

Paying the Bills



Tips for Families on
Financing Health Care for
Children with Special Needs



New England SERVE

Second Edition

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Tips for Families on Financing Health Care for Children with Special Needs

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Dedication

This booklet is dedicated to all families of children with special needs, who are working hard to understand and make the best of the present American health care financing and delivery system, and to the many dedicated professionals who work with them. We hope that reforms of this patchwork and challenging system will soon offer all children access to affordable quality health care for all their medical needs.

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Introduction

For many families, the system for financing health care in this country is just not working. Health care costs are rising and the benefits provided through our health insurance plans are shrinking. When this booklet was first written in 1992, there were 37 million Americans without health insurance coverage and an additional 50 million Americans whose health insurance was inadequate to meet their families' needs. Health care reform was a major issue being debated at the national level and there was the hope that universal access to health care would become a national priority.

By 1998, the number of uninsured Americans had grown to over 40 million, including an estimated fourteen percent (14%) of American children under the age of eighteen. That means over ten million children in our nation had no health insurance coverage at all. Paying for necessary health care services remains a daily worry for many families, and when the family includes a child with a chronic illness or disability, inadequate coverage or the total absence of health insurance can become a nightmare.

While the major reforms of the health care system envisioned in 1992 have not occurred, we have seen significant changes in the way health care services are both financed and delivered. As health care costs continue to rise, families have experienced cut-backs in their health benefits, fewer choices of providers as well as more limited options for employer sponsored health plans. Such changes can result in an unexpected loss of access to long-trusted providers or interruptions in long term plans for care. Widespread access to private health insurance and family benefits through employment is declining, while the numbers of children covered by public programs such



as Medicaid are growing. Between 1987 and 1995 the percentage of children with employer-based health insurance dropped from 67% to 59% of all children, while in the same period the percentage of children receiving Medicaid increased from 15% to 23%. While nearly ninety percent of privately insured children continue to receive their insurance through a parent's employer, such coverage, when available, is increasingly expensive, less likely to cover a full range of benefits and service and more likely to require out-of-pocket expenses and higher co-payments from families.

Another major change affecting American families is the growth of managed care. In 1988 the number of Americans enrolled in managed care plans represented less than a third (29%) of those with private insurance and included almost no Medicaid participation. Traditional indemnity plans covered over two-thirds of those with private insurance. Ten years later, in 1998, enrollment in managed care plans nearly tripled, now including 86% of privately insured American families with only 14% of Americans covered by indemnity health insurance plans. In addition, during this ten-year period almost every state Medicaid program began to plan for or entered into contracts with managed care organizations to deliver health care services to children and families who are eligible for this publicly funded health insurance program. In an attempt to provide even more children with access to basic health care, Congress established the State Child Health Insurance Program (CHIP) as part of the Balanced Budget Act of 1997. As states begin to participate in CHIP, this new program will have the ability to dramatically reduce the number of uninsured children.

Throughout this period of rapid change in the health care system, families of children with special health care needs have continued to struggle with how to pay for their child's medical and health-related services. They continue to need information as well as answers to a variety of questions in order to manage a complex and changing environment. Over 17,000 copies of the first edition of *Paying the Bills* have been distributed to families, health care providers, hospitals and training programs for health professionals. This second edition has been revised to include more information on managed care and the strategies families can use to make this system more responsive to children with specialized needs. Information on public insurance programs has also been updated. Children with ongoing health conditions remain the focus of this booklet. Since these children are heavy users of the health care system, their families spend a great deal of time negotiating to get their child's health care needs met. This often includes a complicated mix of benefits from private health insurance and public programs.

Paying the Bills: Tips for Families on Financing Health Care for Children with Special Needs is a booklet written by parents who have children with special needs. The parent authors have tapped their own experiences, as well as those of other families and professionals, in order to share information and techniques for getting payment for children's health care. ***Paying the Bills*** encourages families to ask questions, be persistent and learn about the health care financing system. As families learn more about how the system works for their own family, they are often able to help others do the same.

Paying the Bills includes tips in the following areas:

- ◆ Getting started
- ◆ Making your child's health insurance work for your family
- ◆ Making public programs work for you
- ◆ Tackling medical bills
- ◆ Influencing decision-makers
- ◆ Documenting your child's special needs
- ◆ Changing decisions
- ◆ Cost savings
- ◆ Finding other sources of funding
- ◆ Connecting with other families

Paying the Bills

Getting Started

Get a diagnosis



Ask questions



Read ... read ... read



Talk to other parents

Before you can plan how to pay for your child's care, you must try to find out what your child needs now or might need in the future. Tell the professionals who work with your family that you are trying to create a financing plan for your child's medical expenses. You need to get their best assessment of what your child will need even though it may be hard to predict. It may also be helpful to talk to other parents who have children with similar needs.

◆ **Get a diagnosis**

A specific diagnosis for your child's health problem or disability can be a very important element in getting payment for services or getting access to public programs. It is helpful to discuss with your doctor the **best words to use** in describing your child's condition. Concerns about giving a child a "label" must be balanced with the practical requirement of getting payment for the services your child requires.

◆ **Ask questions**

Gather information by asking many questions. Ask your child's health care providers, including doctors, nurses, therapists, as well as teachers and other families, what kinds of services, tests, equipment, supplies and other medical goods they think your child will need. Try to make lists of these needs in time segments, i.e., needed this year, next year, within the next five years. Ask how often these **needs might change**. This kind of information will be helpful to you in financial planning. Always ask your providers if the services or equipment are usually covered by health insurance. If they are not usually covered by insurance, ask how or where you might get something paid for! A sample list of services is included to help you in gathering information.

◆ **Read...read...read**

Read whatever you can find about your child's special health condition. Written materials may mention new treatments, medications, therapies or equipment that you want to research further. Go to your **public library**. Ask your child's providers for suggested reading material. Newsletters from self-help organizations and advocacy groups often include very helpful information.

The **Internet** or World Wide Web is another source of information for families. The Internet can put you in touch with other families and give you access to recent research or publications about your child's condition. If you do not have a personal computer or on-line service to connect you to the Internet, check with your public library. See Appendix A for a partial list of web sites or addresses on the World Wide Web that specialize in information that may be helpful to families of children with disabilities or special health care needs.

Sample List of Health Care Services

Therapies, Home Care, Planning Services:

- Speech and Language Therapy
- Physical Therapy
- Occupational Therapy
- Nutrition Counseling
- Home Nursing
- Personal Care Attendant
- Home Health Aide
- Counseling/Mental Health
- Genetic Testing and Counseling
- Hospice
- Case Management/Care Coordination
- Diagnostic Testing

Durable Medical Equipment:

- Ventilator
- Suctioning Equipment
- IV Stands and Equipment
- Air Compressors
- Feeding Pumps
- Monitor
- Wheelchair
- Braces
- Casts
- Prosthetic Devices

Medications and Supplies:

- Prescription Drugs
- Tracheostomy Tubes
- Gastrostomy Tube
- Feeding Bags
- Specialized Dietary Products/Formula
- Dressings
- Diapers

Adaptive Equipment:

- Prone Standers
- Corner Tables
- Specialized Car Seats
- Bath Aids
- Van Adaptations
- Ramps
- Corrective Shoes
- Eyeglasses
- Specialized Orthodontics
- Prosthetic Devices
- Communication Equipment
- Home modifications

◆ **Talk to other parents**

Other parents who have children with special health care needs are an extremely valuable source of information. Talk to other parents, both informally and through parent groups. Let your child's doctors or other providers know of your willingness and interest in talking with other families. **Family organizations, such as *Family Voices***, a national network of families and friends of children with special health care needs, or parent-to-parent groups can connect you to other families at the national and state level. Local organizations, such as school advisory councils for children with special needs, family organizations or parent support groups can also be a way to meet other families. You can learn about family support or advocacy groups through your child's doctor, school, hospital or other agencies where your child receives services.

Making your child's health insurance work for your family

Choosing a plan



Look for ways to join a group plan



Request a copy of the contract



Remember who is the customer



Talk with your employer



Plan for the future

The health insurance world is both complex and confusing, with dramatic changes in recent years. There are different ways to buy health insurance and different types of insurance plans to buy. How you get your family's insurance and the type of plan you have will affect what services your insurance is likely to cover, and what costs you will have to pay yourself.

◆ Choosing a plan

A wide variety of insurance plans are available in today's market. You may have a choice of what kind of plan to buy through your employer or you may be very limited if you are purchasing health insurance on your own.

There are **important differences** among health plans and understanding these differences can help you to make the best choice for your family. Be sure to check whether the benefits offered in a specific plan will address your child's and family's needs. If a benefit or a specific service that you know your child will need is not mentioned, ask specifically if it is covered. Ask about any limitations on services covered, and the frequency or amounts of services allowed. Ask if there are any waiting periods for coverage, pre-existing condition exclusions or annual or life-time "caps" or limits on the amount of services that will be paid for.

Traditional indemnity plans: These plans used to be the most common type of health insurance available. The insurance company covers a portion of the cost of the service, with the remaining cost the responsibility of the family. The family's part is called a co-payment. In addition to **co-payments**, indemnity plans often have annual deductibles, an amount you must pay each year before the plan will pay for services. Whether this type of plan is the best choice for your family depends on your particular needs and the specifics of the plan. While traditional indemnity plans allow you the **widest choice of providers**, your out-of-pocket costs may be



higher than some other plans require. However, the availability of indemnity plans is much more restricted in recent years, with fewer employers offering them as a choice. When an indemnity plan is offered, it is almost always more expensive than the managed care options.

Managed care plans: Managed care plans are now the most common type of health insurance offered by employers today. Managed care organizations vary in the way they provide services, with some plans providing care through their own staff, including doctors and other providers who work directly for the plan. Others contract with physicians and other groups to provide care to their members. A major difference between these types of plans and the traditional indemnity plans is that your choice of **provider may be restricted**. It is important to check whether a managed care plan includes the providers you want to use for your child's specific needs.

If you have been seeing a particular specialist who knows your child's history and needs, ask if that **provider is included in the plan's network**. Even if the specialist is included in the plan's network, your access may be limited to specific provider units or referral circles depending on your choice of primary care provider.

Some plans will cover care from providers outside of their preferred network with special arrangements or at a higher co-payment. If you use the network providers, managed care plans require **fewer out-of-pocket costs** for your child's care and **less paperwork** for you. You may pay a small co-payment at the time of service rather than a percentage of the total cost. Such plans usually provide good coverage for primary or preventive care such as physical exams or routine tests but may be more restrictive of specialty or habilitative services or physical therapy (PT), occupational therapy (OT), or speech therapy.

Compare plans in terms of the choice of providers, referral process for specialty care, and coverage for other services your child may need.

◆ **Look for ways to join a group plan**

When people purchase their health insurance through their employer, they are part of a group plan. Group plans provide you with the best coverage for the least cost because the costs of services are being spread over a group. The larger the group, the better. Usually, members of a group do not

have to answer questions about their own or their family members' health status when applying for coverage. In addition, employers may pay for all or part of the premiums. Self-employed people may be able to **join a group health plan** offered by a professional, trade, or fraternal organization, an association of small businesses, a chamber of commerce, or another group. Investigate all the possible options available to you and know when the **open enrollment period** is scheduled. This is the time when you can change plans without penalty for pre-existing conditions.

Some people, when they are unable to buy through a group, will buy individual health insurance directly from an insurance company or through an insurance agent. In this case the individual or family pays the entire premium. The applicant will be asked to provide information about present and past medical history and must agree to release medical records.

Important health care insurance reforms were made in legislation passed by Congress in 1996, the **Health Insurance Portability and Accountability Act (HIPAA)**. This legislation provides some important protections for persons with pre-existing conditions. The bill prohibits employers who offer health insurance from limiting or denying coverage to any person covered under a group health plan for more than 12 months for a specific medical condition. Once this 12-month limit expires, no new "pre-existing condition" limits may ever be imposed on people who maintain their health insurance without any gaps in coverage. The HIPAA also helps people who leave or lose their job to maintain their health coverage. The bill guarantees continuing availability of individual health insurance coverage to people who have had their employment-based coverage for at least 18 months. State regulations may offer even more protections.

Check any plan to see what provisions it has for renewal. A renewal process may result in changes in your premiums or benefits.

◆ **Request a copy of the contract**

Once you obtain health insurance, the **contract** is the legal document that will give you complete information about what is covered and what is not. The brochures that are commonly given to customers with a summary of benefits are not enough. You will have to request a copy of the whole **policy, the contract or the certificate of insurance** from the insurance company, health plan or from your employer. It may, however, be difficult to understand, with many words open to interpretation. Read all the materials carefully. Some of the terms used will have very

specific meanings in the context of the health plan, which may not be in the dictionary. You will need to ask someone knowledgeable about the benefits in your plan for clarification. Ask your employer, benefits manager or insurance agent to explain any parts you do not understand. You can also ask a legal advocacy group for help. There are **consumer protection offices** or ombudsmen in many states. These services may be located in the Governor's office, the Division of Insurance or the Attorney General's office. They can help you understand the state laws that may offer protection for your rights as a consumer. A list of words commonly associated with health insurance coverage is included at the back of this booklet.

◆ Remember who is the customer

You are the customer. Insurance companies and health care plans are businesses and you or the company you work for are the consumer. They have sold you a product and you should expect the best quality as well as courteous and helpful service.

Most of your communication about your child's health insurance will be by phone. When you contact the insurer or health plan, ask for a **toll-free telephone number**, which will save you money. If no toll-free number is available, ask the insurer to call you back. Have a list of **specific questions** ready for each phone call and take notes on what was discussed. Keep careful records of who you talk to — write down the date, the person's full name, position, and telephone number, and brief notes on what was discussed. Sample telephone logs are included at the end of this chapter.

◆ Talk with your employer

If your child's health insurance comes through your employer, it is often helpful for the employer to know what your child needs. Some parents worry that this discussion might endanger their job. You will, of course, have to weigh the desirability of this approach in your own situation. However, the health plan options offered by your employer may not include the services your child needs if your employer does not know what they are.

Some businesses and organizations write their own plans to cover health care costs for employees. These plans are referred to as **self-insured or self-funded**. Benefits and costs are determined by the employer. These plans may be administered by an insurance company, or

involve an insurance company when costs go above a specified amount (referred to as reinsurance). Self-insured plans, which are particularly common with large employers, are not governed by state insurance regulations. This means that you may not have certain state-level protections, and state officials may not be able to intervene on your behalf with a self-insured plan.

◆ **Plan for the future**

A family may continue to cover their child under their family policy after he or she turns age 18 if this child is disabled, regardless of whether the child is enrolled in school. Families should check with their insurance company to determine **coverage for their child after age 18**. Many (if not most) policies allow continued coverage for a child after age 18 if the child is considered disabled.

Health Care Financing Telephone Log: Health Insurance

Child's name _____ Address _____
 Telephone _____

Health Insurance Information:

Plan #1 _____	Plan #2 _____
Policy # _____	Policy # _____
Policy Holder _____	Policy Holder _____
Group Name _____	Group Name _____
Group # _____	Group # _____
Contact Person _____	Contact Person _____
Address _____	Address _____
Telephone _____	Telephone _____
Fax _____	Fax _____

Date	Name of person whom I telephoned, wrote to or visited	Person's title & phone number	Agency	Main points of discussion Action taken or expected

Health Care Financing Telephone Log: Public Programs

Child's name _____ Address _____
 Telephone _____

Public Program Information:

Name of Program #1 _____	Name of Program #2 _____
Child's ID # _____	Child's ID # _____
Contact Person _____	Contact Person _____
Address _____	Address _____
Telephone _____	Telephone _____
Fax _____	Fax _____

Date	Name of person whom I telephoned, wrote to or visited	Person's title & phone number	Agency	Main points of discussion Action taken or expected

Making public programs work for you

Identify public programs



Get it in writing



Find an ally



Ask for coordination



Use the advisory board



Contact your legislator



Plan for the future

There are a variety of public programs in every state that might provide health care benefits to your child with special needs. These include the state Programs for Children with Special Health Care Needs (CSHCN), Early Intervention (EI), Medicaid, Supplemental Security Income (SSI), the State Children's Health Insurance Program (CHIP), as well as Special Education. Although some of these programs are set up under federal law and partially funded by the federal government, the eligibility requirements and benefits offered may vary state by state. In addition, there may be special programs that your state has developed for children with special health needs, or for uninsured or high risk individuals.



Investigate programs within your state to find out what specific services may be available for your child. The Program for Children with Special Health Care Needs that is funded through the Maternal and Child Health (MCH) Block Grant in your state is a good place to start. These programs are usually located within the State Department of Public Health; they are required to provide information and referral services to families and they will have a statewide toll-free number.

◆ Identify public programs

Your child may be eligible to receive health insurance through a state-supported public program such as Medicaid or the State Child Health Insurance Program. Even if your child is currently insured, he or she may be eligible for one of these public programs in addition to his or her private insurance.

Medicaid: Basic eligibility for Medicaid is determined by family income and the levels for eligibility vary state by state. Medicaid can provide your child with comprehensive health benefits.

In some states, Medicaid may offer a choice of enrollment in a managed care plan or a more traditional program that operates like an indemnity plan. Other states may mandate enrollment in a choice of managed care plans.

SSI: Another way your child might be eligible for Medicaid is through the federal Supplemental Security Income program (SSI) which provides a monthly cash stipend to eligible children. In most states, eligibility for SSI automatically makes a child eligible for Medicaid. Eligibility for SSI is based on both a disability and financial determination. In order for a child to be eligible, he/she must meet requirements concerning functional abilities and impairments. The financial determination is based on a combination of earned income, assets and resources. Once a child is 18, the family income or assets are no longer considered. There are also special conditions where a family income may not be considered in determining eligibility for a child. The overall requirements are listed in Appendix B.

State Child Health Insurance Program (CHIP): This health insurance program was created in 1997 to encourage states to extend health insurance coverage to uninsured children. CHIP is a federal program that gives funds to participating states to design health insurance programs for low-income children who are **not** eligible for other public insurance programs including Medicaid. In some states, it expands Medicaid eligibility. CHIP targets children whose family incomes do not exceed 200% of the federal poverty level or 150% of the state's Medicaid eligibility, whichever is higher. In 1999, 200% of the federal poverty level is \$33,396 for a family of four. Information on your state's CHIP program is available through the Medicaid agency or the Maternal and Child Health Program usually located in the state Department of Health. CHIP programs may be called something different in each state. Ask about any special state programs designed to serve children without health insurance.

When dealing with public programs, remember:

◆ **Get it in writing**

Ask for a **written list of benefits** including any restrictions on the amount of these benefits and a description of eligibility criteria for any public program. Ask about the application process, any supporting information you will need to supply in your application, and when this information will

need to be updated after your initial application. Applications are often long and complicated. After looking over the application, don't hesitate to **ask for help** in filling it out if you think you need it.

◆ **Find an ally**

Identify someone who knows the public system who can help you through the red tape. This might be another parent, a case manager, nurse, or program administrator. Educate him or her about your child's and family's needs. This person could be located in a family organization, hospital, school, doctor's office or your state Program for Children with Special Health Care Needs. **Try to meet your ally personally.**

◆ **Ask for coordination**

Ask for help in seeking out and **coordinating all possible sources of funding**. If your child is covered by a variety of payors, both public and private, request a meeting. Ask all payors to sit down with you and your child's providers, if possible, to map out a financing plan. This is an opportunity for you to have an active role in planning and coordinating your child's care. If your state has a case management or care coordination program for which your child is eligible, the case manager may help to bring this group together.

◆ **Use the advisory board**

Public programs are often required to have **advisory boards with consumer representation**. Ask who is on the board and who represents consumers. Call or write to these board members and tell them how you see the program working. Consider getting on the advisory board yourself.

◆ **Contact your legislator**

Programs funded through public money are voted on by your legislators at either the state or federal levels, or both. Make sure these representatives know how important specific public programs are to you and your child and let them know how well they are working. Legislators are interested in hearing from their constituents and can be **important advocates** for your child within the bureaucracy.

◆ **Plan for the future**

There are Social Security Benefits for older children with disabilities and for adults disabled since childhood. When a child who has been eligible for dependent's or survivor's benefits from Social Security reaches age 18, those **benefits will continue as long as the child remains disabled**. You can get a free booklet called "Social Security: Benefits for Children with Disabilities," by calling the Social Security Administration at 1-800-772-1213 (SSA Publication No. 05-10026).

Paying the Bills

Tackling medical bills

Keep accurate records



Help providers bill correctly



Check itemized bills



Keep track of paid bills



Understand the collections process

Your child's medical bills may be confusing for several reasons. Billing procedures vary. In some cases, providers require you to pay them directly and then you must submit a claim to your insurer for reimbursement. In other cases, the provider will bill the insurer directly and you are billed any amount left unpaid. You may be billed by several providers or departments for the same procedure or hospital stay. For example, you may receive a bill from a hospital or medical facility for a test or procedure, a separate bill from the physician who reads or interprets the test, and another bill from the physician who is in charge of your child's care. Many parts of the bill and your insurance company's explanation of benefits may be written in code and therefore may be confusing. Although it is hard to keep track of all this paperwork, it is important to have an accurate record in order to avoid later hassles. Whenever you have a question, ask for clarification. Keep all important bills, papers and correspondence in one place.



Some important things to remember when dealing with bills are:

◆ **Keep accurate records**

Keep all information about your child's coverage handy, including policy or identification numbers, billing addresses, and telephone numbers. Keep a copy of each bill you receive and each claim form you have submitted for your files. You may need these copies if any questions arise. Filing these by date of service and **keeping insurance forms and provider bills together** will help. Staple bills to claim forms when submitting. A sample medical bills log is included at the end of this chapter.

◆ **Help providers bill correctly**

Providers may have pre-arranged billing agreements with different insurance plans or public programs. Be sure to let providers know at the time of each service what programs your child is eligible for that may pay for the service. **Provide all up-to-date identifying information.** Ask for help and cooperation from the providers in order to coordinate your benefits and get the most coverage for a particular service. Give providers any referral forms or signed claim forms that your health plan requires at the time of service.

◆ **Check itemized bills**

Bills should include dates of service and full descriptions for charges. Bills will probably be sent out to you monthly, but only **the first copy sent may have the complete billing** information. Therefore, subsequent bills may be confusing. There are special code numbers for each procedure or service. Reimbursement is sometimes denied because this information (dates, descriptions, codes) is incomplete. Look at each bill carefully as soon as you get it. Call the provider for clarification if any information is unclear or inaccurate. In addition, request that your provider send you copies of all bills sent directly to your insurer for payment.

◆ **Keep track of paid bills**

Keep track of bills that have been paid. Your insurance company or health plan will send you an explanation of benefits (**EOB**) or **statement of benefits paid or denied**. Public programs may not send you these statements, however, unless you request them. Match these statements to your provider bills to track what has been paid, to report any errors and to keep track of balances due. This may require some detective work especially if the insurer has lumped several claims together. Sorting out what has been paid will enable you to know what remaining charges are your responsibility, a public program's responsibility or what the insurer still owes. Call the insurance company or health plan to clarify any questions.

◆ **Understand the collections process**

Many providers will automatically turn unpaid bills over to outside collection agencies after a specified period of time. This may be prevented by notifying the provider of any delays in payment. If the insurer has caused this delay, ask them to notify the collection agency.

If the bills are referred to a collection agency, **know the rules**. You must be allowed to negotiate a schedule for payment, and you should do this in writing. Collection agencies are not allowed to call you at work, talk to your boss or other employees about your bill, hound you, threaten you or nag you. They may only talk to the person who is responsible for the bill.

Always ask if a collection agency is registered in your state. You can call the Attorney General's office or Office of Consumer Affairs to check on a specific collection agency. Report unregistered collection agencies to these state agencies. If the company is not registered in your state, they are not permitted to call you. These state agencies may also be helpful if a company is being overly aggressive.

Medical Bills Log		Child's name: _____					
Date of service	Service description procedure code	Provider & location	Date of bill	Bill sent to	Action	Amt. paid	Balance due

Paying the Bills

Influencing decision-makers

Identify decision-makers



Use a friendly style



Be persistent



Follow the prior approval system



Negotiate

Although benefits are outlined in the policy, certificate of insurance or program materials, each health plan or public program has its own method for making decisions about paying for services. You will want to find out what this decision-making process is and how it works. Recognize that many decisions are negotiable, and that you, as the person who understands your child and family best, can play a crucial role in this negotiation. You have a unique perspective on what works for your child, and you need to let the decision-makers know your child's specific situation and needs.

◆ **Identify decision-makers**

There is always a **chain of command** for decision-making about claims. If you are part of a group plan, start by identifying who in the group negotiates the health benefits as well as the representative within the insurance company or managed care organization who is assigned to your group plan. Let them know about your child's specific needs. If the health plan is not responsive to your concerns, talk with the **benefits manager** of your employer. This person will be knowledgeable about state and federal laws and regulations that apply to the health plan. The benefits manager can request an explanation thereby putting additional pressure on the health plan. If you have purchased an individual plan, the agent who sold you the policy and the representative within the insurance company or managed care organization may be helpful if they know your needs.

Within public programs, you will also need to know the decision-makers in order to track the status of your requests. Since persons who are not familiar with your child's diagnosis or needs may be the decision-makers, include detailed information in each request for service or equipment. With both public and private insurance, try to identify the chain of command for decision-making. Ask about the availability of **any case management** or **flexible benefit programs** that may allow approval for services not originally in your package of benefits.

Try to talk with the same person each time you call so that he or she can get to know you and your child's needs. Complicated questions or requests may need to be answered by another level of decision-maker. Always ask the person you are talking to if he or she is able to make the decision, and if not, who you should talk to. Remember to **keep records of your conversations**.

◆ Use a friendly style

Begin with **expressing thanks** for services and items already paid for or approved. This helps in establishing a foundation of cooperation and appreciation before continuing with requests for unmet needs. Be extremely pleasant. Keep your sense of humor and non-blaming attitude.

◆ Be persistent

Request statements, promises, decisions or denials in writing or offer to send a letter with your understanding of the discussion. Keep a copy of your letter. Ask for the date by which you can expect a specific action, payment or written response. Some public programs may require a denial in writing from your insurer in order to access public services. Call back if you do not get a response. Do not easily accept “no” for an answer. “No” really means — **ask someone else!**

◆ Follow the prior approval system

Many health plans as well as public programs require that you notify them and request prior approval in order to receive payment for certain services, equipment or scheduled hospitalization. Most health plans also require **notification within 24 hours** of any **emergency services or hospitalizations**. You need to know when prior approval is required, how it is to be requested, and any rules for notifying the plan or program in order for services to be covered. Always ask for a copy of the approval in writing.

◆ Negotiate

Your child may be covered by more than one health plan. For example, when each parent has a benefit plan through work, or when a child has both private health insurance and public benefits, there will be multiple payors. Each agency may want to be the payor of “last resort.” There may also be state rules that govern how multiple benefits will be coordinated. Try to clarify who will pay for what by asking directly. If an insurer or public program indicates that they think your request may be denied, ask if they could **fund part of your request**. Another strategy is to ask, “Who *do* you think should pay for this need?” If all else fails, ask for the name of the supervisor of the person to whom you are talking and start over.

Paying the Bills

Documenting your child's special needs

Explain the need in medical terms



Personalize your request



Emphasize cost savings



Seek inside support

You can influence decisions best when the decision-makers have an understanding of your child's specific need. Decision-makers are often ready to go to bat for your child if they have the right information.

◆ **Explain the need in medical terms**

A medical professional must describe the **medical necessity** of the service or special equipment that you are requesting for your child. You may need to document why the "basic" equipment or usual medication will not work for your child. Get help to do this. For example, if your child needs special formula or dietary supplements, have your doctor write out a prescription for the product to demonstrate the medical necessity. Make it clear that any supplies or equipment are intended solely for use by your child for treatment of a medical problem. Use the right language. Avoid words such as "respite," "educational" or "custodial care" with insurance companies or many Medicaid programs. These terms often trigger a rejection of your claim. Use medical terms and concepts such as "home nursing" and "therapeutic services" instead.



◆ **Personalize your request**

You may want to send pictures of your child when requesting help. Follow up with pictures of your child and family using the equipment, services, or supplies, if appropriate. This kind of "thank you" will also serve as a reminder that you may have future needs.

◆ **Emphasize cost savings**

Explain how the service or equipment will prevent more costly medical needs in the future. For example, if adequate home care for a child will prevent costly hospitalizations, say so. **Cost savings** is a very effective rationale for getting approval to pay for services or equipment.

◆ **Seek inside support**

It helps to have identified some key allies among your child's providers, who can **help you to document** your case. The company that manufactures and sells the equipment or item your child needs may also have good ideas about what should be included in the documentation or request. Ask them to help you describe why the service or equipment is medically necessary.

Paying the Bills

Changing decisions

Seek clarification



Always be ready to resubmit



Use the appeals process



Seek legal assistance



File a complaint



Use the press

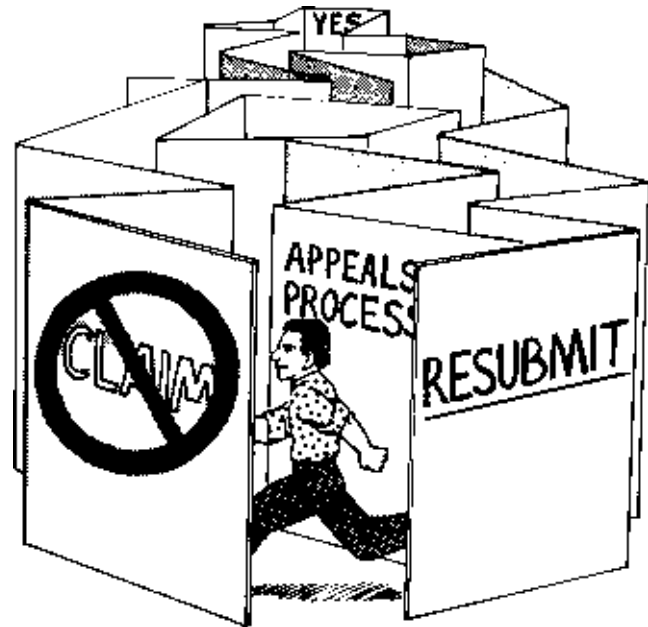
Either private health plans or public programs may deny your application or claim for benefits. Don't be surprised. Insurance companies are usually not penalized when they deny a claim even if they are later found to be responsible. Public programs such as Medicaid also deny some claims, which are later accepted. Do not be discouraged by an initial negative response.

◆ Seek clarification

Always ask why a claim was rejected, and request this explanation in writing. It may be because the documentation was incomplete or even inaccurate. It may be due to the wording of a request. Sometimes, just by sheer persistence, you can get a company or a program to rethink a decision.

◆ Always be ready to resubmit

Keep complete records so that you are always ready to resubmit your claim. New procedures or treatments may require insurance companies and public programs to **develop new policies**. An initial rejection may be due to the insurer's lack of experience with a particular service or piece of equipment. Be understanding, but persistent. All companies and programs make exceptions, so ask for one. Decisions are sometimes made on a case by case basis. Be sure to ask that all exceptions, when agreed upon, are put in writing. If your claim is rejected, find out the reason for the denial. Re-submit with **additional justifications**.



◆ Use the appeals process

Every private health plan and all public programs will have a process for appealing decisions. Ask for their appeals or grievance policy in writing and ask for assistance in filing an appeal.

The insurance agent who sold you a private policy may be willing to help you negotiate with the insurance company. Your state Insurance Commissioner can provide you with a copy of any **state regulations that require an appeals process** in your state. This may include a right to appeal outside your health plan. This agency may also be helpful to you in appealing your claim. However, self-insured plans may not be covered by these regulations. Be prepared to re-state and document your child's medical need for the service or equipment. Include letters from physicians, therapists, teachers, etc. explaining the importance of this medical need when you resubmit your claim. A sample letter is included as Appendix C.

◆ Seek legal assistance

If you feel that your request has been wrongfully denied, you may want to seek the advice of a lawyer. A lawyer might be able to assist you in **interpreting your policy** or evaluating your disagreement with the insurer or public program. Do not reject this possibility because you feel it may be too expensive. There are groups in every state that offer free legal services to families who meet financial eligibility guidelines. Contact a disability advocacy group to help you locate a **Legal Services** program or a Protection and Advocacy agency in your state. These are two publicly funded programs offering professional legal advice. These agencies may also be able to offer some guidance over the telephone regardless of your income. Your state Bar Association may maintain a list of volunteer or "pro bono" attorneys who may be willing to donate their time to help you. You can also ask your employer or union if there is a legal representative available to assist you.

◆ File a complaint

If you disagree with a decision made by a private health insurer or managed care organization on either a claim or application, file a **formal complaint or grievance** with the Commissioner of Insurance in your state. This office may be able to investigate the issues in your complaint, and at

the very least you are providing important evidence of unmet needs. If your child receives health insurance from a public program and your appeal is denied, you will want to write letters documenting your need and their denial to the director of the program, the funding source of the program, and your legislators. Names and addresses of state and federal legislators are available at your local library. Legislators need to know how public programs and private insurers are serving their constituents. A single letter with copies sent to the others is fine.

◆ **Use the press**

Many families have turned to the press to tell their stories and to raise awareness of the unmet health care needs of children. **Increasing public awareness** of these issues can be successful in helping persuade programs or plans to pay for services rather than face a great deal of negative publicity.

Cost savings

Ask for prices

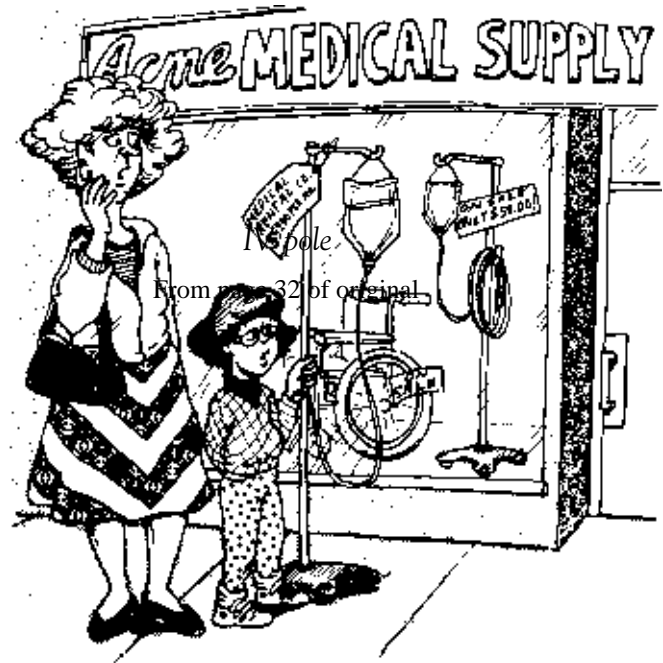


Recycle equipment



Speak up

It is in the best interest of families, as well as public programs or health plans, to provide quality care in the most cost effective manner. Families often have excellent suggestions on how to provide services in lower cost settings. Many families go to great lengths to investigate the least expensive sources for equipment or services. This information should be shared with the payor. Working around the payors' constraints or usual procedures may not be easy. Even if the insurer does not act on this information immediately, your input may influence policy in the long run.



◆ Ask for prices

Always ask for specific costs of supplies, equipment or services. Ask for copies of bills to keep track of charges. Point out any mistakes you find. Share any information you have on **less expensive alternatives** with your insurer or health plan.

◆ Recycle equipment

Sometimes families are sent supplies or a piece of equipment that does not work out, or is the wrong size, etc. Try to return it, of course, but if this is not possible, consider **equipment exchanges** through parent newsletters, groups or school programs. An equipment exchange program may already exist in your state. Check with your health department, community agencies, local advocacy groups, or vendors.

◆ **Speak up**

If you think a less costly alternative would work for your child, say so. Document your concern when you see that a **system is wasteful or more costly** by writing to the Member Services or Clinical Services department of the health plan, or the director of the public program. For example, one family reported in frustration that their health plan required that they rent an IV pole for 5 years at \$11.00 per month when it could have been purchased at a much lower cost.

Paying the Bills

Finding other sources of funding

Identify special discretionary funds



Use tax savings



Negotiate payment



Find the right match



Explain your family's needs



Recognize and thank everyone who has helped

You may find that even with coverage from your private health plan and available public programs, your family is left with uncovered health care expenses. Other financial help may be available through your providers or hospital, and there may be private or voluntary organizations that can offer financial aid. Disability or health related organizations such as United Cerebral Palsy, Spina Bifida Association, Muscular Dystrophy Association, and the Easter Seals Society, as well as charitable organizations such as the Make A Wish Foundation, Elks Club, Lions Club, Junior League, etc. often respond to specific requests for assistance. You may also be able to take a tax deduction for large out-of-pocket expenses.

◆ **Identify special discretionary funds**

These funds may be available through hospitals, health departments or clinics in your local community. You can generally learn about such funds through the **social service department** at your hospital or where your child receives care. Some communities have access to private endowments with which to help families. Ask at your local town hall.

◆ **Use tax savings**

You may be able to itemize out-of-pocket medical expenses for a tax deduction. A booklet entitled, “**Medical and Dental Expenses**” (**IRS Publication #502**), explains how to do this and lists approved medical expenses. Ask for this booklet at your local Internal Revenue Service (IRS) office or order a free copy by calling 1-800-829-3676. The items that are allowed by the IRS for these deductions are considerably broader than what is typically covered under insurance plans. These deductions, for example, might include home adaptations, transportation to medical appointments, cost of food and clothing above and beyond that needed to feed a healthy child, and many others.

A second mechanism for using tax savings may be available through your employer. Your employer may be able to help you set up a **Health Care Reimbursement Account**, also called a Flexible Spending Account, which is described in Section 125 of the IRS Code. If your employer doesn't yet offer such accounts, speak to the Director of Human Resources (HR) or

Benefits Director at your place of employment. Each employer's plan can be a little different. Plans run on the calendar year. You decide in December what you want to put aside, and your employer then deducts this amount in equal installments from your paychecks for the year before calculating your taxes. This means you can pay for medical expenses with pre-tax dollars. You submit receipts for out-of-pocket expenses for reimbursement. When using this process, however, be careful not to overestimate the amount withheld. Once money is placed in this account, it cannot be retrieved except for medical reimbursement.

◆ **Negotiate payment**

Hospitals and other health care providers may be willing to negotiate reduced payment. When your family has unpaid medical bills, you may be able to arrange a small monthly payment toward the bill. Hospitals are often required to provide a certain amount of **free or reduced cost care**. Ask for information about their free care program.

◆ **Find the right match**

Many voluntary and social organizations identify themselves with a particular disability or illness for charitable purposes. Others will **earmark their funds for specific services** such as family support, or equipment or home adaptations. Disability related organizations may provide funds or refer you to other groups. When seeking help from these organizations, you need to do some investigating to find out which group will be most interested in the specific needs you have. For example, local vocational schools may be a source for home adaptations.

One mother reported how their family paid for a \$4,000 van lift to accommodate their child's wheelchair. The parent began by calling local agencies, i.e., Lions Club, Police Benevolent Association, United Cerebral Palsy and Catholic Daughter's Association, and telling them of the need. She wrote letters and enclosed a photo of her daughter with her father lifting her into the van. From these efforts, she eventually secured funding for the lift from a variety of **public and private agencies**, including a state program that provided more than half of the money needed.

◆ **Explain your family's needs**

When applying to voluntary or social organizations for help, include the full medical description of the needs. You can also **emphasize the human and family side** of your need. Explain how the problem affects your whole family. Try to paint a picture of your family and what your life is like, especially if the request is for a piece of equipment or service that would have an impact on the whole family. What would having this need met mean to your family? Enlist these organizations in helping you find other funding if they cannot meet your need.

◆ **Recognize and thank everyone who has helped**

Let those organizations to which you are applying know of other organizations that have already contributed. This knowledge may create a little friendly competition. Always remember to personally thank everyone who has offered you help. Try to find ways to **publicly thank organizations** as well. A letter to the editor of your local newspaper acknowledging everyone's support can serve to increase public awareness and reinforce their generosity.

Connecting with other families

Support each other



Share concrete ideas



Speak up for reform

Getting to know other families of children with special health needs can offer you much needed support and many good ideas. You may find ways to connect with other families through support groups at your child's school or hospital or by contacting a state or national disability organization. Most states have some statewide parent advocacy organizations that can also put parents in touch with other parents. Ask your child's doctor or other providers for suggestions, as well.

◆ Support each other

Sometimes it is crucial just to have **another person to talk to** who has been through the same crazy maze trying to pay for his or her child's care. Families can also help each other through telephone calls, letter writing, writing newsletter articles, or through personal contact at parent meetings or even in waiting rooms.

◆ Share concrete ideas

Connecting with other families can also offer you concrete ideas on how to get a needed service or piece of equipment funded. Another family's success or failure in approaching an insurance company or public program may lead to very **useful advice**. Other families in your community may have ideas on where else to go for possible sources of funding for something your child needs. Many families have creative solutions they want to share with others.



◆ **Speak up for reform**

By banding together with other parents, families have an opportunity to raise a **unified parent voice** about the serious inadequacies in our present health care financing system. As families speak out — through the press, in public forums, and to legislators — they can influence the reforms that will inevitably come to the health care financing marketplace. Speaking up, both individually and in groups, may help direct these reforms so they can more adequately meet the needs of children and their families. A national organization that speaks for families is **Family Voices**. There are state coordinators in each of the states. See page 69 for more information.

Paying the Bills

Conclusion

The process of finding funding for your child's health care is bound to be complicated and at times frustrating. Keep in mind, however, that parents have accomplished amazing things, both for their own children and for the larger system. By clearly stating their child's needs, investigating all possible benefits through their private health insurance and public programs, enlisting allies when they need support, and finally by sheer persistence and hard work, many families have found the financing they need for their child's care — including the authors of this booklet. As families have pointed out inequities in the system and identified their changing needs, health plans and public programs have also changed their policies.

We hope that these tips developed for parents by parents will help you in paying the bills for your child's health care. It's never easy — but is it worth the effort. Good luck!

Paying the Bills

Appendix A

Resources on the World Wide Web for Parents of Children with Special Health Care Needs

◆ General Information Sites

CODI - Cornucopia of Disability Information
<http://codi.buffalo.edu>

The Family Village
<http://www.familyvillage.wisc.edu>

Internet Resources for Special Children (IRSC)
<http://www.irsc.org>

Rare Genetic Diseases in Children
<http://mrcr4.med.nyu.edu>

Yahoo: Health: Diseases and Conditions
http://www.yahoo.com/Society_and_Culture/Disabilities

◆ **On-Line Resource Directories**

The Family Village Library

<http://www.familyvillage.wisc.edu/library.htm>

National Information Sources on Disabilities

http://codi.buffalo.edu/text_based/.national.infor

◆ **Family Support and Parent-to-Parent**

Family Voices:

National network of families and friends of children with special health care needs

<http://www.familyvoices.org>

MUMS National Parent to Parent: Matches all disorders

<http://www.waisman.wisc.edu>

Association for Birth Defect Children (ABCD):

Matches for parents of children with any disorder, especially birth defects

<http://www.birthdefects.org>

National Parent to Parent Support and Information System (NPPSIS):

All disabilities

<http://nppsis.org>

Parent-to-Parent E-Matches: E-mail matches for families

ematches@waisman.wisc.edu

Appendix B

What is SSI?

SSI stands for Supplemental Security Income. It is a federal program that provides a monthly payment from the Social Security Administration to people with limited income and resources who are aged, blind or disabled.

◆ What can an eligible child receive?

- ◆ **A monthly check:** The exact amount a child receives depends on the family's income and resources.
- ◆ **State supplement:** About half the states currently supplement the federal SSI benefit with an additional amount.
- ◆ **Medicaid:** Children who receive even \$1 of SSI benefits automatically qualify for Medicaid in 38 states and the District of Columbia. The other 12 states use different eligibility criteria for Medicaid and SSI, but most SSI children become eligible for Medicaid.

◆ What are the eligibility requirements for children?

- ◆ **Blindness:** "Central visual acuity" of 20/200 or less in the better eye with the use of a corrective lens or a limitation in the field of vision of less than 20 degrees.
- ◆ **Disability:** A mental or physical impairment, or combination of impairments, that so limit a child's ability to function independently, appropriately and effectively in an age-appropriate manner that the impairment and the limitations resulting from it are comparable to those that would disable an adult.
- ◆ **Citizenship:** Must be an United States citizen or a lawfully admitted permanent resident or a non-citizen given permission by the Immigration and Naturalization Service (INS) to remain in the United States.

- ◆ **Residency:** Must reside in the United States or must be a child of someone in military service assigned to permanent duty overseas.
- ◆ **Limited income and resources:** Family income must fall within dollar limits established by regulations.

◆ **When is a child considered to be disabled?**

- ◆ If the physical or mental impairment severely limits the child's ability to function independently, appropriately and effectively in an age-appropriate manner, and
- ◆ If the resulting limitations are comparable to those that would disable an adult, and
- ◆ If the condition is expected to last at least 12 months or to result in the child's death.

◆ **Why appeal the denial of an SSI application?**

SSA turns down well over a third of applications for children's SSI benefits. However, when applicants appeal these decisions, many are able to reverse the denial. If a denial is reversed, the child may receive retroactive benefits, back to the date of the original application.

Appendix C

January 5, 1999

Patient: Judy Jones
I.D. #: 555-44-3333
Employee: Jasper Jones
Group: Acme Associates
Claim Number: 026439782

XYZ Insurance Company
555 Insurance Company Plaza
Anytown, USA

Dear Insurance Company Representative:

Thank you for reviewing our appeal of the denial for a Touch Talker for our daughter, Judy Jones. We were dismayed, however, to receive a letter upholding the previous denial dated December 10, 1998 (see the enclosed copy), and would like to ask that you reconsider this decision. We understand that the denial of this request is based on the premise that the Touch Talker is "not considered a prosthesis under this plan and it does not meet the Plan's definition of durable medical equipment." Since electronic communication devices are new in the medical field, some insurance companies have not yet been made aware of the medical nature of the devices or of the function they serve.

Judy is a nine year old girl with cerebral palsy. Her larynx is non-functional for speech due to cerebral palsy, and this condition cannot be surgically corrected. The Touch Talker would serve to replace this nonfunctional organ, the larynx. Page 32 of the policy book states as covered items "...a prosthetic appliance replaces a limb or organ..." The Touch Talker seems to clearly meet your requirements for a prosthesis.

Page 22 of the policy book describes "durable medical equipment" as equipment that:

1) "...can stand repeated use."

The Touch Talker can withstand repeated use. Because many people who use the Touch Talker do not have total voluntary control of their muscles, the Touch Talker is built of a highly durable material called Kydex, which is intended to withstand rough treatment.

2) "...is primarily and customarily used to serve a medical purpose."

As stated above, the Touch Talker serves to replace the function of the larynx which is non-functional. It is primarily and customarily used for this purpose. This is documented in the enclosed letter from Judy's pediatrician.

Paying the Bills

XYZ Insurance Company
January 5, 1999 - Page 2

3) "...is not useful in the absence of illness or injury."

The Touch Talker provides a voice to people who cannot speak. It does not have functions which would benefit a person who has functional use of his or her speech mechanisms.

4) "...can be used in the home."

The Touch Talker may be used in any setting, including the home.

It is clear that the Touch Talker satisfies the above conditions for coverage of durable medical equipment. Furthermore, I understood from my conversation with Mr. William Wilson of your company, that our request was denied because the Touch Talker was considered to be a computer. The Touch Talker is definitely a medical appliance which replaces a malfunctioning body part.

In the general information section of our policy, on page 42, "medical necessity" is defined as: "A medical condition requiring medical services and treatment. Such services and treatment must be in keeping with generally accepted medical practices for the diagnosis and condition of the patient."

Enclosed is a prescriptive letter from Judy's attending physician, Dr. Penelope Perkins, certifying the medical necessity of this equipment for Judy. Judy has significant speech apraxia that can be specifically habilitated with an oral communicator. Without this device, should Judy find herself in an emergency situation, she has no other means of conveying her needs. Without a means of communicating a medical problem, it could go undetected until it became more serious, requiring more extensive treatment, and ultimately greater expense to the insurance company.

Thank you for your attention to this appeal. I trust that with this clarification of the Touch Talker communication device, you will see that it should definitely be a covered expense under our plan.

Enclosed please find copies of all correspondence to date related to this request. Please contact us if you have any further questions.

Sincerely,

Jane Jones

Jasper Jones

Enclosures

Further readings

Some of these books may be available from a local parent resource center or your public library.

Choosing and Using an HMO, Ellyn Spragins, 1998. Bloomberg Press, 100 Business Park Drive, P.O. Box 888, Princeton, NJ, 08542-0888.

This book provides practical advice on how to select an HMO and describes some of the industry-based quality measures. The book also contains a helpful chapter on strategies you can use to get the most out of your HMO.

Fighting Back: A Guide to Challenging Health Insurance Denials, Robert Peterson, J.D. with David Tenenbaum, M.A., 2nd Edition, 1994. Published by the Center for Public Representation, Inc., P.O. Box 260049, Madison, WI, 53726-0049. (608) 251-4008.

A book that introduces parents of children with special needs to the world of health insurance and suggests tips for getting the best type of coverage and strategies for combatting claim denials. The book outlines the most common reasons claims are denied, arguments and evidence parents can present to insurance companies and what to do when all else fails.

SSI – Help for Children with Disabilities, December 1997. Published by the Bazelon Center for Mental Health Law, 1101 15th Street, NE, #1212, Washington, DC, 20005-5002, December 1997. (202) 467-5730. Available in Spanish.

Written for families, this 20-page booklet explains how children can qualify for SSI under the new law and regulations.

The Castle Connolly Guide to the ABC's of HMOs: How to Get the Best from Managed Care, 1997. Castle Connolly Medical Ltd., 150 East 58th Street, New York, NY, 10155. (212) 980-8230.

This book is a practical guide that describes the realities of managed care. It defines the terms used in managed care plans. It also provides a list of questions you should ask about your managed care plan.

Your Family and Managed Care: A Guide for Families of Children with Mental, Emotional or Behavioral Disorders, December 1997. Published by the Bazelon Center for Mental Health Law, 1101 15th Street, NE, #1212, Washington, DC, 20005-5002. (202) 467-5730. Available in Spanish.

This is a clearly written 16-page booklet that explains what parents can do to improve their child's access to services.

Paying the Bills

Terms to know: Health insurance

Annual maximum limits or caps: The limit an insurance plan sets on a given service. It may be a certain number of visits or a dollar amount. If your child needs more of a given service than is allowed by the limits in your plan, you will need to request an exception.

Case management program: Special programs now offered by many insurance companies and managed care plans, particularly for individuals who require high cost care. Under such a program, a case manager is assigned to oversee all of a given child's claims and arrange for alternative benefits, which may not be part of the original contracted insurance plan. These alternative benefits may not be more costly than the stated benefits in the plan. Case management programs have sometimes chosen to pay for home-based care instead of costs of long-term hospitalization. Find out whether such a program is available under your plan, who is eligible, and how it works.

Certificate of insurance: A description of health benefits included in a group health plan, usually given to insured members by the employer or group.

COBRA P.L. 99-272: A federal law that includes important benefits for individuals who lose their employee health insurance because of a loss of job or a death. This law provides the opportunity for individuals to continue the same insurance coverage for 18-36 months. The individual is responsible for paying the full insurance premium. There may also be language in your policy on provisions for continuing the same coverage. The Insurance Commissioner in your state or your employer may offer information on your rights for continuation. A recent federal law, the Health Insurance Portability and Accountability Act of 1996 (HIPAA), made three changes to COBRA: (1) a disabled person is entitled to 29 months of COBRA continuation coverage; (2) COBRA cannot be terminated because of other coverage where the plan limits or excludes coverage for any pre-existing condition; (3) children who are born, adopted, or placed in adoption with the covered employee during the COBRA continuation are treated as "qualified beneficiaries."

Community rating: An insurance practice of pooling people within a defined geographic area, and charging everyone a set premium for a set benefit package without considering their individual health status.

Conversion: The way that you may shift your health coverage from a group plan to an individual plan without review of your insurability. There may be language in your policy on this issue. Also check your state insurance commission for regulations in your state on this process.

Coordination of benefits: A process for how various health benefits will be applied if a person has more than one insurer or health plan. Regulations on coordination of benefits may exist within your state or your insurance plan may describe how such coordination should happen. Usually one plan is designated to pay all claims first and the residual bills are the responsibility of the secondary carrier. These provisions are to prevent individuals from collecting more than once for the same medical charge.

Co-payments: The portion of the charge that you are responsible for paying yourself when using a specific health service. Indemnity plans typically require a co-payment to be a percent of the charge for the service. It may vary based on the type of service, when the service was received (for example within a certain number of days of an emergency) or where the service was received (out-patient versus in-patient). When there is a co-payment in managed care plans, it is usually a small fixed amount regardless of the cost of the service, paid at the time you receive the service.

Current procedural technology (CPT): A set of codes developed by the American Medical Association that describes medical procedures for billing. Each item submitted by your provider to an insurance company for payment must be listed by CPT code on the bill.

Deductibles: The amount that you must pay out-of-pocket for covered medical services before the actual benefits of the coverage begin. Check what this amount is per family member. There may also be a total family limit. Deductible amounts vary a great deal from policy to policy. Deductibles are usually set as an annual amount.

Explanation of benefits (EOB): The statement from your insurance plan that itemizes the actions taken on claims that have been submitted.

Experience rating: An insurance practice of setting premiums based on previous use of health services and health status. This practice generally discriminates against persons with disabilities or chronic illness.

Experimental treatment: Medical treatment not covered by insurance companies or public programs because its efficacy is considered unproven. Insurance companies or public programs may reject claims when they decide that the treatment is experimental. Insurers may rely on an internal medical review, consultation with outside experts, or a combination of these and other means to determine if a treatment will be considered experimental. Articles in the current medical literature may influence decisions. Individuals have won claims by proving that other insurance companies have paid for the treatment in question, or that the treatment has been beneficial in other instances.

Fee for service: A form of payment where a provider is paid for each service, supply, or equipment. Traditional indemnity plans are fee for service plans.

Grace period: A period of time after a premium is due but before payment is received during which your health coverage is still in effect. States may have laws requiring health insurance policies to allow a set number of days of “grace.”

Health maintenance organization (HMO): A managed care organization that combines the functions of a health insurance company and a health care provider.

Lifetime maximum: The total amount that an insurance policy will pay out for medical care during the lifetime of the insured person. Check into other options you have for enrolling in another group plan during an open enrollment period well before your child is approaching a lifetime maximum.

Managed care: A term used to describe a range of strategies used by health care plans and insurers to monitor and control costs and utilization of health services and providers.

Managed care organization (MCO): Any organization that offers health plans which limit the choice of providers and may require varying levels of approval for access to services. This type of organization is in contrast to traditional indemnity health insurance or fee for service plans.

Mandated benefits: Specific health benefits that insurers are required to offer by state law. Each state has its own legislation on mandated benefits.

Medicaid: A federal health insurance program for persons with low income or disabilities created under Title XIX of the Social Security Act. Medicaid programs are operated by the states using both federal and state dollars, and state programs may vary in terms of benefits, structure and eligibility. A child may be eligible for Medicaid assistance even if he or she already has private insurance.

Medically necessary: A term used in insurance policies to identify covered services. Insurance companies limit coverage to services they deem medically necessary. It is very important to identify how your coverage plan defines this term. The definition may be included in your policy. If not, ask in writing for information on how this term is defined. If the definition is fairly general, ask for specific information on how the company decides on medical necessity, especially for children. This information will help you to present your request in the most appropriate way.

Open enrollment period: A period when you may sign up for a health plan without waiting periods or consideration for pre-existing conditions. Many employers offer these periods yearly. You may also be offered an open enrollment opportunity to join a health plan when you begin a new job.

Out-of-pocket costs: A sum of all the expenses for health care that you pay yourself, including deductibles, co-payments and charges for services not covered by any health plan.

Out-patient benefits or coverage: Treatment or services received in a setting (such as a clinic or doctor's office) where no room and board is charged. Check the out-patient benefits in any plan you are considering carefully since most of your child's care will take place on an out-patient basis.

Pre-existing condition: A condition that has been medically treated or would normally have been medically treated before a person enrolls in a medical insurance plan. In some cases, pre-existing conditions exclude a person completely from buying health insurance. In other cases, the insurance company may decide to charge higher premiums or offer the insurance, but refuse to cover any treatment relating to that specific condition.

Preferred provider organization (PPO): A form of managed care plan in which a group of providers contract with an insurer and agree to provide services at pre-negotiated fees. Subscribers to a PPO must have a primary care physician who is a member of the PPO. Subscribers are given incentives to use providers within the organization, but may use providers outside the plan for greater out-of-pocket costs.

Premium: The total charge that is paid to the insurer for the health coverage. This may be paid weekly, monthly, quarterly or annually and it may include payments made by your employer as well as your own contribution.

Primary care: Routine medical care, usually provided in a doctor's office.

Prolonged illness clause or extended benefits: A possible option in your coverage for 100% reimbursement (instead of partial) for all services relating to your child's condition. This option may also add to your child's lifetime maximum. Inquire if this kind of clause is part of your plan and how you apply.

Provider: Any physician or other health care professional or organization that provides medical care or other health services.

Reasonable and customary charge: The amount the insurance company determines it will reimburse a provider for a given service or procedure. This amount varies in different parts of the country for the same service.

Renewal: The clause in your insurance plan that describes how you might renegotiate the contract after the term is finished. Guaranteed renewability of an insurance policy protects you from ever losing your child's health coverage, although the insurer may still raise the premiums.

Rider: A legal document added to an insurance plan that either restricts or adds to coverage. States may have regulations about riders.

Self-insured: Some places of employment write their own plans to cover health care costs for employees. Benefits and costs are determined by the employer. These plans may be administered by an insurance company, or involve an insurance company when costs go above a specified amount (referred to as reinsurance). These types of plans, which are particularly common with large employers, are not governed by state insurance regulations.

State insurance regulations: Every state has laws and regulations that govern insurance companies that operate within the state. There is also a state process for filing complaints and appeals. Check with your state Commissioner of Insurance for information and assistance.

Stop-loss: A clause that limits your total liability to a specified amount on medical expenses covered by the policy. After expenses reach that amount, the insurance company would pay all of your remaining covered medical expenses for the year including deductibles and co-payments.

Underwriting: An insurance company practice of assessing risks of illness and costs, and setting premiums based on these assumptions.

Waiting period: The period of time required by the insurance company after a person is covered by a policy before specific health services are covered by the plan. This time can vary from a number of months to a number of years.

Wrap-around: A supplementary insurance plan designed to pay for additional health benefits not covered by another plan. A wrap-around policy can provide more comprehensive benefits for a child with extensive needs.

Terms to know: Public programs

The following are basic definitions of public programs that help to finance some health costs for children with special needs. Each state may have its own eligibility criteria and benefits for these programs, and may have developed other programs as well.

Children with Special Health Care Needs Programs: These state operated programs are federally funded through Title V of the Social Security Act as well as with state dollars. The federal agency that regulates these programs is the Maternal and Child Health Bureau, within the Health Resources and Services Administration of the Department of Health and Human Services. Decisions about how the funds are spent are made within the state and will vary from state to state. Some state programs provide services directly or pay for identified health services for children with specific health conditions. Other states use these funds to improve statewide systems of care.

Early Intervention (EI): P.L. 99-457 provides federal dollars to each state for planning programs for children age birth to three who have special needs or are at risk for developmental delays. If P.L. 99-457 is fully implemented in a state, direct services will be provided to this population. In these states, children identified as having special needs must have an Individual Family Service Plan (IFSP) developed, which identifies all needs and services. If you have a young child with special needs, check on the availability of Early Intervention programs in your state.

EPSDT: Early Periodic Screening Diagnostic and Treatment (EPSDT) is a category of services required by federal Medicaid regulations that can be used to broaden the array of services available to Medicaid eligible children. It requires that Medicaid eligible children be screened, and if any problems are identified, the child is eligible to receive necessary treatment that is included on the federally approved optional list of services, regardless of whether that service is part of the state Medicaid plan.

Family Leave Act: A federal law passed in 1994 that requires employers with more than 50 employees to provide up to 12 weeks of unpaid leave for employees to attend to the medical needs of a family member.

Health Insurance Portability and Accountability Act (HIPAA): This federal legislation, passed in 1996 and sometimes referred to as the Kennedy-Kassenbaum Bill, limits exclusions for pre-existing conditions. The law prohibits employers offering health insurance from limiting or denying coverage to people covered under a group plan for more than 12 months. Employers and insurers must credit previous continuous coverage toward any pre-existing condition requirement under a new plan. The bill also prohibits insurance carriers and health maintenance organizations (HMOs) from denying coverage to employers with between 2 and 50 employees who wish to purchase plans.

Home and Community Waivers and Medicaid Plan Amendments: These programs, which are specific to each state, allow some children with special needs whose parents are over income limits for Medicaid to qualify for Medicaid benefits. Some states offer benefits beyond the regular Medicaid plan to eligible children. Benefits and eligibility requirements vary from state to state. Some states do not have these waivers or amendments to their state plans.

Maternal and Child Health (MCH) Block Grant: A federal program of grants to states that supports care and services to mothers and children. A certain amount of these funds must be earmarked for children with special health needs, and specific guidelines require that programs be family-centered, community-based and coordinated. Each state must provide a toll-free number that offers information and referral to services. In order to qualify for these funds, each state submits an annual block grant application that outlines how the MCH dollars will be spent. There must be evidence that the state provided opportunities for citizens to give public input to the block grant application.

Medicaid: This public program, established as Title XIX of the Social Security Act, jointly financed by state and federal monies, provides health care benefits for those who meet certain income requirements. In some cases, income may be waived as mentioned above. Both the income requirements and specific health benefits offered vary state by state and are regulated by the U.S. Department of Health and Human Services, Health Care Financing Administration (HCFA). There is a core package of basic services that each state must offer, and a large array of optional services that your state may or may not include. When Medicaid is paying for services, the providers your child uses must be approved Medicaid providers.

Related services under Special Education: P.L. 94-142, reauthorized as the Individuals with Disabilities Education Act (IDEA) in 1990, mandates that certain therapies, equipment and services be provided by your local school district if your child has an Individual Educational Plan (IEP) that documents the need for these services. These may include physical therapy, occupational therapy, speech therapy, psychological testing, counseling, assistive technology and other services that are required for your child to learn in school.

Supplemental Security Income (SSI): This federal program under the Social Security Act provides monthly cash stipends as well as access to Medicaid (in most states) for children and adults who have specific disabilities or chronic illnesses. In 1991, the Social Security Administration made major changes in the way medical eligibility for SSI is decided for children. Be sure the physicians who are documenting your child's medical needs understand the criteria for eligibility. For a child to be eligible, parents must also meet income criteria. Parental income guidelines do not apply after a child has been in an institution, such as a hospital, for 30 days in one calendar year. When the child is discharged from the hospital or other institution, however, his/her SSI eligibility ends unless that eligibility was originally based on parents' income.

State Child Health Insurance Program (CHIP): This federal legislation was passed in 1997 as Title XXI of the Social Security Act. This law encourages states to extend health insurance to uninsured children. The program mandates, for participating states, the establishment of a program of assistance to targeted low-income children for a portion of the child's health insurance premium. The law prohibits pre-existing condition exclusions and any discrimination on the basis of health status.

Paying the Bills

Getting more information

For help in locating other parents or parent organizations in your state, contact:

Family Voices National Office
P.O. Box 769
Algodones, NM 87001
Tel: (505) 867-2368
Toll Free: (888) 835-5669
<http://www.familyvoices.org>



For name, address and telephone number of the Insurance Commissioner in your state, call the state government information number in your state, or contact:

National Association of Insurance Commissioners (NAIC)
444 North Capitol Street NW, Suite 701
Washington, DC 20001
(202) 624-7790
<http://www.naic.org>



For the name, address and telephone number of the Title V, MCH Children with Special Health Care Needs Program (CSHCN) in your state, call the Department of Health in your state, or contact:

Association of Maternal and Child Health Programs (AMCHP)
1220 19th Street, NW, Suite 801
Washington, DC 20036
(202) 775-0436
<http://www.amchp1.org>

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