks and experience the consequences, positive and negative, without compromising safety or overall well-being.
- Involve your child in making decisions for purchases, health care, assistive technology, accommodations, managing money, vacations—for any situation that helps your child better “know thyself.”
- Involve your child in coming up with creative solutions for reducing expenses, managing time, and staying organized.

Networking

As the years pass, the network of people that support your child grows, through family and friendships, person-centered planning, the professional that care for your child, or through his or own networking activities that were part of a transition plan. Your child’s network may be full of people eager to see him or her.
succeed. Encouraging your child to contact people in this network may result in job leads, or the names of other people to contact for job leads.

The key to successful networking is to keep at it—to keep following up with people contacted so they think to call your child when an appropriate opportunity opens up.

**Vocational Rehabilitation Services**

Your child can apply for VR services at any time—during or after high school, or post secondary education.

**How Vocational Rehabilitation Services Work**

These federally-funded services are provided to your child through local agencies free of charge. To receive these services, you or your child must apply for them and meet the state’s eligibility requirements. Eligibility is based on a disability that is a barrier to getting a job. Your child is automatically eligible if he or she receives Supplemental Security Income (SSI) or Social Security Disability Income (SSDI).

If the VR agency has to purchase any services to assist your child, you or your child may first need to demonstrate financial need before they are ordered, and you may have to help pay for those services. As an example, your local VR agency may pay a company to provide assistive technology services and related training.

**The Post-Secondary School Connection**

The best time to contact your state VR agency is while your child is still in high school. PACER recommends that families invite VR counselors to attend their child’s IEP meeting no later than the student’s junior year in high school.

**The Individual Plan for Employment (IPE)**

Once your child becomes eligible to receive VR services, together with a VR counselor, your child will develop an Individual Plan for Employment (IPE). The IPE is based on your child’s employment goals and abilities. Here is a list of services that might become part of your child’s IPE.

- Vocational counseling and guidance
- Job placement assistance
- College or vocational training
- Skills training
- Job coaching or tutoring
- Transportation
- Interpreter and reader services
- Assistive technology services

To find a VR office near you—there might be more than one if you live in a large city—contact the Job Accommodation Network (JAN):

**Call** 1-800-526-7234 (Voice) or 1-877-781-9403 (TTY)
**Visit** www.askjan.org

**Work for the Federal Government—The Workforce Recruitment Program (WRP)**

Federal government job recruiters work with post-secondary Disability Support Services (DSS) offices to screen, interview, and hire highly motivated and talented students with disabilities for summer jobs. Often these jobs lead to full-time work.
program, the Workforce Recruitment Program (WRP) is implemented by colleges and universities of four-year programs. WRP recruiters visit campuses once per year to conduct interviews with qualified job seekers. To be eligible for this program, your child must be a full-time undergraduate or graduate student, or have graduated within 12 months since the month of March of any year. Not all schools participate in this program. If you think your child might be interested in a federal government job, he or she should ask if the post-secondary school of choice participates in the WRP, or apply online.

Find Workplace Accommodations—The Job Accommodation Network (JAN)

A service provided by the U.S. Department of Labor, the Job Accommodation Network (JAN), helps all individuals with disabilities identify workplace accommodations that will enhance their employment options. JAN does not help individuals look for actual jobs.

Through JAN’s effort, employers come to know the value that individuals with disabilities add to the workplace. In this way, Jan helps pave the way for employment opportunities for all individuals with disabilities.

Through JAN’s Searchable Online Accommodation Resource (SOAR) database, your child can explore accommodation options based on his or her disability and for educational and work settings.

For more information about the Job Accommodation Network (JAN):

**Call** 1-800-526-7234 (Voice) or 1-877-781-9403 (TTY)  
**Visit** [www.askjan.org](http://www.askjan.org) and click “Search Accommodations Database”
Where Workers with Disabilities Look for Jobs

Through the advocacy work of many individuals and organizations, workers with disabilities have growing employment support among corporations and other organizations. Two job search Web sites created expressly for job seekers with disabilities offer a variety of job search tools and support.

**GettingHired.com** provides job seekers with an online community of support through a mentoring network, the ability to link with others who share similar health and life experiences, and blogs about experiences in the workplace. To check out GettingHired.com:

**Call** 1-866-352-7481  
**Visit** www.gettinghired.com  
**Write**  
GettingHired  
1545 US RT 206, First Floor  
Bedminster, NJ 07921

**DisaboomJobs.com** is an online job search tool. It was created by a physician, Dr. J. Glen House, who is a quadriplegic and came to know first-hand what challenges workers with disabilities face while looking for jobs. Visitors to the site can post a profile and resume that potential employers use while searching for qualified candidates. Other job search resources such as salary negotiation and Supplemental Security Income (SSI) and Social Security Disability Income (SSDI) salary supports are also available through the site. To check out DisaboomJobs.com, visit www.DisaboomJobs.com.

Work While Remaining Eligible for Government Benefits—The Ticket to Work Program

Through its Ticket to Work Program, the Social Security Administration encourages individuals with disabilities to find employment and reach their employment goals. This program provides career and job search services through Employment Networks (ENs) located throughout the country. Individuals who use the program can still receive SSI, SSDI, and Medicaid benefits, as long as income received from employment doesn’t exceed a certain level.

How Employment Income Affects Supplemental Security Income (SSI) and Social Security Disability Income (SSDI) Benefits Under Ticket to Work

**SSI benefits** will decrease as a worker’s income increases. The first $85 of earnings is not counted in determining a reduction of SSI benefits. For someone receiving both SSI and SSDI, the first $65 is not counted. And, only half of a workers income amount is subtracted from the SSI benefit amount.

1. \[\text{Gross monthly earnings (before taxes are applied) – $85 (or $65 for recipients of both SSI and SSDI)} \div 2 = \text{Countable Income}.\]

2. Monthly SSI benefit – Countable Income = Adjusted SSI benefit

SSDI benefits work differently. One either receives the full SSDI benefit or not at all. SSDI rules allow workers to gradually increase their earnings and still receive benefits, potentially over an eight-year period (see Social Security Online. “Program Development & Research: Work Incentives—Detailed Information.” Retrieved from http://www.socialsecurity.gov/disabilityresearch/wi/detailedinfo.htm#TWP on November 23, 2010.).

Here’s how it all works. Workers can work intermittently over a five-year period to accumulate the equivalent of nine months of work. This is referred to as a “trial period” so workers can test their ability to work for nine months. During this trial period, workers receive SSDI benefits no matter how much money they earn as long as their work is reported and they have a disabling impairment (see Social Security Online. “Program Development & Research: Work Incentives—Detailed Information.” Retrieved from http://www.socialsecurity.gov/disabilityresearch/wi/detailedinfo.htm#TWP on November 23, 2010.).

After that five-year period is over, if a worker earns over $980 per month (according to 2009 rules), he or she will stop receiving benefits. But if that income drops below $980, a worker can begin receiving benefits again. This fluctuation in benefits can occur with a worker receiving or not receiving them for the three-year period beginning on the date that the five-year period ended (see Social Security Online. “Program Development & Research: Work Incentives—Detailed Information.” Retrieved from http://www.socialsecurity.gov/disabilityresearch/wi/detailedinfo.htm#TWP on November 23, 2010.).

For more information on how employment income affects SSI and SSDI benefits, contact the Social Security Administration:

Call 1-800-772-1213 (Voice) or 1-800-325-0778 (TTY)
Visit www.ssa.gov/work/receivingbenefits.html

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Your Child’s Home—Options for Independent Living

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Your Child’s Home—Options for Independent Living

Supplemental Security Income (SSI) recipients, many of whom are individuals with disabilities, receive on average $668 per month (see John R. Vaughn, “The State of Housing in America in the 21st Century: A Disability Perspective.” Letter of Transmittal. National Council on Disability. January 19, 2010. Retrieved from ncd.gov on September 25, 2010.). Finding a decent and safe place to live is challenging, especially for individuals with limited means. Some federally subsidized programs help this situation. Private sector initiatives are beginning to provide new housing options. And the trend away from institutionalization toward home- and community-based services will add housing options as well.

PACER’s Housing Project

The PACER Center is stepping up to the need for more housing options. Through its Housing Project, Minnesota parents can learn what funding supports are available, how to work with county services, how to find a housing provider, and information on housing advocacy groups. To find out more, visit PACER Center’s website, and search for housing to find national resources on this topic.

Call 1-888-248-0822 (Voice) or 1-952-838-0190 (TTY)
Visit www.pacer.org
Write PACER Center, Inc.
8161 Normandale Blvd.
Bloomington, MN 55437
Federal Programs—Public Housing and Housing Vouchers

Both of these programs are similar. One provides public sector housing (Public Housing), the other provides private sector housing (Housing Vouchers). They are federally funded programs and administered by local Public Housing Agencies (PHAs).

Eligibility is based on financial need. By law, a PHA must provide a certain number of individuals housing. That number varies by geographic region and its income level. Individuals who participate in these programs may be responsible for utility payments, but only up to a certain percentage of their income.

To find out more about these programs in your area, contact your local Housing and Urban Development (HUD) office.

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State Programs—Centers for Independent Living (CIL)

In 1992, the Rehabilitation Act of 1973 was amended to provide states with greater flexibility in supporting independent living options for individuals with disabilities. Each state in the country has several Centers for Independent Living (CIL) that provides advocacy and services to help individuals with disabilities live independent and self-sufficient lives.

While CILs do not provide actual housing options, if your child needs help with independent living skills, your local CIL may be able to provide needed assistance in developing them.

To find out what independent living services a CIL can provide:

Call 1-713-520-0232 (Voice) or 1-713-520-5136 (TTY)

Visit [www.ilru.org](http://www.ilru.org)

Write

Independent Living Research Utilization Project
The Institute for Rehabilitation and Research
Your Child’s Housing Rights—The Fair Housing Act

The Fair Housing Act prohibits discrimination against individuals with disabilities. The Act’s basic provisions follow:

- No one may refuse to sell your child a house or rent your child an apartment based on disability.
- A housing provider, say of an apartment building, must provide “reasonable” accommodations for easy access to a housing unit or common area, such as a parking facility. What is “reasonable” is not clearly defined, but housing providers must do everything they can to provide access without incurring excessive financial burden.
- Your child can request to make “reasonable” modifications to improve access and enjoyment of a housing unit. An example is requesting that a wheelchair ramp to a building’s entrance be installed.
- Your child can make modifications to their own unit, but may have to pay for them him or herself. A landlord may also require a renter who such changes pay to have the modifications removed when the renter moves out.

Next Chapter: Resources/Conclusions
Conclusion

As you raise your child with a disability, you may think you cannot make financial plans because you simply don’t have the time to do it or the income to make it matter. And considering high health care costs you deal with, you might wonder what value there is in planning for the future. The value is knowing you did everything you possibly could do for your child.

It takes courage to plan. Watching financial resources dwindle can crush the spirit. Through your bravery you will find empowerment and inspiration for creative ways to meet your family’s needs.

Try to work steadily through each planning phase. Pick areas you think need the most attention, then try to be methodical about implementing a plan. You will accomplish what you set out to do. Depend on your mind. It is a powerful tool. By being as determined as you ultimately want your child to be, you will accomplish things that surprise and delight you.

One final note: Your circumstances may not be easy. Only you and other parents who have similar experiences can know how really difficult they are. Stay connected to parents you meet through your local Parent Center, other parent groups, and your community. They are part of your lifeline of support, just as you can be the same to them.

Thank you for using this publication. Throughout our research we tried to anticipate what questions you might have or topics you would find most helpful in improving the financial well-being for you and your family. We wish you luck in seizing opportunities to accomplish your dreams and goals.

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# Resources

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Resources

Resources that can help you raise your child with a disability change continually, and different states provide different services, so the resource list in this section is not exhaustive. However, this list does provide resources to the major topic areas presented in this publication. As you look into these resources, you will begin discovering others.

Next >

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**Possibilities: A Financial Resource for Parents of Children with Disabilities**

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**Assistive Technology & Covering “Associated” Costs**

**Air Charity Network**

National nonprofit charitable organization that flies ambulatory patients unable to afford the cost of travel to medical facilities to specialized health care centers for diagnosis and treatment: www.AirCharityNetwork.org; 1-877-621-7177.

**The Alliance for Technology Access (ATA)**

One of the nation’s largest resources for assistive technology: www.ataccess.org; 1-800-914-3017.

**Simon Technology Center (STC)**

A PACER Center program that provides publications, training programs, technology consultations, and workshops on assistive technology (AT) to help Minnesota families and children with special needs achieve greater independence in school and work; STC Web resources are available to all: www.pacer.org/stc; 1-888-248-0822 (Voice) or 1-952-838-0190 (TTY).

**Teens Succeeding with Technology (TeST)**

A PACER Center project to increase the number of individuals with disabilities employed in science, technology, engineering, and math (STEM) careers; offers Web-based seminars (Webinars), podcasts, online activities, and other multi-media tools to help students identify what classes they must take to prepare for post-secondary STEM coursework that will lead to promising careers: www.pacer.org/stc/teenssucceedteach/index.asp; 1-888-248-0822 (Voice) or 1-952-838-0190 (TTY).

**Technical Assistance on Transition and Rehabilitation Act (TATRA)**

A PACER Center program that provides publications, training programs, and special events and workshops to help parents guide children with special needs through the transition from scholl to adult life: www.pacer.org/tatra; 1-888-248-0822 (Voice) or 1-952-838-0190 (TTY).

**The Foundation Center**

Provide information on a variety of private foundations, including corporate foundations; maintains a database on grant makers and their grants: www.fdncenter.org; 1-800-424-9836.

**The Job Accommodation Network (JAN)**

A service of the Office of Disability Employment Policy and the U.S. Department of Labor, JAN provides resources for finding and funding accommodations for the workplace and general information on workplace issues: www.AskJan.org; 1-800-526-7234 (Voice) or 1-877-781-9403 (TTY).

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Comprehensive Information/Referral Centers

Disability.gov

A comprehensive site that helps connect individuals to disability-related resources, programs, services, and legislation; topics covered include benefits, civil rights, community life, education, emergency preparedness, employment, housing, health, technology and transportation; www.Disability.gov. To find a Disability-Specific Organization at Disability.gov: www.disability.gov/community_life/disability_organizations.

Exceptional Parent Magazine

Publishes a comprehensive annual directory of resources; monthly magazine includes articles on financial planning: www.eparent.com; 1-800-372-7368.

National Information Center for Children and Youth with Disabilities (NICHCY)

Focus is on children and youth (birth to age 22); information and referrals include planning and financial issues relating to disability; services available in Spanish: www.nichcy.org; 1-800-695-0285.

The Arc

Through its local chapters and national Web site, The Arc provides cross-disability information, services, and resources: www.TheArc.org; 1-800-433-5255.

Independent Living Research Utilization

Provides information on independent living for individuals with disabilities; includes information on the Americans with Disabilities Act (ADA), home and community based services (HCBS), and health issues for people with disabilities: www.ilru.org; 1-713-520-0232 (Voice) or 1-713-520-5136 (TTY).

Parent Center Network

Provides resources, and information and referral services on special education, the Individuals with Disabilities Education Act (IDEA) and related issues to families of children with disabilities ages birth to 26 years, and to the professionals who work with them. Parent Centers can also make referrals to organizations outside the scope of their own activities: www.ParentCenterNetwork.org; 888-248-0822 (Voice) or 952-838-0190 (TTY)
Consumer Protection

Federal Trade Commission (FTC)

Provides practical information for consumers in a variety of topics that include: automobiles, computers, the Internet, credit and loans, identity theft, shopping for products and services: www.ftc.gov (click "Consumer Protection" then "Consumer Information"); 1-877-382-4357 (Voice) or 1-866-653-4261 (TTY).

OnGuardOnline.gov

Provides information for computing so you can safely send personal information over the Internet, such as your social security and bank account numbers: www.OnGuardOnline.gov.
Education

Foundation for Educational Choice
A site devoted to empowering parents in sending their children to public, private, charter, or magnet school of their choice: www.EdChoice.org; 1-317-681-0745.

The Center for Early Literacy Learning (CELL)
Guides parents to create building blocks of literacy for their children, and encourages them to begin engaging their children in literacy activities as early as possible; offers video, audio, and library resources for infants, toddlers, and preschoolers: www.EarlyLiteracyLearning.org; 1-800-824-1182.

The National Association of Private Special Education Centers (NAPSEC)
Represents private educational institutions serving individuals with disabilities; provides information about private schools located across the country and how to apply for financial: www.napsec.org; 1-202-.434-8225.

Parent Center Network
Provides resources, and information and referral services on special education, the Individuals with Disabilities Education Act (IDEA) and related issues to families of children with disabilities ages birth to 26 years, and to the professionals who work with them: www.ParentCenterNetwork.org; 888-248-0822 (Voice) or 952-838-0190 (TTY)

College

College Board
A Web site for both students and parents; provides information on preparing and planning for college, finding and applying to a college, and then funding for it: www.CollegeBoard.com; 1-212-713-8000.

College Goal Sunday
A national initiative that brings together financial aid professionals and families for the purpose of completing the FAFSA: www.CollegeGoalSundayUSA.org.

Disaboom.com
An online resource that covers many topics specifically for individuals with disabilities; includes a comprehensive list of disability-related scholarships: www.disaboom.com.

FastWeb

Free Application for Federal Student Aid (FAFSA)
The free site for applying for college financial aid: www.fafsa.gov.

FinAid.org
A site for help in finding scholarships and grants for college and for some private elementary and secondary schools: www.FinAid.org; 1-724-538-4500.

Student Aid on the Web
An office of the U.S. Department of Education; helps students find federal financial assistance (includes grants, loans, and work-study programs) for education beyond high school: www.StudentAid.ed.gov; 1-800-433-3243 (Voice) or 1-800-730-8913 (TTY).
The HEATH Resource Center
An online clearinghouse of information for finding post-secondary education for students with disabilities; includes information on financial aid, awareness of post-secondary options, college application process, financial literacy, and self-advocacy: www.heath.gwu.edu; 1-800-544-3284 (Voice and TTY).

Think College!
Information on colleges that offer coursework to students with intellectual disabilities: www.ThinkCollege.net; 1-617-287-4300 (Voice) or 1-617-287-4350 (TTY).

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Employment

Parent Information and Training Programs Funded by the Rehabilitation Services Administrations

These programs currently operate in 10 states and provide information and training to parents and children with disabilities on the Vocational Rehabilitation Program, transitional training, career preparation and related issues. The TATRA website lists the contacts. Visit www.pacer.org/TATRA.

GettingHired.com

Provides job seekers with an online community of support through a mentoring network, the ability to link with others who share similar health and life experiences, and blogs about experiences in the workplace: www.GettingHired.com; 1-866-352-7481.

Office of Disability and Employment Policy

A comprehensive site for individuals with disabilities looking for information on employment issues; topics include disability-related legislation, job search, self-employment, and youth employment: www.dol.gov/odep; 1-866-487-2365 (Voice or 1-877-889-5627 (TTY).

National Collaborative on Workforce and Disability for Youth (NCWD/Youth)

Funded by the U.S. Department of Labor's Office of Disability Employment Policy (ODEP), NCWD provides state and local workforce development programs with resources to better serve youth with disabilities: www.ncwd-youth.info; 1-877-871-0744 (Voice) or 1-877-871-0665 (TTY).

State Vocational Rehabilitation Agencies

Every state has a federally funded agency that administers vocational rehabilitation (VR), supported employment, and independent living services to help individuals with disabilities prepare for, find and keep employment. Some states have separate VR programs for individuals who are blind or visually impaired, and a few states have separate programs for individuals who are deaf or hard of hearing.

To find your state's VR agency, go to http://askjan.org and search for "state vocational rehabilitation agencies."

One-Stop Workforce Centers

These programs are the centerpiece of the Workforce Investment Act of 1998 (WIA). The One-Stop system operates through a network of centers in each state. Centers serve both youth and adults and provide job training, education, and employment services at a single neighborhood location.

To find a center near you, go to www.servicelocator.org.

The Job Accommodation Network (JAN)

A service of the Office of Disability Employment Policy and the U.S. Department of Labor, JAN provides resources for finding and funding accommodations for the workplace and general information on workplace issues: www.AskJan.org; 1-800-526-7234 (Voice) or 1-877-781-9403 (TTY).
Financial Education

General

Community Action Partnership
Provides practical information on money management; topics include turning dreams into goals, employment ABCs, Individual Development Accounts (IDAs), and housing options: www.ManagingMyMoney.com/.

Smart About Money
A site dedicated to your financial well-being as you move through a variety of life events and make financial decisions in each one: www.SmartAboutMoney.org.

Credit

AnnualCreditReport.com
The official site representing the three credit reporting agencies—Equifax, TransUnion, and Experian—where consumers go to get their free credit report once every 12 months: www.AnnualCreditReport.com; 1-877-322-8228.

Credit Reporting Agencies
Equifax: www.equifax.com; 1-800-685-1111
Experian: www.experian.com; 1-888-397-3742
Trans Union Corporation: www.transunion.com; 1-800-916-8800

National Foundation for Credit Counseling (NFCC)
An organization of credit counselors located across the country prepared to help you reduce and manage your debt: www.nfcc.org; 1-800-388-2272.

Individual Development Accounts (IDAs)

Real Economic Impact
A vision of the National Disability Institute, this organization is committed to helping Americans with disabilities improve their financial well-being: www.RealEconomicImpact.org; 1-202-296-2040.

Insurance

Consumer Federation of America
Access to actuarial experts who can tell you whether information contained in an insurance policy is adequate for good decision-making: www.ConsumerFed.org; 1-202-387-6121.

Insurance Information Institute
Find out what insurance is, what it does, and how it works: www.iii.org.

LifeHappens.org
A Web site of the Life and Health Insurance Foundation for Education, provides insurance basics for

LongTermCare.gov
A U.S. Department of Health and Human Services' Web site that provides information on long-term care insurance options, coverage, and benefit choices: www.LongTermCare.gov.

StateHealthFacts.org
Find out if your state offers high-risk insurance pools that subsidized monthly insurance premiums (this program remains effective until 2014): www.StateHealthFacts.org; search on “high risk pool eligibility”.

The National Committee for Quality Assurance (NCQA)

Retirement

My Retirement Paycheck
A site devoted to helping you make wise decisions about your retirement and making the most of the retirement resources you do have: www.MyRetirementPaycheck.org.

Profit Sharing/401k Council of America
Provides information on defined contribution plans to the general public: www.401k.org/; 312-419-1863.

This publication is intended to provide general financial information; it is not intended to substitute for, or supersede, professional or legal advice. The specific needs of every disability or life circumstance have not been covered in this publication. The best course of action must be based on individual circumstances. Note: The content areas in this material are believed to be current as of this publication’s writing, but, over time, legislative and regulatory changes, as well as new developments, may date this material.

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Find a Financial Planner

American Institute of CPAs—Personal Financial Planning Section

An organization for CPAs who provide estate, tax, retirement, risk management, and investment planning advice to individuals: www.aicpa.org; 1-888-777-7077.

Financial Planning Association (FPA)

The largest organization of financial planners who provide financial advice to individuals and are committed to upholding the highest standards of professional competence, ethical conduct, clear disclosure to the individuals they serve: www.fpanet.org; 1-800-322-4237.

The National Association of Personal Financial Advisors (NAPFA)

A leading organization of financial advisors who provide fee-only financial services: www.napfa.org; 1-847-483-5400.

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Find a Lawyer

American Bar Association (ABA)

A national organization of professional lawyers who specialize in many areas of the law, including bankruptcy; provides many resources to the general public about a variety of legal topics, and a way to search for a lawyer in your area: www.abanet.org; 1-800-285-2221.

National Association of Consumer Bankruptcy Attorneys (NACBA)

The only national organization of professional bankruptcy lawyers; contact the NACBA to find a bankruptcy lawyer in your area: www.nacba.org.
Guardianship

National Guardianship Association

Provides educational training and network opportunities for guardians: www.guardianship.org; 1-520-881-6561 (Voice) or 1-520-326-2467 (TDD).
Healthcare Information, Programs, and Resources

Disability.gov
Provides individuals with disabilities with information on benefits; civil rights; education, work health care and housing options; accommodations; and community life: www.disability.gov.

Family Voices
Clearinghouse for information and education; works with policy makers to provide family perspective or health issues: www.FamilyVoices.org; 1-888-835-5669.

HealthCare.gov
A comprehensive site for all individuals who need help finding insurance options, learning ways to stay healthy, comparing different types of health care, and learning about the new health reform legislation; contains a section devoted to people with disabilities: www.HealthCare.gov.

Insure Kids Now
Puts families in direct contact with their own state’s children’s health insurance program: www.InsureKidsNow.gov; 1-877-543-7669.

Medicaid
Provides comprehensive medical care to those who meet eligibility requirements: www.hcfa.gov/medicaid; 1-800-633-4227.

Search for Your State’s Medicaid Program

Search for Your State’s Medicaid Waiver Program (extends coverage for those who don’t qualify for Medicaid but face high medical costs; eligibility requirements apply)

Medicare
A government program available to children with certain disabilities and to dependent adult children whose parents are currently receiving Medicare: www.medicare.gov; 1-800-633-4227.

Social Security Administration

Special State-Chartered Insurance Plans (for wage earners)
The Health Insurance Portability and Accountability Act of 1996 (HIPAA) requires that all states implement policies guaranteeing access by small businesses and "eligible individuals" to health insurance of some kind. ("Eligible individuals" are those considered to be "uninsurable" under other insurance plans.) More than half the states have complied and all are in the process of instituting these special plans. Check with the U. S. Department of Health and Human Services for more information; www.dhhs.gov; 1-877-696-6775.
Laws

Americans with Disabilities Act (ADA)
A civil rights law that protects people with disabilities from disability-based discrimination in four areas: employment, public transportation, public accommodations, and telecommunications: www.ada.gov; 1-800-514-0301 (Voice) or 1-800-514-0383 (TTY).

Equal Employment Opportunity Commission (EEOC)
Offers assistance when you are being treated unfairly at work on account of caring for your child with disabilities: www.eeoc.gov; 1-800-669-4000.

Family Educational Rights and Privacy Act (FERPA)
Designed to protect students’ educational records, which include their health records; applies to students attending federally funded (public) schools, kindergarten through senior year of high school: www.ed.gov; search on “Family Educational Rights and Privacy Act (FERPA).”

Parent Center Network
Provides resources, and information and referral services on special education, the Individuals with Disabilities Education Act (IDEA) and related issues to families of children with disabilities ages birth to 26 years, and to the professionals who work with them: www.ParentCenterNetwork.org; 888-248-0822 (Voice) or 952-838-0190 (TTY)
Mortgages and Foreclosure

Center for Responsible Lending

A national non-profit devoted to promoting fair lending practices that create fair, sustainable loans for all Americans: www.ResponsibleLending.org; 1-919-313-8500.

Making Home Affordable

A program of HUD-approved housing counselors that provides eligible home owners with help in modifying their mortgages to make them more affordable: www.MakingHomeAffordable.gov.
Parent Organizations

Parent Technical Assistance Center (PTAC) Network

Network Provides technical assistance, resources, and information across the nation to all families of children with disabilities, ages birth to 26 years, and to the professionals who work with them: www.ParentCenterNetwork.org; 1-888-248-0822 (Voice) or 1-952-838-0190 (TTY)

National Dissemination Center for Children with Disabilities (NICHCY)

A national organization serving families of children with disabilities—infants, toddlers, children, and youth—informing them on the nation’s general education law, No Child Left Behind (NCLB) and special education law, Individuals with Disabilities Education Act (IDEA), as well as best practices for providing effective education to children with special needs: www.nichcy.org; 1-800-695-0285 (Voice/TTY).

Family Voices

Clearinghouse for information and education; works with policy makers to provide family perspective or health issues: www.FamilyVoices.org; 1-888-835-5669.

The Arc

Through its local chapters and national Web site, The Arc provides cross-disability information, services, and resources: www.TheArc.org; 1-800-433-5255.

TASH, the Association for Persons with Severe Handicaps

1025 Vermont Ave., Floor 7, Washington, DC 20005
www.tash.org
800-482-8274 (toll free);
info@tash.org
Your Rights as a Caregiver

National Family and Caregivers Alliance
Provides information on the legal rights of caregivers: www.nfcacares.org; 1-800-896-3650.

Children’s Defense Fund
Provides a voice for all the children of America who cannot vote, lobby, or speak for themselves: www.ChildrensDefense.org; 1-800-233-1200.

American Bar Association Commission on Mental and Physical Disability Law
Information on all aspects of the Americans with Disabilities Act, the Family and Medical Leave Act, and related legislation, including your rights as a caregiver: www.abanet.org/disability; 1-202-662-1570.
Tax

Internal Revenue Service (IRS)

Call the IRS with any tax-related question, or use its Web site to search on any tax issue or name of an IRS publication: www.irs.gov; 1-800-829-1040.

Volunteer Income Tax Assistance (VITA)

VITA is a government program that provides free tax preparation services for people with certain levels of income. To find out what income level is required to qualify for VITA services and if there is a VITA site located near you, Visit www.irs.gov and search on "VITA"; 1-800-906-9887.

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Parent Advocacy Coalition for Educational Rights (PACER) Center

PACER Center’s mission is to improve and expand opportunities that enhance the quality of life for children and young adults with physical, mental, emotional, and learning disabilities and their families. PACER Center is the ALLIANCE National Parent Technical Assistance Center, which provides technical assistance to 107 Parent Training and Information Centers throughout the country. PACER Center’s programs help parents become informed, effective representatives for their children from early childhood through integration as adults. Paula Goldberg, Executive Director; Mary Schrock, Development Director; Deborah Leuchovius, TATRA Program Director.

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