

WHAT DO YOU MEAN IT'S NOT COVERED?

By Calvin and Tricia Luker

The health care costs related to caring for a child with a disability or chronic illness can be a challenge for you and for your employer or the company that helps you pay your medical bills. Public programs and private insurers have large demands for services from a great many people. By being a responsible consumer and using only the services you or your child needs and at the level of your need, you will help to keep medical costs, insurance premiums and taxes from continually rising.

Every child and family is different. The services and insurance your child requires are unique. You should expect that finding the health care plan that truly meets your child's needs will take planning, energy, time and extra expense.

You probably will need the financial assistance of public and private agencies to pay for your child's medical expenses. Your child's needs might cost thousands of dollars year after year. And if your child's medical expenses rise, you must expand your search for funds. Although you surely will be grateful for the generosity of others, the effort to find funds can become so overwhelming that you may feel that you are scrounging for money. But if you need financial assistance, you have to find a way to get it. Think of your search as a treasure hunt. This attitude will help you keep your focus on the task at hand.

First, you must consider not only your child's medical needs but also how your family spends its money. If you are frugal and try to save, yet medical expenses take more than you have available, you have to locate outside sources of help, which in our society are of three basic kinds: tax-supported government programs at the local, state and national levels; insurance; and voluntary health agencies.

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GOVERNMENT PROGRAMS

Although government programs and regulations constantly change, there are major governmental assistance programs which may help your child. Some programs base services on a family's limited income. Other programs require the child to fit a certain category of service need. However, some programs can provide emergency or periodic help for any child or family in need.

Medicaid

Medicaid is designed to provide medical and related health care to qualified individuals and families with low incomes. It is financed jointly by the federal and state governments. Individuals enrolled in Medicaid services do not pay directly for the care.

There are "required" and "optional" eligibility groups under Medicaid. "Required" eligibility groups are those which must be served by the Medicaid program. "Optional" eligibility groups are those which may be served, with each state determining the benefits package [beyond the basic services] and in most cases, the eligibility requirements beyond those not mandated by the federal government.

Michigan's basic Medicaid program requires at least basic medical services for any child meeting one of the following descriptions:

- ◆ The child's parents receive Aid to Families with Dependent Children [AFDC], a cash assistance program offered and jointly funded by the federal and state governments.
- ◆ The child receives Supplemental Security Income [SSI], a federal cash assistance program for qualifying adults and children with disabilities. Qualification for SSI automatically qualifies one for enrollment in Medicaid.
- ◆ The child is younger than six years old and the child's family income does not exceed the federal poverty level.
- ◆ The child comes from a two-parent family with low income and limited resources.
- ◆ The child receives adoption assistance and foster care in programs administered under the Social Security Act.

- ◆ The child is part of a “protected group”. Protected groups include children who lose cash assistance for a time period due to higher family income; or children of two-parent unemployed families receiving limited cash assistance. Children in such “protected groups” can receive Medicaid coverage for 12 continuous months.

Basic Medicaid Services

Federal Medicaid laws require each state to offer “Basic Services” to all citizens who qualify for and receive Medicaid. Basic Services include the following:

1. Inpatient hospital services;
2. Outpatient hospital services;
3. Physician services -- the services provided by a physician in or out of the hospital;
4. Services in rural health clinics;
5. Laboratory and x-ray services not provided by a hospital or rural health clinic;
6. Care in skilled nursing facilities (commonly known as nursing homes) for individuals 21 years or older;
7. Home-based health care;
8. Family planning services and supplies;
9. Services of a certified nurse practitioner or midwife; and
10. Early Periodic Screening, Diagnosis, and Treatment [EPSDT] Program to screen and treat children for developmental delays.

It is important to note that, except for the EPSDT Program, states may set “amount, duration, and scope” of services limits on the benefits offered even under the required Basic Services program. The only limit allowed for the EPSDT Program is that the service must be “medically necessary.”

Tax Equity and Fiscal Responsibility Act [TEFRA]

Michigan includes several groups of children in the Medicaid program under the Tax Equity and Fiscal Responsibility Act of 1982 [TEFRA]. TEFRA allows states to give home and community-based Medicaid services to children under age 18 who otherwise would be institutionalized. Only the child's income is counted in determining TEFRA Medicaid eligibility. A child's inclusion in Medicaid under TEFRA includes services under the Early Periodic Screening, Diagnosis, and Treatment [EPSDT] Program, allowing access to a wide range of medical and family support services. TEFRA formerly was called the Katie Beckett Waiver Program in Medicaid.

Early Periodic Screening, Diagnosis, and Treatment [EPSDT]

The EPSDT Program is available to all Medicaid eligible children below age 21. EPSDT Program's goal is to ensure that all children in the Medicaid program are examined and evaluated on a regular basis and receive any necessary treatment to correct detected delays or problems. This is particularly important for children who have or are at risk for developmental delay.

Under the EPSDT Program, periodic developmental screens must be done annually and must include, at a minimum, the following:

- ◆ A comprehensive health/developmental history, including health, education, nutrition, immunization, and developmental milestones;
- ◆ An unclothed physical examination;
- ◆ Laboratory tests;
- ◆ Vision and hearing testing; and
- ◆ Dental screening.

EPSDT requires all children between age 1 and 5 be tested for lead poisoning. The EPSDT Program also provides preventive services normally not included in a state's Medicaid Program. A child enrolled in Medicaid is automatically enrolled in the EPSDT Program. Separate EPSDT program enrollment is not needed.

Children's Special Health Care Services Program [CSHCS]

The Children's Special Health Care Services Program is a federally funded program that provides disability-related services to children with chronic illnesses or disabilities. The CSHCS program, administered by the Michigan Department of Community Health [DCH], pays for approved special medical treatment, equipment and supplies. The DCH also will help families problem-solve and obtain needed services from other agencies.

Specialty medical care and treatment under CSHCS means unique services provided by specialists who generally do not have first contact with patients. Examples include pediatric surgeons, cardiologists and speech-language therapists. Services for injuries or illness not related to the disease or disability (*e.g.*, services for repair of a broken bone resulting from a sidewalk fall) are not covered.

CSHCS services are broad and they include:

- ◆ Office care for the eligible condition by a doctor listed on the Eligibility Notice;
- ◆ Specialty clinic care;
- ◆ Hospital stays;
- ◆ Home care;
- ◆ Special therapies;
- ◆ Prescription medicines; and
- ◆ Medical equipment and supplies.

CSHCS Program serves children from birth to age 21. They serve people with cystic fibrosis or blood clotting disorders like hemophilia at any age. Medical condition is the sole measure of CSHCS eligibility. Severity also can be a factor. Family income has no bearing on a child's eligibility for CSHCS specialty medical care..

Families of all income levels are eligible to enroll in CSHCS Program. While many pay no costs, some are required to share in the cost of their child's care through a client payment agreement. An income chart determines what costs, if any a family must pay for CSHCS specialty medical care. Families may subtract costs from income, (*e.g.*, alimony, child support, job-related expenses and child care paid by working

parents).

CSHCS may approve specialty medical care and treatment for more than 2,000 conditions. They include, but are not limited to:

- ◆ amputation
- ◆ birth defects
- ◆ blood clotting disorders
- ◆ cancer
- ◆ cerebral palsy
- ◆ certain heart conditions
- ◆ certain visual disorders
- ◆ cleft palate and lip
- ◆ cystic fibrosis
- ◆ epilepsy
- ◆ hearing loss
- ◆ insulin-dependent diabetes
- ◆ kidney disease
- ◆ myelodysplasia
- ◆ muscular dystrophy
- ◆ paralysis/spinal injuries
- ◆ sickle cell anemia
- ◆ spina bifida

MANAGED CARE

Managed care delivers health services using a closed network of physicians and other health care professionals, clinics, and hospitals. Managed care agencies monitor and coordinate patient care, costs, and quality to provide cost-effective health care. A managed care organization charges set patient fees and refers them to its own providers.

Managed care organizations or corporations serve large groups of people. A business, corporation, school system, governmental unit or programs, or health membership organization charges set prices for health coverage. Physicians or providers in the network work for a salary, rather than charging fees for each service. Usually a primary physician decides which services will be provided and whether referrals will be allowed to providers outside the network.

The most common form of managed care is a Health Maintenance Organization (HMO) in which all health services are delivered and paid for through one organization. Preferred Provider Plans (PPO) offer a group of doctors and hospitals who give a discount on their services to an insurance company. In a PPO, consumers

must choose their primary health provider from an approved list and pay extra for specialty services received outside the PPO group.

Health insurance plans using the managed care model to provide quality health care while controlling costs, through one or more of the following strategies:

1. Offering financial or other incentives to health care providers -- all of whom work directly for or contract with the HMO or PPO plan -- who successfully limit most care to basic essential services.
2. Requiring that a single primary physician (usually pediatrician, family practice physician, or internist) direct, coordinate and control what care you receive and from whom you receive it.
3. Offering financial incentives to you (*i.e.*, lower premiums, small deductibles) if you agree to use doctors who have agreed to fixed or reduced charges in exchange for a guaranteed amount of business.
4. Obtaining your agreement that if you make unauthorized use of health care services either within or outside of the plan, you must pay for this care yourself.
5. Aggressive corporate and administrative review of how health care services are used by plan providers and patients.

SOME CONCERNS ABOUT MANAGED CARE ARE:

- ◆ Access to specialists, including a pediatric specialist, may be limited.
- ◆ Cost incentives may discourage primary providers from referring patients to specialists outside the network, leading to problems in obtaining speech, physical and occupational therapy; new medication and treatment; and medical or therapeutic equipment.
- ◆ Caps on mental health services or restrictive service coordination for dual diagnoses (mentally ill/developmentally disabled) could limit care.
- ◆ The restrictive definition of “medically necessary” depreciates or disallows training or therapy which would maximize – rather than

merely maintain – a persons' capabilities.

- ◆ With cost containment as a priority, **timely, appropriate care** may be come more difficult to obtain.

SOME POSITIVE FEATURES OF MANAGED CARE ARE:

- ◆ More efficient coordination of services within a single provider network.
- ◆ Fewer out-of-pocket patient expenses.
- ◆ Single location service.
- ◆ Fewer unnecessary, duplicative or excessive procedures are performed.
- ◆ Provider services often are located more conveniently to patients.
- ◆ Consumer satisfaction is regularly surveyed.
- ◆ Patients receive continuity in care if they stay with providers in the network.

Ultimately the issue is not whether managed care is a good or a bad thing, but whether the health care system is committed to insuring adequate health care services and support for children with special health care needs and their families. Managed care programs must be closely monitored and shaped.

PRIVATE HEALTH INSURANCE

For middle income families, for whom government assistance will not pay for medical care, medical insurance is the best option. Health insurance is a complicated matter for most consumers because a variety of plans are available from many different insurance companies. Basically medical insurance operates on the principal of “spread the risk,” meaning that if everyone pays in a small amount to a central fund, the few who need a large amount of assistance can be aided. Benefits vary greatly. Generally the more you pay in, the greater the coverage. Most plans cover two major areas.

Basic coverage plans

Basic coverage plans commonly provide limited coverage using a fee schedule often well below the actual fee you are charged by a doctor or a hospital. Each hospital admission may require a deductible, commonly \$250, and you may have to provide a modest co-payment toward the cost of daily hospital care. Preventive care (e.g., immunizations, routine checkups) often is not covered at all. These exclusions limit costs to the insurance company while giving you and your dependents reimbursement for some of the more expensive outpatient and inpatient medical and surgical procedures and hospital room and board costs.

Major medical plans

Major medical plans rely less on limited reimbursement for specific types of services. Instead, these plans contain an overall lifetime limitation on total reimbursements and, as with basic coverage plans, use deductible and co-payments to control the use of services. Only selected services are subject to additional limitations (e.g., reimbursement for inpatient and outpatient psychiatric care).

An example of how major medical plans limit their expenses is the common practice of requiring one or more family members to pay an annual deductible of at least \$100 before receiving any reimbursement and requiring at least a 20% co-payment on most outpatient services. That means a family must pay at least 20% of the cost of the family's medical care. This percentage can be higher if the insurance company declares that the fee the professional charged is more than the "*usual and customary rate*" [UCR] for a geographic area. In that case, the insurance company will pay only its 80% share of costs on the UCR. You, the insured, will have to pay **all** of the difference between what the insurance company pays and what the health care provider or facility charges, **plus** your 20% share of the UCR.

Evidence of Insurability and Preexisting Condition Exclusion Clause

In a health insurance plan using a fee-for-service approach, the insurance company may require "evidence of insurability" for you and your family members. This means that an insurance company can exclude coverage or limit benefits for "preexisting conditions." These generally are defined as "injuries or sicknesses" that have existed for a specified period -- such as 6 months or 12 months -- before the person obtains insurance.

Preexisting conditions often are covered by group insurance. If your employer offers a variety of programs, preexisting conditions usually will be covered only if you take out

the insurance at the time of your initial enrollment or if you change policies during the annual “open enrollment period” which usually occurs during one month of the year.

LEARN THE RULES

With any health plan, you can make the system work well for your child and improve the quality of care your child receives. If you are fortunate enough to have your child’s care covered by a health insurance policy or plan, **be sure to read the policy or plan information carefully.** Carefully read through the policy and enrollment materials you receive. In any type of plan you’ll want to know:

What types of services are covered;

- ◆ What service limitations and exclusions there are;
- ◆ What pre-authorization is needed --- and how to arrange it --- prior to hospital admission, surgery, or other expensive services;
- ◆ How to file claims;
- ◆ What rights you have to a second opinion, including who pays for it and it is arranged;
- ◆ How to call for customer service;
- ◆ How to complain about poor service;
- ◆ How and when to challenge a denial of service; and
- ◆ How to appeal if your complaint is not handled fairly or with what you feel is the proper result.

IF YOU ARE IN AN HMO, YOU’LL ALSO WANT TO FIND OUT ---

- ◆ How to select a primary care doctor;
- ◆ How to set up an appointment;
- ◆ How to get a referral for specialty services, including whether you can self-refer; what paperwork if any, you need from your primary

care doctor; and how often a referral has to be re-authorized;

- ◆ Whether there is a special phone number to call for medical advice and when it operates;
- ◆ What to do in an emergency including where to go, when and whom to call and what to say to the emergency care provider;
- ◆ When and how to get care when you're traveling outside the plan's service area, including whether you must use certain providers; when and how you should notify your plan; and what you should tell the out-of-area provider;
- ◆ How to switch primary care doctors, including how often you may do so and how quickly it can be done;
- ◆ What choices of providers exist for specialty or hospital care, including whether you are limited to providers affiliated with your primary physician or plan; and
- ◆ What special programs exist for exercise, weight loss, stress management, prenatal care, and other prevention care and how to access them.

If you don't understand the rules and procedures, ask for clarification from the plan's customer service staff, your insurance agent, or your employer's personnel office.

Make a file of all the written materials you get from your plan and keep sections on:

- ◆ Your provider directory [in an HMO or PPO];
- ◆ Plan forms and procedures; [for filing claims, switching doctors, getting authorization for hospitalization, etc.];
- ◆ The contract describing plan benefits and limitations;
- ◆ All medical bills and statements of benefits that have been paid; and
- ◆ A photocopy of your plan ID card. (carry your original plan ID card

with you at all times.)

Look for key words

No matter what type of health plan you have, look for certain words:

*Who are the **insured**?* That is, who are the people covered under the plan? The language should clearly say that you and your family members are covered.

*What are the **deductibles**?* These are the payments you'll have to make out of your own pocket before your insurance will apply.

*What are the **co-pays**?* These are the amounts you may have to pay when you receive services, supplies or prescriptions. Co-payment amounts usually are stated in percentage terms for services and equipment, and in dollar amounts for prescriptions.

*What are the **exclusions**?* These are items or people the policy does not cover. Check these carefully to see if any needed services, medications, or equipment are excluded. This section may have another title, such as "Limitations" or "What's Not Covered".

*Is there a **preexisting condition clause**?* These deny coverage for a known condition that starts before the policy began. They may also deny coverage for an adopted child with a chronic health condition. Sometimes the policy may cover such conditions, but only after a waiting period which can vary from six months to several years. A pre-existing condition may also limit the amount or type of coverage under the policy.

*Is there a **maximum or lifetime benefit provision**?* Most insurance policies have a maximum liability clause that states the total amount the insurer will pay in claims over the insured's lifetime. These lifetime maximums vary widely from policy to policy. Policies sometimes set a total amount the insurer will pay for claims in connection with a specific kind of health problem. Policies may also have annual ceilings, which state a maximum amount of coverage for a 12-month period.

*Is there a **cancellation or non-renewal provision**?* These clauses may terminate coverage if you fail to pay premiums on time, use up an annual or lifetime benefit limit, or fail to provide timely notice of services, changes in medical condition or family status.

*What about **coordination of benefits**?* This applies when you and your spouse both

receive health plans through your jobs. In that case, one plan becomes “primary”. The primary plan is the first to pay covered costs. The second plan may pick up covered costs not paid by the primary plan.

*Is there a **grace period** for paying premiums?* Some plans (or state laws) allow payment up to 30 days after the premium is due.

Choose a good primary care doctor

You have the right to expect certain things when seeking health care for your child. As a first step, remember your expectations as medical service recipients and parents:

- ◆ Respect for you and your child;
- ◆ Willingness to listen patiently;
- ◆ Taking your concerns seriously;
- ◆ Returning phone calls promptly; and
- ◆ Courtesy from the office staff.

These are not “**luxuries.**” They are “**musts**” for getting the care your child needs.

One of the biggest decisions you’ll make is who should be your child’s physician. Some parents choose the doctor they saw as a child. Other parents ask a friend or medical professional to recommend a doctor, or they seek the doctor with the best reputation. Many parents have little choice because their health plan determines which doctor their child sees.

Finding a good primary care doctor is essential to getting good care in any type of plan but especially critical in an HMO, where the doctor will be the “gatekeeper” controlling access to all other services.

Be aware that in many HMOs the primary care doctor you choose will be affiliated with a certain hospital or hospitals and a specific group of specialists. These may be the only providers the doctor can refer you to, even though many more providers might be listed in the plan’s provider directory.

If you have a choice of doctors, decide what skills you value most. Some parents value a good listener. Others want a doctor who knows the child's condition well. Use the same values to choose other people who care for your child, such as nurses and therapists.

Your child may need to see a specialist, such as a neurologist or an orthopedic surgeon. Ask your child's regular doctor to suggest a specialist. If you do not already have a regular doctor, ask parents of children with similar problems about their doctors. One way to do this is to contact a support group for your child's condition.

Continually assess your relationship with your child's doctor

Once you've selected a doctor to care for your child, you should continually assess whether the doctor is giving your child the quality of care and service they deserve. You may want to use some of the following questions to judge your doctor's performance.

- ◆ How convenient to you and your child are the doctor's office or clinic hours?
- ◆ How easy is it to contact the doctor or to get medical information or advice by telephone?
- ◆ How easy is it to get an appointment when your child is *sick*: how long will you have to wait between making an appointment and the actual office visit?
- ◆ How easy is it to schedule an appointment for *checkups and other preventative care*: how long do you wait between making an appointment and the actual office visit?
- ◆ Does your doctor make house calls?
- ◆ How long do you usually spend waiting in the doctor's waiting room and exam rooms when you arrive on time for an appointment?
- ◆ What kind of access will you have to specialty care for your child?
- ◆ What kind of access will you have to medical care in an emergency?

- ◆ What access do you have to hospital care?
- ◆ Will your doctor or office staff be able to communicate with you or your child, if necessary, via American Sign Language, assistive technology or other appropriate communication devices?
- ◆ How thorough, careful and competent is the examination and treatment your child receives?
- ◆ What kind of follow-through does your doctor provide to check your child's progress, tell you about test results or reminding you to seek follow-up care?
- ◆ How well do the medical professionals work together to coordinate your child's care?
- ◆ How well does the doctor listen to you and your child; include you and your child in making decisions about care; and make you and your child feel comfortable about asking questions?
- ◆ How well does the doctor explain what is wrong, what options exist, what is being done and what you can expect?
- ◆ How well does the doctor involve you in making decisions about your child's care, including giving you information needed to make informed decisions?
- ◆ Does the doctor and staff show courtesy and respect to you and your child?
- ◆ Does the doctor show a personal interest in your child and your child's medical problems?
- ◆ How much and what kind of advice has the doctor given about ways to stay healthy and avoid illness?
- ◆ How much time does your child have with the doctor or other medical professional during a visit?
- ◆ What are the results of care --- how much has your child been helped, how well your child's care has met their needs?

Being able to communicate and work well with your child's physician is critical. Research shows that patients with a good relationships with their doctors tend to get more accurate diagnoses, respond better to treatment, put up better with symptoms, and recover more quickly. Certainly, you're more likely to do your part in your child's care --- giving medications and making lifestyle changes --- if you understand what is expected of you, why it is important, and what effects you can expect to observe.

GETTING THE MOST OUT OF YOUR INSURANCE COMPANY

Insurance alone is not enough. You have to learn how to *use* the policy. Since you may have claims or require unique services, consider the following strategies:

1. **Withhold paying medical bills** until receiving insurance payments if on a tight budget. If you explain your financial situation to your doctor, he or she may let you withhold all or part of your payment until you are reimbursed by the insurance company. The monthly statements from the physician's office will remind you to file your claims regularly and will draw your attention to any slow processing of your claims. Legally, you need only make a small payment every month (as little as \$1) to keep the bill collectors at bay.
2. **Work directly with one particular claims examiner.** If you have many claims, you should deal with a person who knows your child's needs and who has authority to help you. If your claims are not processed locally, you can try to find the appropriate person by mail, but it is usually faster and easier to call the supervisor of claims for your area and discuss your situation. (Place a collect call to the insurance company, stating that you are a customer. Your call will either be accepted or you will be asked for your number for a return call on their line. If this fails, dial direct, since that is cheapest.) When you reach a knowledgeable person, explain your problem and ask if in the future you may send your claims directly to him or her. If so, the examiner will get to know the special needs of your child and be able to write instructions on your child's chart and enter the relevant information into the computer, thus greatly facilitating the processing of your claims.

If the company is slow to pay or rejects a claim, you can then call this individual and ask for help. Be sure to keep notes on telephone conversations about your child's claims, including the date, agents, and decisions reached.

3. **Submit claim forms methodically.** It saves time and effort if you ask all medical services vendors to submit bills directly to the insurance company for you. However, many will ask you to pay and then submit your claim form to the insurance company for reimbursement. Have a separate "Claims Submitted" folder for each member of the family.
4. **Fill out claim forms carefully.** It is better to spend a few extra minutes to do so than to have the insurance company withhold payment because it needs additional information.
5. **Make a copy of every claim form and bill you submit.** If your forms are numbered and you use carbon paper on an extra form for your own copy, be sure to write in the number of the original claim on your copy. However, some computers now assign a new number to a claim form when it is processed, rendering that original number useless to you and them. Your copy is important protection against loss of the originals in the mail or by the insurance company; you will need it for your own reference when you receive claim payments.
6. **Keep a list of prescription numbers with the names of the drugs** in your folder. Often your receipts will list only the number of the prescription; however, the insurance company wants the drug's name.
7. **Don't claim too many different kinds of items on one form.** If one item is rejected: it usually delays processing of the whole form. Even though the form is divided into two parts, such as health-care services and prescriptions, fill in only one part. Although you will end up with more pieces of paper this way, by limiting how much you submit on each form you ultimately simplify and expedite the processing of your claims.

If you were denied payment for care that you believe your health insurance policy clearly covers for your child, you can challenge it. We suggest the following steps:

1. Appeal your denied claim to your health insurance company at least twice.
2. If you are not reimbursed after these appeals and do not believe you were given an adequate explanation, contact your state Department of Insurance and report your reimbursement problem. Send the person you talk with a written description of the problem and a copy of the section in your insurance certificate, booklet, or plan summary that states that you are covered for the disputed service. Include any other information you feel is important to establish your claim as well as any information the Department of Insurance requests when you call. **[Make a copy of your letter before sending it.]**

Give the State Department of Insurance two weeks to reply to your letter. After two weeks, call and ask to speak with the person to whom you sent the letter, to clarify the status of your complaint.

Wait another two weeks. If you still have no satisfactory response from your State Department of Insurance and the amount of money is sizable, consider the next step.

3. Contact a lawyer. After hearing the facts of your case, a lawyer may tell you that he or she will not take the case. This is because he or she believes you do not have a good chance of getting reimbursed for the money you claim is owed you.

PRIVATE NON-PROFIT FOUNDATIONS

Caring Program

The Caring Program was created to help pay for needed medical care for children. One of the program's priorities is to help families with children who have chronic illnesses and disabilities afford the medical and related care their children need.

To help ensure that there are enough funds to go around for all children in need, the Caring Program emphasizes payment for preventative care (*e.g.*, well-child visits, immunizations) and outpatient services of all kinds including physician office visits for illness, diagnostic services, emergency care, outpatient medical and surgical procedures, outpatient therapies (*i.e.*, physical and occupational therapy), medical equipment, medical supplies, and prescribed medications.

Civic Organizations

Many civic organizations have a specific charity they sponsor on a national basis. In other cases, local chapters of national organizations sponsor specific illness or disability groups in their area. Still other local chapters of national civic organizations decide annually on a charity or a “cause” to sponsor for a given year.

Religious Organizations

Religious organizations also can help a family trying to manage any difficulty involved with raising a child with a chronic illness or disability, including the stress to the family because of the high cost of care. In times of stress, it is natural for a family to turn to a member of the clergy for help. Clergy often can provide both emotional support and specific leads to help resolve problems causing stress.

In addition, most churches have emergency assistance or loan funds. Clergy also can refer you to sources of temporary or longer-term financial help, including multi denominational sponsored “ministries.”

THE REQUEST FOR ASSISTANCE

If you do not have private health insurance or have a modest health insurance policy that leaves you with many medical bills, there are other private sources of help for medical and related care for your child. Many disease- and disability-related, civic, social welfare, and religious organizations have funds available for at least emergency or short-term medical needs. Local charitable foundations can help as well.

Various individuals can help you search for funds. Doctors often can direct you to sources of financial assistance in your community. Social workers at hospitals, government agencies or voluntary health agencies can also help. These are people to work *with* you, not for you, meaning that you must do your part, indicating your needs and providing any necessary information. Parents of children with special needs also can provide support and information, especially if they have been successful in obtaining money.

When you look for help in finding financial assistance, remember that you best know your financial needs and medical problems and that you can be your child’s best advocate. You must be able to provide all pertinent information to anyone helping you in your search for assistance.

Regardless of which agency you contact for assistance, the appropriate approach is important.

Telephone inquiries

Telephone inquiries are the first step in your search for financial assistance. There is a technique to making an effective phone call:

- ◆ Consider the points you want to cover before placing your call. It may be helpful to write these down.
- ◆ Introduce yourself in a friendly voice: “Hello, this is Tricia Luker” (or “Tricia Luker, mother of Jessica Baccus”) if such identification is appropriate. People like to know who is calling, and a friendly tone gets things off to a good start.
- ◆ State with whom you wish to speak and why.
- ◆ Write down the name of the person with whom you speak. If someone gives you information, you may need to call him or her back later. Furthermore, if someone gives you a commitment of some kind, you need to remember who that person was.
- ◆ Be well organized and *concise*. Refer to any notes you have made before calling if this will help.
- ◆ Take notes during the phone call. Do not assume you will remember everything you are told.
- ◆ Be friendly and polite. Since people have good and bad days, don’t take a grouchy or curt response personally. Even if you get “no” for an answer, watch your manners. You may be able to get the party to change his or her mind or at least to help you or someone else in the future.

Interviews

If an agency needs more information about your request, its representative may wish to

arrange an interview. Make an appointment for a time when you know you will be punctual and calm and when you have the attention and interest of the agency (WHICH EXCLUDES APPOINTMENTS ON FRIDAY AT 4:45 P.M.) Your general appearance is important. If you come dressed with diamonds, people may wonder if you really need help. But if you arrive looking bedraggled and worn you won't create a positive impression either.

Again, be organized and write down notes in advance, to make your case convincing. Don't take up more of their time than is necessary.

You sometimes can arrange interviews at home. Not only may this be more convenient for you, but it will enable the social worker or other agency official to actually see your child in the home environment and thus better appraise your child's needs. Someone who has been to your home is more likely to remember you when you contact him or her again.

Written requests

You probably will need to put your assistance request in writing. Written requests may take time to formulate, but they ensure that an agency has all the relevant information. A written request makes the best impression if you include a photo of your child. You can give a person the request at the time of an interview or mail it following a phone call. A written reply to your letter will verify the agency's general policy or a specific response to your request.

Refusals

Do not take refusals personally. People are not saying they don't like you or your child. They are saying that, as they perceive the situation, they can't help you.

BE SURE YOU KNOW WHY A REQUEST IS REFUSED. In some cases, a refusal is due to an inflexible policy. But in other cases a policy is open to interpretation. Check with the agency to make sure you have given all the information they need.

DON'T BE AFRAID TO ASK AGAIN. Assistance programs exist to help people. If you think you have a reasonable request, keep making it. People must understand your need before they can help you. Also, some programs change. While you may not be eligible for something now, you may well be later.

This packet is only intended to be a starting point as you think about possible community resources. Be creative. Try not to become frustrated when a source or two cannot or will not help you. It will take time and effort to get the help you need. Your efforts and persistence should be well worth the time your research will require. In the process, you will be educating a large number of business and community leaders about the needs of children and families with disabilities like yours and the ways the community leaders can get involved and help.