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ABSTRACT

This booklet documents the ability of parents of children with special health needs and disabilities to achieve balance in their lives, by moving from crisis to control, from challenge to opportunity, from questions to answers. The booklet discusses concerns that confront parents of children with special needs, and answers the most common questions families have as they move through hospital, home, and school experiences. Individual chapters cover: the hospital experience; after hospitalization; home care, home nursing, and respite care; financing health care; equipment; education; vocational training and planning for adulthood; and recreation and travel. Appendixes offer: (1) suggestions for record keeping; (2) a list of organizational resources, including government agencies, general disability groups, health and professional associations, parent groups, and groups dealing specifically with such issues as education, financing, recreation, and legal aspects; (3) over 50 suggested readings; and (4) a glossary. (JDD)

WORKING TOWARD A BALANCE IN OUR LIVES

A Booklet for Families of Children with Disabilities and Special Health Care Needs

Project S[illegible]
Children's Hospital Boston MA

WORKING TOWARD A BALANCE IN OUR LIVES

A Booklet for Families of Children with Disabilities and Special Health Care Needs

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This booklet is dedicated to:

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Joshua David Arbetter
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Kyle Mumford
Jenna Ottow
Debbie Rosenbaum
Michael Still
Sarah Swift
Andrea Tildesley

Table of Contents

Preface

Achieving balance in our lives is a goal of all families raising children in the 1990s. For families of children with special health needs, such a balance sometimes seems beyond reach. When families are first confronted with the challenge of a child with special health needs and disabilities, they may find the scales tipped. A similar sense emerges at times of major transitions, such as entrance to or graduation from school.

This booklet testifies to the strengths and resourcefulness of families, singly and collectively. It documents the ability of parents to achieve balance by moving from crisis to control, from challenge to opportunity, from questions to answers.

The preparation of this booklet represents the joint efforts of parents of children with special health needs and the staff of Project School Care, a program of the Children's Hospital, Boston which was established to foster educational opportunities for children with special health needs, particularly those assisted by medical technology. A Jonathan Lindbergh Brown grant from the Lindbergh Foundation, awarded in 1991, provided support for the establishment of parent focus groups to plan this book and for staff to carry out the project.

Ten parents met on a regular basis with Project School Care staff to articulate the areas of concern that confront parents of children with special health needs and disabilities and to outline the most common questions families have as they move through hospital, home and school experiences. Together, the parents and staff gathered information and helpful suggestions to serve as answers for common questions regarding the in-hospital experience, home care and respite care services, financing, equipment, education, recreation and vocational planning. The group also compiled an extensive appendix of national resources and prepared a glossary of common terms. The booklet stands as a resource for families to use at different junctures for different purposes as they encounter new situations and challenges.

The richness of the information in this book comes from the unconditional sharing by the parents in the focus groups. They brought a wide range of experience: their children range in age from infancy to young adulthood. As a group they have dealt with a host of medical conditions and managed an array of technologies, including supplemental oxygen, peritoneal dialysis, gastrostomy feedings, and central venous lines. The parents were most generous in offering suggestions, special "how to's" and useful information they hope will ease the road for parents in the future. We are most grateful for the participation of Nancy Anselmo, Karen Arbetter, Garrett Conrad, Marcia Conrad, Anne-Marie Gordon, Cheryl Gresek, Barbara Kaminski, Jeannine Marr, Faye Rosenbaum, Ann Swift and Mary Ann Tildesley. Jill Ottow and Judy Still deserve special thanks for their invaluable services as focus group coordinators.

We are also very fortunate to have had many experts to review the booklet or who provided valuable information. We wish to thank Barbara Abrahams, Betsy Anderson, Karen Ayers, Mario Becker, Julie Beckett, Madeline Berube, Judith Bond, Richard Bourne, Elaine Brainerd, Judith Brewer, Nancy Childs, Jean Ciborowski, Lisa Collins, Debbie Croucher, Joan Daley, Marge David, Chris DeGraw, Beth Donegan, Betty Ficken, Miguel Figueroa, Patti Fougere, Robin Friedlander, Maureen Gallagher, Lisa Gildea, Meg Harding, Gail Havileck, Artie Higgin, Julie Jones, Kay Keaney, Stan Klein, Cheska Kommissar, Marcia Libman, Sharon Lisnow, Julie Magee, Peggy McManus, Louis Meyi, Sara Miranda, Sherril Moon, Sue Murray-Larson, Terry Ohlsen, Peg O'Toole, Kathy Peabody, Linea Pearson, Peter Rappo, Gary Roberts, Jayne Rodgers, Howard Shane, Beverly Silva, Nora Wells, Barbara Weston and Lisa Zeig. We would also like to thank the staff of: the BPD Support Group, Massachusetts Department of Public Health, NAPAS, NICHCY and the Social work Department at Children's Hospital. Timaree Bierle and Marilynn Haynie, our in-house experts, lent tremendous support to the project. Ashley Hunt, Nicole Borrego and Berenise Reyes also provided valuable support. Joan Lowcock provided her wonderful calm and precision to the entire process.

Finally, booklets like this arise out of need, but also from the determination of individuals to make things a little easier, a little better, a little more balanced. Two such individuals are Stephanie Porter and Julie Burkley, who devoted extraordinary time, energy and care to the production of this booklet. They moved the endeavor from concept to focus group to reality.

The model collaborative relationship this book represents among families, health care professionals and staff clearly works. This book is offered now in the hopes that such efforts will continue in some small way toward bringing balance for families into closer reach.

Judith S. Palfrey, M.D.
Director, Project School Care

Introduction

During the focus group meetings and the process of putting together this booklet, our ever-changing role as parents of children with special health needs remained foremost in our minds. Some of our children were diagnosed at birth, others later on, and another was injured in an accident later in life. While our individual circumstances are different, we were all united by our desire to help make the road less difficult and scary for others.

This booklet is dedicated to answering the most frequently asked questions we have as parents. And while it is easy to become focused on technical information, we felt it was important to first address some of the emotional and less tangible issues and concerns that we all face as parents of these special children. Our view is one of parents reaching out to help other parents who are embarking on a journey to add balance to the lives of their children who are assisted by medical technology.

In trying to balance our role as parents of children assisted by medical technology with the more normal aspects of everyday life, we have learned that the process is very cyclical. There are times when our lives are very stressful, when we feel almost overwhelmed by circumstances and seem unable to make decisions, and other times when our lives are more manageable. The times when we felt hopeless and needed financial, practical, and emotional assistance have, for the most part, turned into learning periods when we again felt in control. These cycles of acceptance and coping are variable and ongoing.

During the periods when we feel more in control, we may need to take on two new roles: that of a researcher and an advocate. The researcher role includes becoming aware of educational laws and policies. And in our experiences, advocacy has included interpreting our child's emotional needs to caregivers e.g.: "He needs this blanket to sleep," insisting on familiar and proper techniques during routine medical procedures, and calling ahead to plan and facilitate trips and social occasions. As time goes on, we have learned which language to use with which agency and how to best advocate for our children's needs.

When we have begun to feel overwhelmed by this burden of responsibility, it has been important for us to remember that strength comes from using the supports that are available: a friend, other parents of children with special health needs, the state health department, a social worker or professional counselors. As we inform others of our children's needs, we provide balance in their lives and pave the way for smoother transitions for others who will come this way.

Our hope is that you will have confidence in yourselves as parents, no matter what part of the cycle you might be in at any one time. We also feel it is important to recognize that each of us has his or her own style and values for coping and dealing with our child. What works for some may not work for others. What works at one time may not work at another. We also believe that our own emotional health and that of other members of our family are extremely important. We must all choose how and when to effectively care for our family's emotional well-being.

We realize that there are times when we are ready to hear new information and times when we and our children simply are not ready. Accepting and adjusting to the fact that our children have special needs is a lifelong task. Each event should be considered on its own. Attempting to isolate and simplify each problem can help you regain a feeling of accomplishment and control.

When we do make mistakes, one useful tool has been a sense of humor. The catastrophes, both large and small, which were so serious and stressful at the time often later become the memories of our most wonderful moments. An optimistic attitude has also helped get us through the depressive thought that this is indeed a lifelong situation. Grief, guilt, anger, disbelief, pride and joy are all feelings that a family can experience. There is a process that accompanies the loss of a "normal" family that has to occur in order for us to see the gains we have made on a daily basis.

As parents of children with special health care needs, we must deal with a tremendously long list of professionals who can provide services to enhance the well-being of our children and our families. Despite the presence of so many professionals and experts in our life, it is important not to lose sight of the awesome expertise that we have or will gain as parents. While we must rely on the technical information that professionals can provide us, we are the only ones who truly know our children. We must remember the value of our own "non-professional expertise," and we must not let others lose sight of this. We parents always need to remember to trust ourselves. Usually our instincts have directed us to make the right decision for the well-being of our children and our families.

Using the various services available to us can be frustrating and confusing. Doctors, health-care providers, agencies and technologies are constantly changing due to the demands of our children's needs. We are consumers and have the right to compare the services that provide medical equipment, education, respite, recreational and vocational care. We are entitled to, and sometimes expected, to get second opinions and to question caregivers and service providers. When choosing a service or product, it is essential to look at past performance, ease of accessibility, reliability of people and products, and to get an explanation of options and billing procedures. We have a choice regarding the caregivers and private companies we use in our children's care and should consider ourselves valuable and important members of the health-care team.

As a practical and simple solution to coping with the phenomenal amount of information we accumulate, many of us have purchased an inexpensive notebook or "blank book." This book goes everywhere with us, and in it we enter dates, times, and name of persons contacted. An open-ended timeline of surgical/medical interventions can be useful as well. Many parents also ask for copies of all reports. These are then kept in the child's personal home file.

One of the least recognized concerns of caring for a child with high-technology needs is the emotional impact that outside caregivers can have upon the family structure. Parents can experience intense relationships with caregivers at school, in-home nursing personnel and respite care providers. These situations can cause confusion and frustration for both family members and health-care providers as the boundaries between each person's role and responsibilities in the family unit become blurred or fluctuate. Questions about the amount of time, quality of relationships, impact of others caring for the child, and parent versus "expert" knowledge and expertise can arise.

There are no set answers about how to deal with these situations, since each will vary according to individual circumstances. But being aware of and thinking about these issues can help you prevent potential problems or deal more effectively with problems when they do surface. For example, some parents may choose to rotate caregivers to prevent children's over-attachment, while others may feel one caregiver gives their children the stability they need. Well-thought out strategies and alternative plans are invaluable when routines are changed.

Helping our children keep a positive self-image while educating others about our children's differences can be a challenging task. Planning family events and taking part in recreational and social activities can help minimize difficulties and enhance our children's self-esteem. Our ability to access services and activities for our children allows them to enjoy as rich and normal a life as possible.

The siblings of a child with special health needs are also an important part of the family structure. Because a child with special needs affects the identity of the family. the question often arises about how to make our other children feel special too. Some strategies we have used to help siblings work through feelings are: enlisting the aid of trusted relatives or friends, having teachers or other professionals act as sounding boards or outlets, taking special time with each child, and making time for planned activities that include the whole family.

So we wish you well as you join us on your journey as a parent of a child with special health care needs and disabilities. Our work together on this project has shown us how frequently we share experiences and feelings with other parents. We hope you will have opportunities to meet other parents and share your ideas, frustrations, joys and growth with each other. Our hope is that this booklet will not only be a resource for technical information, but will serve as a connection that links us together as parents. This common bond of shared experiences and friendship enables us to accept our challenge and to move forward.

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CHAPTER 1 The Hospital Experience

While your child is in the hospital

Hospitalization is a common experience for children with special health care needs. Whether this is your child's first hospitalization or one of many stays, this experience can be frightening for you, your child and your family.

There may be times during your child's hospitalization when you feel out of control; you may be unsure of what's going to happen, what procedures will be done or what is wrong with your child. By becoming knowledgeable about the hospital environment, the daily routines, and by asking questions, you may feel better able to deal with the situation and more in control. You will also be able to support your child more confidently.

Who is available to answer my questions? What kind of help can they provide?

There are many professionals in a hospital available to help you during your child's stay. They can provide you with information and support. Remember that they all want to try to make your child's hospital stay as smooth as possible. They also want to help you plan for when your child is ready to leave the hospital.

The following people and departments are available to help you. Some of these people are readily available close to where your child is, while others you may have to ask for and go to offices in other parts of the hospital.

Try to be clear and concise when you approach staff with questions or concerns. It may be helpful to keep a written list of questions. If possible, try to propose solutions or alternatives. If you feel uncomfortable about anything, don't be afraid to ask for more information or options.

Your child's doctor(s): A child with special health needs will usually have a health care team that is made up of different people. In addition to your child's "attending" or main physician, specialists may be called in to help understand and manage a particular problem. In a teaching hospital, your child's team will also consist of an intern and a resident, often called "housestaff." The housestaff are supervised by your child's physician. At night and during the weekend, there are also other doctors on the team who will care for your child.

Your child's doctors on the team work together as a team and you can ask any of them questions. However, your child's attending physician and housestaff team coordinate your child's care and will know your child's needs best. Because you see so many different faces while your child is in the hospital, make sure they tell you their name and how they help with your child's care.

Doctors make daily visits (rounds) to see all of their patients. Most days, it will be possible to talk a short time with the doctor about how things are going, but you may also want to talk longer about your concerns. It may be appropriate to ask your doctor for an appointment to discuss how your child is doing and what information s/he has learned from your child's hospitalization. If your child is in the hospital for a long period of time, you may want to set up specific meeting times with the doctor two or three times a week.

Let your physician know you want to be informed about your child's care: the purpose of any tests, procedures, medications, side effects and risks. Remember, you can always ask for second opinions or question your child's doctors about any concerns you have or things you don't understand. You have the right to change or refuse a treatment plan or procedure for your child.

Your child's nurse(s): Depending on the hospital, your child may have nurses who are assigned primarily to him/her. The nurses work as part of a health team who provide your child's care, teach you how to care for your child and help explain what is happening. Any of your child's nurses can answer your questions or can set up time for you to talk more with your child's doctor. If you have any further problems or questions, you can ask to speak to the nurse manager or head nurse.

Social worker: Social workers provide support to patients and families through the following types of services: assessments of a child's or family's needs, referrals, supportive counseling, and locating appropriate in-hospital, community and financial resources. Social workers are often available at any time during your child's hospital stay, including on an emergency basis during evenings and weekends. They can have an active role in discharge planning as well. (See *Leaving the Hospital*)

Discharge planner: Discharge planners are a team of nurses, social workers or other staff who help the health care team plan for your child's follow-up care after s/he leaves the hospital. They help create a smooth transition to health caregivers in the community. The discharge planner works with the family and the health care team to identify specific needs and goals for your child's care. S/he may also assist your child's health caregivers in the community with coordinating any related services your child needs. Ask to speak to the discharge planner early on. (Also see *Leaving the Hospital*)

Child-life specialist/Patient Activities Department: Child-life specialists, also called activity therapists, help a child cope with hospitalization and illness through the use of play and other related activities. They have training and experience in child growth and development and work closely with the medical, nursing and other hospital staff.

Education tutor: Some hospitals have educational tutoring programs, usually coordinated with the child's school. This service may be run by the Patient Activities Department.

Patient Relations Department: Helps families with any special questions, unmet needs, problems or special concerns during regular working hours. They will also have copies of your hospital's or state's patient bill of rights. After-hours and on weekends an administrative staff person is available from the department to deal with a family's immediate concerns. Ask at the reception/information desk, call the hospital page operator or ask a hospital staff member how to contact this department.

Reception/Information desk: Has information on public transportation, nearby housing, restaurants, banks, places of worship, local recreational activities and sights, other non-medical services, and can help locate lost articles.

Pastoral care staff: Provide religious and spiritual support for children and their families.

What resources are available to me and my child?

Hospitals provide a variety of resources to help you and to ease your child's stay in the hospital. Some hospitals have a parent information booklet available or post other services on bulletin boards or in elevators throughout the hospital. Resources may include:

- meal tickets
- parking vouchers
- lending libraries
- in-hospital parent and sibling support groups and/or referrals to community groups
- parent information center
- activities for child and siblings/playroom
- interpreter services
- religious services/counseling
- educational tutoring
- volunteer services
- supportive counseling
- check cashing
- lodging and/or short-term housing for parents while your child is in the hospital
- information on blood donation
- laundry and cooking facilities
- gift shop
- sibling care

How can I help my child cope if s/he is hospitalized a lot?

If you know ahead of time, you may want to plan for your child's hospital admission by using age-appropriate books and videos. Check with Nursing, the Patient Activities Department or the Admissions office in the hospital for pre-admission programs, which help prepare children of all ages for their hospital stay. Within the hospital, the Patient Activities Department (described on the previous page) is available to help children with illness and hospital stays. Below are some suggestions that you can do as a parent.

- Ask whether you can stay with your child in his/her room. Almost all hospitals have services or accommodations to allow for this.

- Keep your child's habits and routines as normal as possible. Make a poster of his/her routine and keep it in the room. Some routines you may want to think about are:
  - bedtime, awake/sleep patterns
  - amount/type of TV allowed
  - personal care: brushing teeth, washing up, etc.
  - procedures, like catheterization, s/he normally does
  - school studies

- Give your child familiar objects and reminders of home. This could include:
  - photo album of family, friends and pets
  - tape recording of stories or music
  - toys or stuffed animals
  - pajamas
  - school books and work

- Ask to have non-routine procedures that might be uncomfortable or painful done in a treatment room, rather than in your child's room. Procedures should never be done in the playroom.

- If you want to be with your child for any tests or procedures, let the doctors and nurses know ahead of time.

- Depending on your child's age, ask the doctor, nurse or child-life therapist to use a doll to act out tests or procedures before the real thing.

- If your child has difficulty speaking, make the nurses aware of how your child communicates (e.g., sign language, communication board).

- Consider how best to limit visits by friends and relatives so your child receives important emotional support but does not tire out.

- After you leave the hospital you may want to send a thank-you note or letter describing your experiences there. Hospital staff also enjoy receiving a picture of your child. This can strengthen relationships with your child's caregivers and acknowledges them for a job well done. It is also an opportunity to give helpful advice for improvements. This will help improve care for others in the future. Your relationship with the hospital staff is important, especially if your child returns to the same hospital.

Do I have to answer all of the questions from staff about my family? How do I know what I say will remain private?

Staff ask questions to decide how your family's situation relates to your child's overall health status. They want to figure out the reasons for the illness and what will help the most in treating it. They also want to look for resources in the hospital and community that would help. If you feel uncomfortable with a particular question, ask why it is being asked or let the person know you feel it is a personal question. Keep in mind that hospital staff do not always know how comfortable a family is in answering certain types of questions.

Any member of your child's health care team, including a social worker or other mental health professional, can share information with other medical staff or write it in your child's medical record. However, the information shared between hospital professionals and a patient or family is considered confidential and private and cannot be released to outside agencies or people without your signed consent. You can always ask to read the records yourself. The only exception, per state law, is that health professionals have to break confidentiality or privacy in the case of suspected child abuse or neglect or if the person is a serious danger to him/herself or other people.

If you have concerns about whether information will remain private, contact a social worker, a nurse manager or legal staff in the hospital about your rights or your state's laws. In addition, you can also ask for a copy of the hospital's patient bill of rights.

Leaving The Hospital

Discharge Planning/Continuing Care is a hospital department usually staffed by professionals who know community health resources. In some hospitals, your child's main nurse may do the discharge planning if the hospital does not have a separate staff for this service. The main goals of discharge are:

- to help the health care team plan for your child's health care and follow-up after your child leaves the hospital
- to make sure that the right community services are in place to help your family care for your child.

Some of the things a discharge planner does are:

- teaches or gives information about continuing care to patients, families, primary nurses, doctors, social workers, and other health care team members
- helps health team members outline and set up all the health services your child needs in the community
- helps to find special services in summer camps, school systems, and other community agencies.

What do I do now? What do I need to know before I leave the hospital?

Discharge planning should begin the day your child is admitted into the hospital. You should ask to meet the person who will work with you while developing your child's discharge plan. This person sometimes works with social workers and other hospital staff.

Try to get a copy of your child's discharge plan as early as possible so you can give your ideas and ask questions. If there is important information in the discharge plan that you'd like to add, ask your doctor or nurse to add it. You can ask for a translation of the plan into your primary language. You should also ask that the discharge plan be mailed to your child's pediatrician, school or other provider. While discharge plans may be different from hospital to hospital, they should include the following:

- your child's diagnosis
- special care instructions, including:
  - detailed instructions for any procedures that will be performed at home
  - medication and dosage levels
  - activity or diet restrictions
  - equipment, supplies or monitoring devices needed at home
  - physical or other changes that need to be made to your home (i.e. ramp, additional electrical outlets, etc.)
- what are considered health emergencies and what to do
- how long your child needs to recover from the illness
- who to call after working hours
- doctor's and primary nurse's telephone numbers at the hospital
- appointment times for follow-up visits with doctors and other health professionals involved in your child's care
- referrals to necessary nursing agencies, respite agencies, equipment vendors and/or community providers, with names and phone numbers of contact people
- referrals to Early Intervention services if necessary.

Are there other questions I should ask before I leave the hospital?

Here is a checklist of information you may want to get before you leave the hospital:

☐ How will I be billed? What information do I need for the insurance company for reimbursement or approval of equipment and services?

☐ What resources at the state level, e.g. Women, Infants and Children Program (WIC), Supplemental Security Income or Medicaid, might I be eligible for? (also see *Chapter 4: Financing health care*)

☐ How far in advance do I need my child's equipment set up at home?

☐ What prescriptions or doctor's orders does my child need for school?

☐ Have I given my written permission to have the hospital medical records department send my child's medical information to my child's pediatrician, school nurse or home care agency?

☐ What services can be performed by my local pediatrician and what services need specialty care at a hospital? Who will contact my child's primary care physician and when should the first appointment be?

☐ Is there information about parent support groups, advocacy groups or other families with children with similar medical needs that I can talk to?

☐ Who in the community should be notified of my child's condition/hospitalization? How far in advance?

☐ Are there any special directions, i.e. regarding physical therapy or dietary needs, that my child's school program needs to be made aware of?

☐ Can my child be cared for by a babysitter? A regular child care program?

CHAPTER 2

After Hospitalization: Common Questions

In the hospital and at home, you will always take an active role in your child's care. During hospitalization, you may have initially felt overwhelmed and wanted hospital staff to assist with any necessary arrangements and decisions. At home, you will assume more responsibility in the coordination of your child's care. In consultation with health professionals, you will act as the final authority regarding your child's care. This change may help you feel more comfortable and more in control again.

Who can help provide care and services for my child? Who will help to coordinate these services?

Because your child has special health needs, s/he will probably require care and services from a number of different community providers. Working as a team is important to your child's care and, as the parent, you may have to act as the central coordinator and advocate for your child's needs. The following is a list of some of the community providers who can participate in your child's care and help you coordinate the services your child receives.

Your **local pediatrician** will provide most of your child's medical care and can help act as the central coordinator for all of your child's care. This would include: directing you to other community resources, keeping up-to-date on any hospitalizations or other changes, referring to specialists when appropriate, and helping coordinate your child's medical care in school. (Also see *role of local pediatrician* in this chapter.)

Your child's **hospital** can refer you to different agencies or pediatricians and help you access additional resources even after your child has left the hospital. (See *Leaving the hospital* section in the previous chapter.)

Home care or visiting nurse agency can provide home and nursing care for your child. Most agencies will assign a case manager to your family who will coordinate the services provided by that agency with other services your child receives.

School systems have staff, like school nurses, educators, and social workers, who can provide services for your child (see *Chapter 6: Education*).

Your **state mental health, mental retardation agency, welfare office, or state health department (division of special health care needs)** may have case managers who can answer questions and help you coordinate your child's care at home, in the hospital and at school. Not all states have case managers and their roles may vary from state to state.

Parent-to-parent organizations or parent groups, such as those listed in the *Appendix*, have information on community resources, advocacy services and educational programs.

Local handicapped affairs commission can assist people with disabilities on issues of vocational rehabilitation, independent living, employment, housing, transportation, equal access and architectural access.

Private insurance companies often have case managers to assist families with complex medical needs. You may have to ask for this service.

How can I encourage communication among my child's providers?

- Your child's local pediatrician can play a large role in encouraging and supervising communication among your child's various caregivers. (See *role of local pediatrician.*)
- Keep a notebook of all your child's doctor appointments, medications, signed consent forms, admission forms and any other documentation.
- Keep your own copy of your child's medical records so you have quick access to everything that a new provider will ask to see.
- Consider having a notebook or "communication book" in your home so that home care, home nursing, respite care or school caregivers can leave notes for each other. Leave copies of any reports about your child that you receive in this book.
- Discuss your situation with the coordinator or case manager at your home care company, who may also assist in coordinating services from different agencies or providers.

What is an advocate? Who can help me in advocating for my child's needs?

An advocate is someone who can listen to your problems and ideas and help you find solutions or make decisions. An advocate can be someone who helps you: through an application process, obtain financing for a piece of equipment, or resolve disagreements on school issues. They can brainstorm with you about possible ways to solve a problem or get a needed service. They can also help you choose the right language to use when talking to your insurance provider about home, nursing and respite care. You will need to list your needs clearly and give the advocate as much information as possible.

The following is a partial list of people or agencies who can act as a resource or provide advocacy services:

- another parent who has developed skills in advocating for children
- parent advocacy organizations or parent support groups (see *Appendix*)
- state health department
- state department of education
- state mental health/mental retardation services
- local city and town handicapped commissions (also called Coalitions for Citizens with Disabilities)
- national or state bar association, generally located in state capital city. Ask for any firms that give low cost or free legal help or firms that specialize in services for individuals with disabilities.

While other professionals and parents can act as an advocate for your family at different times, as the parent you are often the main advocate for your child. While this may seem like an overwhelming responsibility, it is helpful to remember that a lot of what you learn in the process of advocating for your child can be useful for yourself or other family members when dealing with health care providers about a wide variety of family issues.

What should be the role of my local pediatrician?

Your local pediatrician should be willing and comfortable providing care for a child with multiple and complicated needs. The ideal situation is one in which the local pediatrician helps with case management or acts as a "quarterback" in coordinating and organizing your child's medical care. Do not be surprised if the doctor needs to learn with you about your child's illness and the management plans and routines used in the hospital, especially if your child has an uncommon condition. Once familiar with your child's diagnosis and management plan, your pediatrician can:

- help with both acute and chronic problems
- keep up-to-date when your child goes into the hospital
- perform routine well-child care
- help arrange for home care or nursing coverage
- act as back-up for questions from home care agencies and schools
- make referrals to Early Intervention and other services
- review Health Care Plans and/or instructions for care in school
- participate in your child's Individual Education Plan meeting (see *Chapter 6: Education*) if s/he receives special education services
- work with you on applications for appropriate health insurance waivers and SSI benefits (see Public Program Questions in *Chapter 4: Financing health care*).

How do I handle emergencies at home?

- Ask hospital staff, pediatrician or other caregivers, what emergencies might happen at home.
- Make sure you and other caregivers, including family members, have first aid and CPR training and instructions on what to do in case of an emergency.
- Have the phone number of Emergency Medical Technician(s) and an ambulance company posted in your home. Make insurance information easily available in case of an emergency hospitalization.
- Post your home address next to the phone for your child's caregivers, in case they need to call an ambulance or EMT.
- Mark emergency equipment in your house. Make sure you, your child (when appropriate), and your child's caregivers are trained in how to use it.
- Prepare a list of your child's condition, medications, names and telephone numbers of doctors and specialists that can be given to EMTs and emergency room staff.
- Call your local emergency vehicle or fire department before an emergency happens. Many agencies keep records of known high-risk individuals so they can anticipate their needs, prevent delays, and send appropriate personnel.
  - Make sure they have the right equipment, e.g. child oxygen mask.
  - Give them a map to your house, an updated brief medical history of your child's condition, and your child's normal range of vital signs.
  - Your child's discharge planner or home care company can also tell you what information you should give to rescue people.
- Contact your local gas, electric and water companies if your child depends on equipment or if the air temperature and quality is important to his/her health.
  - Some companies will put you first on the list for quicker return of power or snow removal.
  - Your child's discharge planner, pediatrician or equipment provider can help you to write a letter regarding your child's needs.
- Have a practice run, imitating an emergency; do a practice drill at least once a month.

CHAPTER 3 Home Care, Home Nursing and Respite Care

During your child's hospital stay, the discharge planning team, along with your physician, will discuss with you the need for home , nursing or respite care. In making the decision to use these services, your child's specific health care needs will be considered as well as your family's abilities to care for your child. Some parents want to do most of the care alone or with other family members helping out, while other parents want more assistance from outside agencies. In some cases, your child may require skilled nursing care. Or there may be times when you need someone to temporarily take over the care of your child and give you a break or "respite." These types of services may overlap and you will need to see what your family needs to preserve home life to the fullest extent. Be open to allowing others to assist you in the care of your child. Remember, your goal is to be involved in your child's care AND to try to take good care of yourself and the rest of the family.

Definitions

What is the difference between home health care, home nursing and respite care?

Home Health Care: Home health care assists with daily life activities and health care in your home. The goal of home health care is to provide these services so that an individual with special health needs can reach his/her full potential. Home health caregivers can be: nurses, occupational or physical therapists, social workers, home health aides, homemakers, or personal care attendants. Home nursing services are one part of home health care.

Home Nursing Care: Home nursing care is skilled care that can only be provided by a licensed nurse, either an RN or LPN. This care can be provided in two forms by a home care agency:

- **Intermittent Skilled Visit** is a brief home visit by a nurse to provide teaching and support, and to perform a skilled procedure(s) or provide a specific therapy.
- **Shift Nursing,** also known as **private duty** or **block nursing,** provides direct nursing care for a "shift" that usually ranges from 4 to 12 hours, depending on the family's needs. Shift nursing is often evaluated on a regular basis. To qualify for shift nursing, there must be a regular need for skilled nursing. Your doctor, primary nurse or home health care coordinator will help you decide what your child's needs are and whether you might qualify for this type of home nursing care.

Respite Care: Respite care is care for a limited period of time in which a family is given a "respite" or break from child care responsibilities. Respite care can help preserve and strengthen normal family functioning, while continuing to promote the growth and development of the person with the disability or chronic illness. Respite care tries to meet both planned or emergency needs and can be provided in or out of the home. The care can be provided by a variety of people, depending on the child's needs and your state's requirements. Services and their availability vary greatly.

Common Issues and Questions

What issues do I need to be aware of when I have someone from a home care, nursing or respite care agency come into my home?

Having a caregiver in your home, while providing an important service, is an experience that sometimes brings up uncomfortable issues for a family. In the beginning, you may not want to think about problems that could arise. Here is some advice that other parents try to remember when someone gives home health care to their child.

- Don't get discouraged if your first home or respite care experience does not work out exactly as you had hoped. Families and agency staff need to work on relationships and learn each other's differences. Generally, with a little patience you should be able to find a situation that will be comfortable for your child and family.
- Know what your child's and your needs are and decide areas where you can compromise and areas where you cannot. Don't expect to anticipate everything correctly at the beginning.
- Keep in mind that there will be some decisions that you can make regarding your child's care and other decisions that require professional advice and support. Parents and caregivers need to respect each other's knowledge and expertise.
- You are the employer. You have the right to choose who will provide your child's care, and to some extent, when and how that care will be provided.
- Interview the potential caregiver(s), just as you would any other person applying for a job.
- Trust your instincts and knowledge about your child and yourself.
- You may want to limit the number of caregivers in order to provide continuity and make your child feel more comfortable.
- If you think a caregiver is too involved with your child, discuss this with the caregiver or with his/her supervisor.
- Talk to other parents about their experiences, problems and solutions.
- Provide a list of your child's likes and dislikes, typical reactions or responses, usual routines and family rules.

What questions should I ask the home care, nursing or respite agency?

☐ What services are available?

☐ How long has this agency been in business?

☐ Has this agency operated under a different name in the last five years? (This will help you when "asking around" about an agency.)

☐ Are your caregivers experienced with children? Do you employ caregivers trained in pediatric care?

☐ Are your caregivers licensed in this state? By what agency?

☐ Do you accept my insurance plan?

☐ Who will assess my child and who will determine the level of care needed?

☐ Who will be the case coordinator at the agency with whom I can talk about my child's needs?

☐ Do you already have the staff to handle my child's needs? Do they have the specific training needed for my child?

☐ Is your agency willing to add personnel to cover my child's needs?

☐ Can I interview the caregiver? Who will pay for his/her time during the interview and training? Is it OK to check his/her references?

☐ Can I obtain agency references?

☐ How will I communicate with my child's caregivers?

☐ How will scheduling be handled? Can the schedule be changed?

☐ Can I request a particular or consistent caregiver for my child or will I be sent a different caregiver every time?

☐ Will caregivers have their own transportation to my home?

☐ What do you do about back-up services?

☐ What are your policies on: transporting my child, staff policies, training, evaluation of care, supervision, and weekend coverage?

☐ Is there a specific person in the agency to help solve problems?

☐ Will your agency's caregivers work with our family's rules?

☐ Will the caregiver watch other children in our family?

☐ Can caregivers care for my child in their own homes? Overnight? Weekend? Vacations?

☐ Can I leave written instructions for the caregiver regarding my child?

☐ Can I cancel services?

☐ Can the caregiver take my child to doctors appointments and school?

What should I do when a new caregiver first comes into my home?

With a new staff person, you may want to suggest talking with them after one or two weeks to discuss your child's care. By scheduling regular meetings, you will be able to evaluate how the care is going. Once you are comfortable with the caregiver, you may choose to meet every four to six weeks.

How do I discuss problems or concerns with caregivers?

There is no set way to handle conflicts with caregivers. Some parents prefer to sit down and discuss problems directly with the caregiver. Other parents prefer to talk to the supervisor at the agency. You may ask the agency to send you a new caregiver if you feel the problem cannot be resolved. You will have to think about your own situation and do what is best for you.

How do agencies get my child's medical records?

The agency will need to have your written permission before they can obtain your child's records from the hospital or physician. However, if you keep your own up-to-date records or notebook, you can share this information with providers.

Home Care / Home Nursing

Arrangements for home health care are usually made by the discharge planning department before your child leaves the hospital, but some families may decide they need home care after their child has been out of the hospital for a while. The following section can help you list questions you may want to ask the home care agency. If you have any questions about your child's health needs, ask your pediatrician or specialists at his/her hospital.

Will home health care agencies accept my child's insurance plan?

Home care agencies generally accept funding from private insurance, HMOs and public programs like Medicare and Medicaid. Special programs or insurance, e.g. disability or car insurance, may also cover home health care services if related to the child's injury. After assessing your child's health needs, most home health agencies will ask your insurance provider for approval for their services. You may want to double-check with your insurance provider as well.

What should I look for in an agency? What can I expect?

- Expect 24-hour access to a nursing supervisor in case of questions or problems.

- See if the agency's personnel match your child's specific needs.
- Look at the qualifications and training of the caregivers.
- The agency should have names of families, professionals and/or hospitals they have worked with, with whom you can speak.
- Ask if the agency has a clearly-defined pediatric program. Ask for specifics, written materials or policies.
- The agency should develop a nursing care plan for your child. The plan should be reviewed and discussed with your family. Reconsider an agency that does not allow or ask for your input.
- It is your choice to compare different nursing agencies.

What questions should I ask the home care agency?

☐ Is your agency certified, accredited, or licensed by the state health department and/or licensed by the state?

☐ Will you visit my child in the hospital to learn specific procedures or physician's orders before s/he is discharged?

☐ What are your policies on documentation of care and nursing care plans?

☐ Is there a primary nurse who will be responsible for my child?

☐ Can I ask for more information to be documented in the nursing notes?

☐ Will you provide for and coordinate my child's equipment needs or do I have to seek an outside equipment vendor? If necessary, can you refer me to an equipment vendor?

☐ Will all or most of related services, like nursing, physical or occupational therapy, be coordinated through your one agency?

☐ What other kind of specialty programs and other non-medical supportive services do you offer? (For example, home care agencies may offer any of the following: case management, respite care, transportation programs, separate departments for specific technologies, medical equipment and supplies, support groups or referrals, therapies, emergency planning assistance, social services, nutrition services, personal care, homemaking services and child care.)

☐ Are you willing to act as "co-vendors" (i.e. use nurses from another agency) with another home care agency if you are unable to cover all of the hours needed for my child's care? Who will be in charge if that happens?

☐ Will home care agency staff assist with my child's transition to school?

☐ Are caregivers CPR trained?

Respite Care

How do I get respite care?

Visiting nurse associations, home care agencies, or individuals may provide respite care. You may also find some limited respite opportunities through charitable or civic organizations, like United Cerebral Palsy Association or the Association for Retarded Citizens. For information about respite care and its eligibility requirements in your state, ask:

- hospital discharge planner
- case manager or social worker from your state health department or mental health/retardation services
- advocate
- social worker in the hospital.

Who Pays For It?

Respite care may be paid by:

- state mental health/retardation services
- state health department
- state social services department/agency
- state developmental disabilities council
- state program for children with special health care needs
- insurance provider
- charitable or civic organizations.

You may want to ask an advocate, social worker or case manager regarding the kind of language you should use when talking to your insurance plan about respite care. Sometimes an insurance provider may try to say respite care is "babysitting" and that it is not a benefit they will pay for. It may help to tell your insurance provider that even though you are trained in your child's care, you cannot be expected to provide it 24 hours a day.

How much respite care am I entitled to?

How much time your family qualifies for will depend on your child's individual needs and may be decided by your insurance provider or state agency. You should ask the respite care provider, an advocate, case manager or social worker for more information.

Who can act as a respite care provider?

The term "respite caregiver" can mean a variety of people. Depending on your state and your child's needs, anyone from a registered nurse to friends and neighbors can act as a respite caregiver. Some states have training programs for respite providers. These training programs may not always be required in order for someone to act as a respite caregiver, but having a trained respite caregiver may make it easier for you to be reimbursed by your insurance provider. You should first check with your insurance provider about the payment process. Ask your state health department, respite provider or home care agency for the rules in your state.

What questions should I remember to ask about respite care?

☐ Is there certain language I need to use when asking my insurance provider to pay for respite care? Will I have to pay some of the cost?

☐ What kind of training do the respite caregivers have?

☐ Can I get respite care for the weekend? Vacations?

☐ How do I get emergency respite care?

☐ Can I use my respite hours so that I can go to work?

☐ Will the respite caregiver write down my child's daily activities?

☐ Does my child need short- or long-term care?

☐ If the care is provided out of my home, who will be responsible for the care and safety of my child?

CHAPTER 4 Financing Health Care

This chapter attempts to address some of the most common questions you might have about financing issues and gives you an overview of some of the public assistance programs that exist.* Because of the complexity and differences in state laws, public programs, and insurance company policies, most specific questions and answers will require you to get a copy of your insurance policy and/or public assistance program benefits. Read these through and go over any questions you have with your employee benefits manager, insurance plan representative, primary physician, case manager or parent support group.

Paying For Care and Services

Who can help me identify the financial services for which my child may be eligible?

- social service department in the hospital
- programs for children with special health care needs within the state health department
- pediatrician, specialists or other health caregivers
- advocacy groups, parent support groups or disability organizations
- child's school, specifically the school nurse, special education director, or principal
- state insurance commissioner's office, regarding high-risk pools for the uninsured
- employee's benefits or personnel office
- insurance company's member services
- civic or charitable organizations
- home health agency and supply company
- local Social Security office
- department of human services, social services or welfare office
- state health department, state mental health services
- state department of education

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* In this booklet, we use the term insurance provider to mean both private insurance companies/plans, including Health Maintenance Organizations (HMO) and Preferred Physician Organizations (PPO), and public programs, like Medicaid, unless otherwise indicated.

Can I get someone to pay for 24-hour nursing care?

This will depend on your insurance plan and the needs of your child. Twenty-four-hour nursing care is usually covered if your child needs highly skilled nursing care. Oftentimes, full-day nursing care will only be covered in place of hospitalization. Talk to your child's doctor if you are concerned about getting round the clock care and s/he may be able to work with your insurance provider. Your hospital discharge planning team may also help you in obtaining this type of care.

How can I get supplemental or non-medical services and equipment covered, such as transportation costs, special clothes or adaptive toys?

Since your insurance provider may not cover some of these types of services or costs, you will need to be creative. You may get a variety of agencies to pay for a small part of the cost. Below is a partial list of agencies you can approach about your needs.

- public programs, such as Medicaid, and state programs for children with special health needs
- private insurance
- private charities
- churches
- "wish" groups
- philanthropic/civic organizations, like Muscular Dystrophy Association or Lions Club

What happens when my child becomes an adult? Who will pay for needed services?

While most insurance and public program benefits end by the time a person turns 22, there are some provisions for people who have been disabled since childhood.

- Under a 1986 federal law called COBRA, anyone who works for a company that offers health insurance as a benefit and which has 20 or more employees (regardless of how many of those employees are covered under the company's group plan) must offer you the right to:
  - purchase coverage for you and your family for a limited period of time when you stop working for that employer
  - purchase coverage with no pre-existing condition exclusion for your children who are no longer considered dependents.

In either case, the family or adult child will have to pay the full amount of the plan.

- Your adult child may be able to remain on your policy as a handicapped dependent. In several states, there are mandates to extend coverage to a dependent child, so long as they continue to be disabled. Check with your employer for further information.
- Many children with disabilities become or remain eligible for Social Security benefits (see *Public program questions*) after their 18th birthday, even if s/he has a job.
- If your adult child works, s/he may be able to deduct work-related expenses from his/her total income and continue to be eligible for public program benefits.
- Your adult child may also be able to save some of his/her income, benefits or other assets for a specific work-related goal by developing a Plan for Achieving Self-Support (PASS) (see *Glossary*).
- Your adult child may continue to be eligible for Medicaid coverage even if s/he has a job and/or is no longer eligible for Supplemental Security Income (SSI) payments (see *Public program questions*).

An adult child or their parent should contact his/her employer, vocational counselor, local Social Security or Medicaid office for more information and eligibility requirements.

What do we do if we have trouble paying bills?

With children who have special health needs, care often comes first and how to pay for that care comes afterward. Because your child's needs may be complex and ongoing, it is important to discuss these difficulties before a crisis occurs. Here are some helpful hints to remember when you plan for costs and for when you need immediate help.

- Work closely with your care providers and case manager to avoid or anticipate high-cost services if possible.
- Work closely with your employer's benefits representative to try and change your benefits so that services and equipment needs will be covered.
- Be aware that there are tax breaks and exemptions that you may be eligible for as a parent of a child with a disability. Contact your local Internal Revenue Service Bureau for more information.

If your child does not have insurance or you have trouble paying bills:

- Discuss your concerns with the caregiver as soon as you think you have a financial problem.
- Arrange with the institution, agency or provider to pay at least a part of the bill each month. Often, providers and creditors will accept this as an attempt to meet your obligations and will not take further action.
- During emergency periods, bills can sometimes be negotiated.
- Ask the provider whether a sliding-fee scale or special payment arrangement can be made. Some hospitals have pools of "free care" money for patients who cannot meet their bills.

Private Insurance Questions

Are insurance benefits negotiable? How do I know if I'm getting the right amount of benefits?

- Talk to your providers, your insurance customer service department, your employee benefits office, or public program benefits office if you have questions.
- Many services for children with complex health care needs are considered "extended benefits" or are under "individual case management" and are subject to an approval process.
- You can appeal your insurance provider's decision. Sometimes services or equipment are funded "on exception," after you demonstrate that a service or item is essential to your child's well-being or is more cost-effective.
- For additional information or advice about what language to use to avoid rejection or delays, you may want to contact your:
  - case manager
  - advocate or parent group
  - home care agency.

What do I do if I am rejected for a program, benefit or insurance plan?

"No" often really means ask someone else, that the information was not presented well or was not understood.

- Find out what the appeal process is.
- Ask, in writing, for an appeal.
- You may need to change the language you use, explain your needs better or justify to the insurance provider why a service or item is essential to your child's well-being.
- Stick with the process because many families receive approval after several appeal rounds.
- The following are some of the people who may be able to help you with negotiating with your insurance company:
  - advocate
  - parent group
  - pediatrician (for a letter of medical necessity)
  - hospital
  - family member.

Should I purchase a supplemental insurance policy?

It is very difficult to purchase health insurance outside of a group plan. If you try to purchase more than one policy, it is important to determine the following:

- Will the services you need actually be covered?
- Does the supplemental plan duplicate your existing coverage?
- Does the supplemental plan pay you for your child's hospitalization or does it directly reimburse the hospital and other providers for their services?

What do I do if my employer switches insurance companies?

You should meet with your employee benefits representative to determine if you will be subject to any waiting periods or pre-existing condition exclusions. Compare the benefits between the old and the new policy. Look at any cost-sharing requirements or limitations regarding who you can use as a provider. If you do not use a plan's participating providers, you may be liable for a greater share of the costs. In some instances, reimbursement will not be allowed, unless approved in advance.

Each year you should refamiliarize yourself with your health insurance coverage. Make your employer aware of your current contract and how the change will affect the child. Some employers can buy an option for the insurance company to obtain other services. Employers can negotiate with their insurance provider, but they do not have to.

Public Program Questions

What are the public programs and benefits my child might be eligible for?

There are a number of federal, state and local public programs for families with children with special health needs. You can find out about these programs by looking in the Yellow Pages under health care, by contacting your state's program for children with special health care needs, or through a social worker or case manager. Because eligibility requirements vary, consult the relevant state program for more information. The following is a listing of several major public programs.

Title V Programs for Children with Special Health Care Needs (CSHCN): These public programs, formerly called Crippled Children's Service Programs, are most often available in state health departments. Most state CSHCN programs offer services such as evaluation, case management, and some inpatient and outpatient care services for children with special needs. Check with your state health department for more information, eligibility requirements and for other public and private resources for children with special health needs.

Supplemental Security Income Program (SSI): SSI is a cash assistance program that pays benefits to children with disabilities under age 18 whose families have limited income or resources.

To qualify for SSI your child must meet the definition of disabled. Either a person's condition must be one of the conditions recognized by SSI or the person must have a physical or mental impairment that prevents him/her from doing "substantial" work for at least a year or that is expected to result in his or her death. A child will generally be considered disabled if s/he has a physical or mental impairment of comparable severity, and is unable to function independently in an age-appropriate manner or perform major activities of daily living, e.g. attending school.

Due to a recent Supreme Court decision, many more children are now eligible for benefits through a broadening of the list of recognized conditions and definitions of financial status. Your local Social Security office, your child's doctors or hospital, and the resources listed in the *Appendix* can help you determine if your child meets the definition and other eligibility requirements.

The whole application and approval process can be very lengthy. But if your child does not qualify as disabled at first, you should consider appealing the decision. Many people are approved during the appeal process and receive benefits that go back to the initial date of their application. In most states, children who receive SSI benefits also qualify for Medicaid coverage. In many states, this coverage comes automatically when SSI eligibility requirements are met.

Social Security Disability Benefits (SSDI): Ordinarily, any child under age 18 can receive payments if s/he receives Social Security survivors benefits or is the son or daughter of someone receiving Social Security retirement or disability benefits. If a child has a disability that began prior to age 22, s/he can continue receiving these benefits well into his/her adult years. This is called "disabled adult child's benefits." A disabled child, upon turning 18, can also become eligible for payments if s/he has earned the minimum number of work credit hours.

Medicaid: Medicaid is a joint federal and state funded health insurance program for people with low incomes and for disabled people with limited assets. In all but 14 states, you can also be eligible for Medicaid if you spend a certain percentage of your income and/or assets on medical expenses. Check with your state Medicaid or local welfare office for eligibility requirements and a complete list of Medicaid benefits.

Medicaid services include, but are not limited to:

- home nursing services
- inpatient and outpatient hospital services
- laboratory and x-ray services
- physician and nurse midwife services
- clinic services
- preventive care or Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) services for individuals under age 21
- family planning and pregnancy services.

Medicaid Waivers: In many states, there is also a special Medicaid program for families who may not qualify for Medicaid due to their income and assets. This Medicaid waiver will pay for home health services for children with care needs so complex that they would be eligible for institutional hospital, rehabilitation or nursing home care. You should check with your state Medicaid office for more information.

Medicare: Medicare is a federal health insurance program for people 65 years and older and for people who have been entitled to Social Security Disability Benefits (SSDI) for 2 years. The Medicare program also covers children with chronic renal disease who need a kidney transplant or dialysis.

State High Risk Pools: In some states, risk pools have been formed to insure people who are unable to qualify for regular insurance due to pre-existing conditions. Information about availability can be obtained from your state's insurance commissioner's office.

Hospital Hill-Burton Fund Programs: Under the Hill-Burton Act, hospitals and other health service organizations can apply for limited funds to build and modernize facilities. In exchange, the health care provider is required to provide free care or care at a reduced cost for people with limited incomes. To find out if a particular health care provider has received any funds under this act, call (800) 638-0742.

What do we do while we are waiting to become eligible for a public program?

Make sure you apply for retroactive benefits when available. Most public benefits are retroactive to the date of your initial application. If you paid your bills during the retroactive coverage period, your doctor can apply for Medicaid payment and reimburse you. In some cases, as with SSI, immediate payments are made if the child's condition is so severe that s/he is presumed to be disabled. You should consult with your local Social Security or Medicaid office, state health department or state program for children with special health needs for more details.

Will I have trouble finding providers who will accept public programs like Medicaid? Will the quality of care be the same?

Check with your regular provider to see if they accept Medicaid. If problems arise, check with your state Medicaid office or hospital for referrals to providers who accept Medicaid. Just as you would with any other health care provider, you will have to evaluate the quality of care that a Medicaid provider offers. Keep in mind that most health providers serve both Medicaid and privately insured people.

What other questions should I ask when I apply for insurance or a public program?

☐ Do you have a brochure or written handout about the program?
☐ How do I apply?
☐ What information do I need for the application process?
☐ What services/equipment will be covered?
☐ Is there a co-payment?
☐ How long will it be before coverage begins?
☐ Are there any circumstances that would change our eligibility?
☐ How will my existing insurance coverage be affected by this plan?

CHAPTER 5 Equipment

Many children with special health care needs use special equipment for many months or years. Families can usually learn to manage this equipment, even though the idea may seem overwhelming at first. After discharge, your child's equipment needs may be taken care of by the home care agency or a separate equipment vendor. As you go along, other parents and professionals may give you advice or suggestions about other systems or a particular product or brand. You should feel free to discuss these questions and any other concerns with your equipment supplier or a member of your child's health care team.

How do I learn about my child's equipment?

Learning about the equipment should begin early on in your child's hospital stay. As soon as your child has a discharge date, the appropriate equipment will be determined and should be ordered and set up before your child leaves the hospital. You and your child's discharge planner should set up home training dates; usually the home care agency or equipment vendor will do the actual training. Training should be done on the same type of equipment that you will be using.

By the time your child leaves the hospital, all the equipment should be in proper working order and you should be comfortable with how it works. It is helpful to ask that your child be discharged from the hospital early in the day so that you have plenty of time to get your child and his/her equipment settled upon returning home.

What are my responsibilities regarding my child's equipment? What are the equipment supplier's responsibilities?

Parent:

- checks each equipment delivery for proper product, size and amount
- keeps a list of all supplies with item or order number
- checks supply levels weekly and orders supplies in advance
- does basic, routine cleaning and informs the supplier of any maintenance problems, whether the equipment is rented or purchased
- sends in the warranty information if you own your equipment
- if lives in a rural area, requests backup equipment for emergencies.

Equipment Supplier:

- delivers, installs and checks the operation of any new equipment
- demonstrates and teaches proper care, maintenance and operation
- leaves instructions for care and cleaning
- has a staffed 24-hour service number
- provides backup equipment while the regular equipment is being repaired
- services rental equipment to factory standards
- may have professional staff available for training, information and questions.

Who will pay for my child's equipment at home?

Possible sources for payment are:

- private insurance companies, including HMOs
- Medicaid and other public programs
- parent's co-payments
- community, civic and religious groups
- disability organizations.

What are the advantages and disadvantages of renting versus owning equipment?

Advantages of renting:

- equipment supplier will maintain, repair and perform major cleaning of equipment, though there may be a charge for these services
- easier to change to the most up-to-date equipment
- your child's need for the equipment may only be short-term or it may be something s/he will quickly outgrow.

Advantages of purchasing:

- can be less expensive over time
- you may be able to purchase used equipment.

Sometimes, the advantages of one method over the other are not so clear. For example, in some cases, insurance companies may pay for the repair of equipment, even when it has been purchased.

More importantly, the decision to own or rent equipment may be made by your insurance provider. In some instances, you may be able to convince your insurance provider about the merits of one method over the other. Your doctor can write a letter to your insurance provider to advocate rental or purchase of certain pieces of equipment. In other cases, insurance companies may have certain guidelines they must follow.

How can I be sure the equipment is appropriate or the correct size?

Be aware of any symptoms your child has, like redness or pain and check with:

- physician
- the hospital staff or therapist
- trained personnel at your equipment company or home care agency.

What do I do in case of power outages at home?

- Notify local utility companies beforehand. Some companies will put a priority notation on your address for quicker restoration of power.
- Notify the local fire department or emergency response team about your child's equipment needs. They may provide emergency assistance and backup.
- Make sure equipment is always fully charged.
- Most fire stations have a backup generator and will allow you to recharge your child's equipment there.
- Have backup plans to transport your child to a shelter or facility with his/her equipment.
- If your child's equipment is not portable, have an alternative site planned where equipment will be available.
- Depending on your child's needs, you may want to consider buying a backup generator.
- Have a practice run.

What can be done with extra, leftover, or old equipment? Where can used equipment be found?

If possible, try to rent rather than purchase equipment that your child will quickly outgrow or that will become outdated. This allows you to exchange any obsolete or outgrown equipment. Consider donating old equipment to charities, schools or other families.

You may be able to purchase used equipment, but you should first check with your doctor about which items should not be reused. Other parents, your child's hospital or school, and the resource organizations listed in the *Appendix* may help you find equipment exchange organizations.

What questions should I ask my home care agency, equipment company or insurance provider regarding equipment?

☐ Can my child try out the equipment before I buy it? (Some companies allow a [illegible] period.)

☐ Can I p[illegible] orders over the phone?

☐ How far in advance do I need to order certain equipment/supplies?

☐ How often will you make deliveries?

☐ How do I get the equipment serviced if it breaks? Who is responsible for repairs?

☐ What do I do while a piece of equipment is out being serviced?

☐ What do I do if I have a problem with a piece of equipment in the middle of the night?

☐ What do I do about storing equipment?

☐ Do I still have to maintain and clean the equipment if it is rented? At whose cost?

☐ Is there another family whose equipment I could see or talk to regarding benefits, problems, etc.?

☐ Can this equipment be transported? Does this piece of equipment come in a portable version?

☐ What equipment and supplies will my insurance plan or public benefits cover? Does this include "durable" equipment? (see *Glossary*)

☐ What is the procedure for direct billing to my insurance provider?

☐ Do I need prior approval from my insurance provider for some equipment?

☐ Does my insurance restrict whom I can use as an equipment vendor?

☐ Are there any annual limits, caps or co-payments for equipment in my insurance policy or public benefits?

CHAPTER 6 Education

This section briefly discusses some of the federal education laws. It gives a general understanding of the laws, and is not meant to be a legal interpretation. Federal regulations are the U.S. Department of Education's interpretation and implementation of the laws passed by Congress. State departments of education further interpret the federal laws, and state legislators often pass additional state laws related to education and special education.

Your specific questions about education may require careful examination of the exact language of the laws and regulations. Local parent groups, federally-funded Parent Training and Information Projects, and other organizations listed in the *Appendix* can help you understand the federal and state legislation and your own state's interpretation.

How do I find out what my child's rights are?

By federal law, all school-age children are entitled to free educational services through public school programs. While federal education laws provide basic standards for states and towns to follow, the actual interpretation of the laws can vary greatly from state to state.

Research is the key to finding out what your child's rights are. Contact your U.S. senator or representative or the federal Department of Education and ask for a copy of any federal law(s) by name. Some of the regulations are simplified and summarized in parent guidelines, which are also available from the federal Department of Education. Copies of the federal regulations are also available for a charge by writing: Superintendent of Documents, U.S. Government Printing Office, Washington DC 20402. You should contact your state department of education for local and state regulations. Other people you can ask for more information are:

- special education director in your child's school district
- the school principal
- your child's teacher
- parent advisory council
- parent teacher association (PTA)
- coordinator of school health services
- state health department
- other parents
- advocates
- your local Congress person
- local TAPP: Technical Assistance for Parents Program (See *Appendix*)
- school committee, school board.

What types of educational placements exist?

- Public schools can provide either regular and/or special education services.
- Collaborative programs allow school districts or communities to combine their resources in order to provide special education services.
- Private settings, which can either be day programs or residential settings, may also provide regular and/or special education services.

Special Education

What are the special education laws?

The cornerstone of the federal legislation is IDEA: Individuals with Disabilities Education Act (PL 101-476), which is based upon the Education for All Handicapped Children Act (PL 94-142). A student must be enrolled in special education in order to receive the services mandated by IDEA. Students with a wide range of disabilities may be eligible for special education and related services. These disabilities include: speech impairment, severe vision and hearing problems, learning disabilities, mental retardation, emotional problems, physical disabilities and other health impairments. There is state to state variation in the way in which a child qualifies for special education services, but in general, if a child has a disability that makes it hard for him/her to obtain education without extra services, s/he is eligible for an evaluation to determine what services need to be provided.

IDEA:

- entitles school-age children, ages three to twenty-one, with disabilities to a free, appropriate public education

- provides federal funds to assist states in developing and supporting special education programs for children with disabilities

- guarantees children an education in the least restrictive environment, which means that children with disabilities should be included in educational and social programs with students without disabilities to the maximum extent possible

- says no portion of the cost of providing related services can be passed onto the parent or guardian. Related services, which help a child with a disability benefit from special education, include but are not limited to:

  - transportation
  - audiology
  - therapeutic recreation
  - school health services

  - psychological services
  - medical services for diagnosis and evaluation
  - physical therapy
  - occupational therapy
  - counseling
  - speech and language therapy
  - social work services
  - assistive technology

- mandates that every child in special education have a written plan, called an Individualized Education Plan (IEP), detailing how and which services the child will receive

- promises that decisions made regarding a student's education are fair and appropriate by:
  - allowing students and parents the right to question placement decisions of school personnel
  - establishing due process procedures for parents to settle differences with school districts.

How will my child receive special education services? How do I determine what special education services s/he may need?

If your child is already in school and you believe s/he is in need of services, you can:

- talk to the teacher and ask if your child is having any difficulties. Your child's teacher can support and assist you.
- call and then write a letter to the special education department and the principal asking for a formal evaluation to determine if your child needs special education services. This evaluation will include formal tests, observations and other information provided by you and school personnel. This evaluation must be done in your child's primary language at no cost to you. Your child's placement will be based on these evaluations and assessments. You may also use current evaluations your child has already had done.
- sign a consent form for a formal initial evaluation to take place.
- request an independent or second evaluation to get additional information; talk to the school about who will perform this outside evaluation and who will pay for it.
- arrange to have private evaluations done for your child at your own expense.
- The school may request additional information from your child's pediatrician and/or specialist to help them learn more about your child.
- your child's teacher or another school staff member may suggest that your child be evaluated. The school will need your written permission before they can do this.

What is an Individualized Education Plan (IEP)?

An IEP, required by IDEA for all special education students, is a written plan in your primary language that contains the following:

- assessments and evaluations of your child, including his/her strengths and areas for improvement
- goals and objectives for your child
- related services your child needs and projected starting and duration dates
- the instructional "plan of action" for your child
- evaluation criteria to measure your child's progress
- amount of time in the school day your child will participate in regular and/or special education
- current academic performance.

The plan is written by your child's education "team." As the parent, you are an important part of the team and should receive your own copy of your child's IEP. Any changes to the IEP or any decisions about your child's educational plans will be made by the team. The team reviews decisions regarding classification, placement, educational goals, curriculum and related services. Your child's team includes anyone who has some knowledge of your child's needs or who is aware of the services your child has received in the past. The team may consist of any of the following:

- parents
- child, when appropriate
- special education director or special education liaison
- child's current or most recent teacher
- child's future teacher
- school nurse
- child's physician
- social worker
- parent advocate
- occupational therapist
- physical therapist
- speech and language therapist
- school psychologist/counselor

The IEP is reviewed annually. You can ask to have the team meet at any time, if you feel there are changes that should be addressed. Every three years, your child should undergo new assessments and evaluations and the plan should be rewritten. Even though the local education system is responsible for providing all services that are included in the IEP, it is important to remember that this does not guarantee that your child will reach all of the goals outlined in the IEP.

What are my rights regarding an IEP? How do I make sure my goals and objectives for my child are included? Can I refuse to sign the IEP?

- You are part of the team and a helpful advocate for your child.
- You, and when appropriate your child, should attend all meetings about education plans.
- Give ideas for goals you think your child should work on and services you think your child should receive.
- You may refuse to accept parts or all of the IEP by not signing it if you find that the plan does not meet your child's needs.
- Explain to the school why you are rejecting parts of the plan.
- You can accept only parts of your child's IEP. The parts you accept will go into effect while you continue to discuss the parts you disagree with.
- You can bring the IEP home to review. The plan needs to be signed within 30 days to go into effect. If the plan is not signed within this time, services for your child will not begin.
- You may want to seek an advocate for additional advice and support.
- You can bring anyone you wish to the meetings (e.g. friend, lawyer, etc.).

What do I do if I have problems with my child's school district? What if we can't agree on my child's IEP?

When problems or differences first arise:

- try to negotiate with your child's team
- request an IEP review meeting
- you may want to withhold your permission for services until you and the school can reach an agreement
- negotiation and compromise will help preserve your relationship with the school district
- you do have "due process rights" guaranteed under IDEA and this is a step-by-step process. Due process rights mean you have the right to:
  - an independent evaluation paid for by the school district
  - a hearing with an impartial hearing officer
  - an administrative appeal and review of your case
  - take civil action with your local Office of Civil Rights (OCR) (see *Appendix*) [34 Code of Federal Regulations (CFR) §300.500-§300.514, 1991]
- find out how the process works where you live because each state may have specific regulations
- check into advocacy/mediation services available to help you work out differences more informally.

Planning For Your Child's Entry or Re-Entry Into School

What if my child is younger than 6 and needs educational services?

In 1986, Congress passed The Education of the Handicapped Act Amendment (PL 99-457) to address the needs of young children with disabilities. PL 99-457 consists of two parts: Title I, the so-called Part H (which addresses the child from zero through 2 years 11 months), and Title II, the extension of special education services to the 3 to 5 age group.

Title I (Part H) of PL 99-457 calls on states to coordinate Early Intervention services (EI) for infants and toddlers and to create a plan for how the services are to be implemented.

Title II of PL 99-457 extends the provisions of PL 94-142 to children aged 3 to 5. This part of the program is run by state departments of education. The educational services may be provided in small integrated groups, in separate programs or through home-based services. Eligibility requirements for different services vary greatly from state to state.

Who provides Early Intervention services?

The regulations of PL 99-457 leave it up to the individual states to decide which agency will run the program. In your state Early Intervention services may be administered by any of the following:

- state health department
- state department of education
- state social service agency
- interagency coordinating committee (see *Glossary*).

Start by calling your local elementary school or state department of education (special education office). Since they routinely receive referrals from Early Intervention, they will tell you who to call.

Who is eligible for Early Intervention services?

Check your state's eligibility requirements to receive EI services. This *may* include children with:

- established risk or disability (e.g. cerebral palsy, spina bifida)
- developmental delay (i.e. children significantly below accepted developmental norms)
- biological risk (e.g. low birth weight, prematurity)
- environmental risk (e.g. teen mother, parental substance abuse).

What services make up Early Intervention?

The services that your child may be eligible for through the Infant and Toddler Program (Part H) are:

- parent education and other educational services
- group programs
- therapeutic services, such as occupational therapy and physical therapy
- vision and hearing services
- home visits
- family support
- social service
- case management services.

Once a child is determined eligible for services under PL 99-457, an Individualized Family Services Program (IFSP) is written. Similar to the IEP for older children, this plan includes:

- assessments on the child
- assessments of the family needs
- services to be delivered
- which agency will deliver which service.

These services can be provided at home or at a separate site by a variety of professionals, including special education teachers and therapists. The IFSP is reviewed every six months. Check with your state for regulations or requirements on payment for Early Intervention services. Also, consult your insurance company or public program benefits; they may cover the cost of some of these services.

What if my child is not eligible for special education but needs special services?

Section 504 of the Rehabilitation Act of 1973 was passed to protect the civil rights of people with disabilities.

Section 504 states:

> "No qualified handicapped person* shall, on the basis of handicap, be excluded from participation in, be denied the benefits of, or otherwise be subjected to discrimination under any program or activity which receives or benefits from federal financial assistance." [34 CFR Sec. 104.4]
>
> *In a memo from the U.S. Department of Education to Regional Civil Rights Directors July 1991, they suggested that the phrase "handicapped person" should be used when citing the wording of Section 504 as the act was passed. "However, in enacting the Education of the Handicapped Act Amendments of 1990, Congress expressed a strong preference for emphasis on the individual, as in, 'individual with disabilities,' 'child with handicaps,' 'students with disabilities,'... and so forth."

- Section 504 also states that a free, appropriate public education be provided to each qualified handicapped child regardless of the severity of the person's handicap. [34 CFR Sec. 104.33 b(1)]
- Most importantly, Section 504 says that a child does NOT have to be enrolled in special education in order to be eligible for related services. Section 504 defines a handicapped person as:
  - having a mental or physical impairment that limits major life activities, which include: "caring for oneself, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning and working"
  - having a record of such an impairment
  - is regarded as having such an impairment. [Source: 34 Code of Federal Regulations (CFR) Section 104.3(j), 1988]

How will I protect my child's privacy?

A student's right to privacy, including school records, is protected by the Family Educational Rights and Privacy Act, 20 USC 1232 (g) (4) (B), also known as the Buckley Act. The school must provide a copy of all records upon a parent's request.

What are the town's responsibilities if my child is in private education/placement?

The team will determine the appropriate placement in the least restrictive environment. This means that the team will usually try to place children with disabilities in educational programs with non-disabled children. In some cases, the education system may instead suggest a private placement to meet your child's educational needs. In this case, the school district is responsible for the placement and/or services, at no cost to the family.

If you make the decision on your own to send your child to a private school or placement when the school district can provide your child with a "free and appropriate education," then you are responsible for costs such as tuition and transportation. The school district is still responsible for arranging any related services your child needs. This usually means that your child will receive therapy services from the public school district.

My child has special health care needs. Where do I start to make sure s/he gets quality care while in school?

- Notify your child's school system early so they can begin planning for your child. Three to six months before your child is to enter school, notify the principal, the special education director and the school nurse.
- If your child has been hospitalized recently, send a discharge summary to the school nurse.

- Have a list of what your child needs on a daily basis to attend school. Your child's pediatrician, specialist, or primary nurse may assist you with this.

- Request a meeting with the school nurse. Usually, the school nurse is your child's school health care coordinator and will work with you to develop a Health Care Plan for your child. A Health Care Plan explains all the student's daily needs, outlines staffing, and reviews possible health problems and solutions. The school nurse or public health nurse who works with the school district will review the plan with the school staff. The Health Care Plan should include:
  - student information
  - anyone who will be providing health care for your child in school
  - substitute staff/backup plans
  - brief medical history
  - special health care needs of the child
  - medication/diet
  - transportation needs
  - health procedures
  - possible health problems and solutions
  - emergency plan
  - doctors' orders
  - parent authorization/consent.

- If your child receives special education services, ask to have the Health Care Plan attached to the IEP.

- Talk regularly with the school nurse. Help the school nurse to obtain your child's medical records and any other relevant information.

Who will make the decisions about my child's nursing needs while in school? Who decides who will carry out my child's procedures while in school?

Decision-making and staffing issues should be discussed during the development of your child's IEP or Health Care Plan, especially if your child has complex needs, like one-on-one nursing care. School nursing decisions will be based on your child's condition and nursing needs. Each state has specific nurse practice acts that nurses follow regarding delegation of procedures to other staff. You can discuss this in detail with the school nurse. The people who are usually involved in making decisions about your child's health care needs at school are:

- supervisor of the school nurses
- the principal
- school nurse or public health nurse
- consultants in your state health or education department

- the special education director

- parent

and may also include:

- your child's pediatrician and/or specialists.

- Oftentimes, if the school needs to hire an extra staff person, an administrative decision is made by the special education director and presented for approval to the school committee/board.

What do I do if the regular school nurse is sick?

- In the planning process it is important to identify all essential staff and contingency staff in the event of illness or emergencies. The backup staff should be trained and their names written in the Health Care Plan or IEP.
- Your child's safety needs come first. If there is no coverage for your child, you may choose to keep your child at home.
- Some schools and families negotiate to have a parent come in to the school if the school nurse is ill. This is on a short-term basis and the details of what circumstances and if you will be paid should be discussed prior to your child's entry into school. You should not feel obligated to act as backup staff.

Balancing Your Child's Classroom Time

Being with peers during the school day is beneficial for your child's growth and development as well as for the other students. Special education tries to balance these social opportunities with the other needs your child may have. For many parents, it is important to have their child with disabilities included in a classroom setting with non-disabled children. To learn what choices are available for your child in his/her school, you can:

- ask for the school's policy on the inclusion of children with disabilities with non-disabled children
- speak with other parents in your town
- address this question to the team when you have the educational team meeting
- work with the school to increase opportunities for your child to socialize with other children
- find out if the school has a disabilities awareness program. There are many programs, videos and books for school-age children that discuss different disabilities.
- request that whatever arrangement you reach with the school be included in your child's IEP goals and objectives.

Do I have to allow my child to receive special services or therapies outside of the classroom? What should be the limit?

- The percentage of the school day in which your child will participate in regular education programs should be outlined in your child's IEP.
- You need to work closely with your child's team at school to work out the most beneficial program for him/her.
- Times and location of services can be negotiated with the school.
- Try to arrange having special education services provided within the regular classroom setting.

Who will work with the regular classroom teacher regarding adaptations to the school program to accommodate my child's special needs?

In some schools, the classroom teacher and specialist work together in the classroom teaching children. However, regular education teachers usually do not have special education training so it will be important to:

- provide the classroom teacher with an overview of your child's special needs
- spend some time acting as a resourse person for the classroom teacher
- give teachers updates, suggestions, or other information regarding methods of learning that have worked in the past for your child
- consider having your child's previous or current teacher talk to next year's teacher
- join a parent advisory committee who works with the special education director.

What can I do to strengthen my relationship with my child's school?

In general, you may want to consider becoming active in the Parent Teachers Association (PTA) or other school activities. This will help create a relationship with your child's school, increase awareness of disability issues, and may make the road a little smoother when dealing with the school on problematic issues in the future.

You can improve communication by:

- having frequent visits with your child's teacher and specialists
- being available to do training or answer questions about your child's procedures, medication or equipment
- asking for suggestions of activities to do at home that will support and strengthen your child's progress at school
- volunteering as a "classroom parent"
- remembering that by working together with the school staff, you will be able to achieve what is best for your child.

Assistive Technology and Equipment in School

What is assistive technology? Could my child benefit from it? Who can I ask?

Assistive technology is a broad phrase that can mean any type or piece of technology that assists a child with a disability: wheelchairs, eyeglasses, hearing aids, computer games, battery-operated toys, specialized switches or mobility systems, speech synthesizers, electronic communication boards or portable computers can all be within the category of assistive technology.

The following is a partial list of resources, many of whom can be found in the *Appendix*, who can provide you with more detailed information about assistive technology:

- your child's school (i.e. occupation, physical or speech/language therapist)
- local hospitals
- community rehabilitation or vocational centers
- parent. disability organizations or community groups, your home care company or equipment supplier
- many large computer and software manufacturers, like Apple and IBM, have special information and programs for people with disabilities
- local computer users' groups in the community
- state vocational rehabilitation office (see *Chapter 7: Vocational training and planning for adulthood)*
- check the suggested readings list in the *Appendix*.

What kind of assistive technology is the school obligated to provide?

While assistive technology can encompass a wide variety of services and devices, when you are discussing who will pay for an assistive technology device a line is often drawn between medical aids—like wheelchairs, eyeglasses and hearing aids—and educational aids, such as speech synthesizers, computers and adaptive keyboards. The line between the two categories can become quite confusing when an assistive technology device, like a switch operated by the foot or mouth, serves equally important medical/mobility and educational needs.

In general, medical assistive technology used in the school is paid for by Medicaid or the student's insurance provider. The payment for educational aids must be arranged between Medicaid or the family's insurance provider and the school system. You will need to discuss not only payment of the device(s), but whether the device can be used at home, who will pay for repairs, liability issues and to whom the device will belong when your child leaves the school. This information should be included in your child's IEP if applicable. You may be able to obtain some financial assistance from civic, disability, religious and philanthropic organizations. There are, however, some key facts you should know:

- IDEA requires schools to provide support services other than the ones specifically listed "as may be required to assist a child with a disability to benefit from special education" [20 U.S.C. Chapter 33, Section 1401 (17)1991]. IDEA defines assistive technology as:

"...any item, piece of equipment, or product system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve the functional capabilities of individuals with disabilities." [20 U.S.C. Chapter 33, Section 1401(25)1991].

- In 1990 the Office of Special Education Programs (OSEP) issued a policy statement saying the school district:

  - must assess a student's need for assistive technology devices or services
  - determine which devices/services will aid the student's education
  - list them in the IEP
  - and provide them to the student.

  [Source: National Information Center for Children and Youth with Disabilities (NICHCY)]

- In 1988 Congress passed the Technology-Related Assistance for Individuals with Disabilities Act (PL100-407). This act made competitive funding available to states to develop programs to increase access, training and information about assistive technology to all individuals with disabilities and their families. Awards are made to and distributed through a state agency, such as the state department of education or commission for the blind and deaf. Each state is allowed to use its own definition of assistive technology.

Who pays for medical or nursing equipment (e.g. a ventilator, oxygen tank, suction machine, or feeding pump) that my child will need in school?

The family, insurance company or public program usually pays for equipment. You should also discuss this issue with your child's school.

Who provides the equipment?

- You should discuss equipment needs with the school personnel.
- Generally, parents are responsible for sending in any equipment needed for daily use.
- If a piece of equipment cannot be transported, you will need to consult with your home care provider and/or case manager to determine if your insurance provider (see *Glossary*) will pay for a second piece of equipment.

Who is responsible for care and maintenance of my child's medical or nursing equipment at school?

- The care and maintenance of equipment at school should be discussed in the planning meeting before your child's (re)entry.
- The family is generally responsible for overall maintenance and repair of equipment.
- The family usually has an agreement with a home equipment company, which will maintain and repair the equipment.
- Give school personnel the telephone numbers of the home or equipment company for questions, concerns, training, repairs or emergencies.
- Daily care and cleaning is usually done by whoever is performing the actual procedure with your child. You may need to advise staff on appropriate cleaning procedures.
- Your child, if old enough and able, may want to take responsibility for the daily care of the equipment.

Who trains a school nurse who is unfamiliar with specific medical or nursing procedures and equipment?

- It is important in the planning stage to discuss procedures that your child needs to have on a daily basis.

- Make sure caregivers at school are familiar with new equipment or changes to it.

- Training for the school nurse or other staff can be provided by:
  - parents
  - staff at your child's hospital
  - agencies that provide technical assistance i.e. state health departments
  - home care agency or equipment vendor
  - nurse in child's physician's office.

Transportation

While public schools are required to provide transportation to all students, there are no federal regulations that address the transportation of children with special health needs in detail. Transportation is listed as a "related service" under IDEA and Section 504, but you will have to work out many of the details with your child's school system.

School systems vary in their dealings with transportation companies. For example, some schools have their own vehicles while others contract with transportation companies. In any case, you should make sure that any details or requirements regarding your child's transportation are included in the IEP or Health Care Plan.

You should check whether your state has any transportation regulations. Your state department of education, home care company, or pediatrician may be helpful in answering questions about special transportation arrangements that your child may need.

What are the safety concerns when my child is being transported?

A transportation plan should include:

- a requirement that the vehicle has a two-way radio in case of emergency. You can suggest to the school that they purchase or seek a donation of a cellular telephone or a CB radio.
- presence of seat belts or restraints
- transportation monitor for supervision or care
- any equipment that the child will need during transport
- any positioning considerations that will make your child more comfortable or safe during transport. Consult your child's therapist or other expert about how your child should be positioned during transport.
- emergency plans.

What other questions should I ask the school about the transportation of my child?

☐ **Will anyone else be available in the vehicle, other than the bus driver, who can attend to my child's health needs during transport? Should I request a nurse or monitor during transport?**

☐ **Will the monitor have CPR certification?**

☐ **Who will train the transportation staff regarding my child's needs?**

☐ **If I choose to transport my child to school, will the school system reimburse me for expenses?**

☐ **If my child becomes ill at school, who will transport my child home?**

☐ **If there is an emergency at school and my child needs to go to the hospital, who will take him/her there? How will I be informed?**

Financing For School Related Services

What is third-party billing?

Third-party billing is when parents use their private or public health insurance plan to pay for care-related costs, like evaluations or other services, for their child at school or elsewhere.

Can the school district ask my insurance plan to pay for services for my child? What if I have Medicaid?

The most important thing to keep in mind is that the school is responsible for arranging services to be provided to your child at no cost to your family. A school district can ask if they can bill certain costs to your insurance, but you should know that:

- you may refuse to allow school districts to bill your insurance
- the school cannot refuse to provide or discontinue your child's services if you refuse to allow third-party billing
- the billing of services to your private insurance may affect your annual cap or lifetime premium. Check with your insurance company
- if a school or provider is not satisfied with the amount paid by your insurance provider, (see *Glossary*) they cannot bill you for the difference of the amount

Due to amendments to the Social Security Act and other Medicaid statutes:

- in some states, school districts may be able to bill Medicaid directly for the cost of related services
- a school or service provider, whether private or public, must abide by the Medicaid rate set in the state. There is usually a rate setting commission for Medicaid-covered services in each state.

Do I have to divide my private home nursing hours between home and school?

Many public programs, like Medicaid or Medicaid waivers, will pay for a specified number of hours of care for your child. Usually they will give you a set number of hours per week. Whether you use these prepaid hours of care for your child at home or at school will have to be negotiated between you and the school system.

If your family has only a few hours of home nursing, you may not be able to use any for school. However, if your family has enough hours to function in your home setting, then you may use some hours for school. Check with your insurance provider or public program, however, because any home care hours or payment by private insurance used for school-time care may apply toward your caps on your private insurance. It is important to negotiate with the school. It is also important for the school to understand that the hours used by families are frequently evaluated and may be reduced.

What other issues do I need to be aware of?

- ☐ Is the school accessible? For example, will my child be able to make it to class on time if s/he has to get to a classroom on the second or third floor of a school building?
- ☐ Are restrooms accessible to my child?
- ☐ Is my child having trouble finishing his/her classwork because of his/her special needs?
- ☐ Is my child having trouble finishing his/her classwork or homework because of his/her special needs? (If the answer is yes, you should discuss this issue with the child's team or individual teachers. Adaptations may need to be made and should be included in the IEP.)
- ☐ Are my child's teachers prepared to deal with the psychological impact of my child's differences and the reaction of his/her peers? Does the school have a disability awareness curriculum?
- ☐ How can I get the school to see my child's abilities rather than just his/her disabilities?
- ☐ How do I deal with transitions in school? How do I ease the school through the different stages of medical care my child needs?
- ☐ How will my child be able to accompany his/her class on field trips? Are special considerations necessary to plan for this?
- ☐ Are there legal requirements for the education of my child while s/he is in the hospital?
- ☐ Will adaptive equipment be available for my child?
- ☐ Will the assigned education coordinator follow my child for more than one year to provide continuity?

CHAPTER 7 Vocational Training and Planning for Adulthood

In general, your child's special education teacher or department, the state vocational rehabilitation system, or your local/city office of handicapped affairs can answer most of the questions you might have about vocational rehabilitation.

How do I go about planning for my child's future?

Your child's disability should not prevent you from introducing the idea of work, responsibility and earning money. These are attributes that will only enhance your child's personal growth. In general, career or vocational planning for a child with a disability is similar to that for a non-disabled child.

- Begin early on to help your child learn independent living skills. Parent groups and other resources listed in the *Appendix* can help with ideas for fostering your child's independence and personal care skills.
- Look at your child's interests.
- Talk to a special educator or counselor who has training or experience in employment issues.
- Make sure that independent living and vocational skills are listed in your child's IEP if s/he receives special education services.
- Be aware that your child's interests and abilities can and will change and so plans for work may change.
- Keep in mind that work may be either volunteer or paid employment, in an integrated work setting or a separate setting, with other people with disabilities.
- Vocational training and employment for your child will depend upon:
  - employment support services available in your area
  - availability of assistive technology
  - accommodations of the employers
  - local economic climate.

There are two positive developments in your child's favor. Both the increase in assistive technologies over the past five years and the Americans with Disabilities Act (see *Glossary*) continue to open new opportunities in the workplace.

Vocational Training In School

Is there any federal legislation on vocational education or training in schools?

There are three main pieces of legislation regarding vocational opportunities for children with special health needs. They guarantee full vocational opportunities for youth with disabilities and authorize funds to support vocational education programs.

- Carl D. Perkins Vocational Education Act of 1984 (PL 98-524)
- IDEA (see *Chapter 6: Education*)
- Carl D. Perkins Vocational and Applied Technology Education Act of 1990 (PL 101-392)

Will the school provide a vocational evaluation and other services for my child?

All public schools are mandated by the Carl D. Perkins Act to provide some vocational or transitional planning for children with disabilities. You should check with your child's school about what vocational programs, training and evaluations they offer. Check with the special education department to see if your child has been scheduled for these services and whether pre-vocational counseling and training are required by your state's special education and vocational laws. You may have to request a vocational evaluation from your child's special education department.

Your child should receive a vocational evaluation at the same time as other students do, around age 12 to 13. The evaluation should outline:

- your child's interests
- current skill levels
- goals and objectives for future vocational training.

Make sure this information is included in your child's IEP if s/he receives special education services. Also try to include any assistive technology your child may need to reach his/her vocational goals in the IEP. (See *Chapter 6: Education* for information on assistive technology.) While IDEA mandates that any transitional services, which include vocational training, must be included in the IEP by age 16, it is generally a good idea to have this included as early as possible.

In addition, your child's school may participate in internships, summer job or other programs designed to introduce students with disability into the workplace. Check with your state department of education or local school district.

Where else can I get a vocational evaluation?

There are vocational evaluators in private practice. You can contact the National Rehabilitation Association (see *Appendix*) for a list of qualified practitioners in your area.

Will my child have to go to a separate vocational-technical school or program or can s/he receive vocational services in his/her regular school?

This depends upon the town you live in. If your child's school provides vocational services on-site for other children, then they should do the same for your child. However, many schools do not have vocational-technical programs within the building, but may send students to separate vocational-technical schools or collaboratives.

Planning For Adulthood

What preparation and planning do I need to do before my child reaches adulthood?

Since many state and federal public services stop when a child reaches age 22, it may become necessary for your child to take care of him/herself completely or to direct his/her care to a Personal Care Attendant (PCA)(see *Glossary*). This means that while your child is still an adolescent, you may have to evaluate whether independent living skills are in place. These skills may include:

- bathing
- toileting
- feeding
- maintaining and ordering equipment
- administering medication
- performing exercise or physical therapy routines
- scheduling his/her appointments
- ability to communicate by telephone or other methods
- ability to recognize when s/he needs to see a doctor
- ability to use some form of transportation.

You may also want to think about whether your child would be able to function in regular housing, which includes group homes, staffed apartments or independent living centers. Your state may also offer rental assistance programs through local public housing agencies or the U.S. Department of Housing and Urban Development. The additional skills needed may include:

- cooking
- cleaning
- shopping
- paying bills
- hiring/firing Personal Care Attendants or other caregivers
- arranging transportation.

You can contact the following for more information about independent living skills and situations:

- your local Center for Independent Living
- local public housing agency
- U.S. Department of Housing and Urban Development (HUD)
- your child's occupational therapist
- your child's special education teacher.

Who can help my child with the transition from high school to the workplace?

Some of the other people who can help you find out what types of jobs your child might be suitable for are:

- state office of vocational rehabilitation
- your child's teachers, to get an assessment of what your child's interests and skills are
- your child's special education teacher
- parents of older children with special health needs in your community or in parent support groups
- special education section of your state's department of education
- school guidance counselor
- vocational education teacher.

During your child's last years of high school, you should contact your state office of vocational rehabilitation (sometimes called the State Division or Commission of Vocational Rehabilitation). The state office(s), mandated by the Rehabilitation Act of 1973, Section 501-504 and the ADA, work to help eligible people with disabilities find employment. This may include providing training, information on assistive technology and other support services. Depending on the local agency and the applicant's financial situation, the individual may have to pay some of the cost of these services.

In order to receive state services from the state vocational rehabilitation system, the goal should be paid employment, regardless of whether it is an integrated or separate work setting. Usually, volunteer work may be used as a means to introduce a person to the idea of work, to try out a particular kind of job or to help learn specific work-related skills. You should consult your local state office—found in the state listings in the telephone directory under rehabilitation services or vocational rehabilitation services—for eligibility requirements, employment planning and assistance or information about the options below.

What further education and training opportunities are available?

There are a number of different programs/opportunities available, each with its own eligibility requirements. Most of these programs are open to individuals with or without disabilities.

- Tech Prep programs are part of the Carl D. Perkins Act of 1990 and are designed to help high school students obtain technically-oriented knowledge and skills. The program usually combines the last two years of secondary school with two years of higher education.
- JTPA (Job Training Partnership Act) funds training programs that are usually administered through Private Industry Councils (PICS) to help prepare youth and unskilled adults to enter the job market.
- On-the-Job Training (OJT) provide short-term training to help an individual learn his/her duties on the job site. Additional opportunities include:
  - internships
  - apprenticeships
  - specific training by disability organizations
  - adult education
  - trade and technical schools
  - college and universities.

What is job placement? Who are the people that can help my child find employment?

Job placement is the activity of finding or creating a job for a particular person. Most often, special educators, job coaches and vocational rehabilitation counselors are the professionals involved in job placement. These people can be found in your state's vocational rehabilitation system, or by contacting the National Rehabilitation Association (listed in the *Appendix*) for a referral.

Job coach:

- assists a person with a disability to find, learn and maintain a job
- trains the person on the job site
- usually stays with the person on-site, providing ongoing training and support until the person is able to work independently.

Vocational rehabilitation counselor:

- has advanced training in rehabilitation counseling and job placement
- may be employed by a private agency or the state vocational rehabilitation agency
- often acts as a case manager, arranging for services, like evaluations and job coaching.

Who can I or my child turn to for help if we are having problems?

There are federally mandated programs designed to provide assistance to people with disabilities. However, you must first meet the new federal definition of developmental disability. Developmental disabilities tend to be lifelong and are defined as:

- chronic and attributable to mental and/or physical impairments
- visible before age 22
- resulting in substantial limitations in three or more of the following major life activities:
  - self care
  - receptive and expressive language
  - learning
  - mobility
  - self-direction
  - the capacity for independent living and/or economic self-sufficiency.

PADD System: Protection and Advocacy for Persons with Developmental Disabilities

- PADD was originally established by the Developmental Disabilities Assistance and Bill of Rights Act of 1975 (PL 94-103).
- It is administered by the U.S. Department of Health and Human Services, Administration on Developmental Disabilities.
- The state agencies that make up the protection and advocacy system provide:
  - advocacy and legal services
  - protection of the rights of individuals with developmental disabilities
  - work with direct service providers, like residential care providers or public schools
- advice and technical assistance to government offices and attorneys on such issues as disability and mental health law.

Client Assistance Program (CAP)

- CAP was originally established by Section 112 of the Rehabilitation Act of 1973 (PL93-112).
- It was improved with the 1984 amendments to the Rehabilitation Act (PL98-221).
- It is administered by the U.S. Department of Education, Office of Special Education and Rehabilitation Services, Rehabilitation Services Administration.

- State CAPs work to:
  - protect the rights of individuals with disabilities
  - provide information and assistance to individuals seeking and receiving services under the Rehabilitation Act
  - coordinate with state departments of vocational rehabilitation and other agencies that receive funds under the Rehabilitation Act.

While the Protection and Advocacy System and the Client Assistance Program are two separate federal programs, in many states they are administered by the same agency. In other states, the CAP program may be administered by the state vocational rehabilitation agency or other non-profit agency.

In addition, there is a membership organization for the state protection and advocacy systems and CAPs called **NAPAS: National Association of Protection and Advocacy Systems.** State NAPAS offices work on behalf of individuals with developmental disabilities or mental illness. The national office monitors congressional activities and can refer people to their state office, which in some cases may also be the state's CAP agency (see *Appendix*).

What happens when my child becomes an adult? Who will pay for the needed services?

While most public program benefits end when a person turns 22, there are some provisions for people who have been disabled since childhood. Adult children or their parents should contact their employer, vocational counselor, local social security or Medicaid office for more information and eligibility requirements.

- Under a 1986 Federal Law called COBRA, anyone who works for a company that offers health insurance as a benefit and which has 20 or more employees (regardless of how many of those employees are covered under the company's group plan) must offer you the right to:
  - purchase coverage for you and your family for a limited period of time when you stop working for that employer
  - purchase coverage with no pre-existing condition exclusion for your children who are no longer considered dependents.

  In either case, the family or adult child will have to pay the full amount of the plan.

- Your adult child may be able to remain on your policy as a handicapped dependent. In several states, there are mandates to extend coverage to a dependent child, so long as they continue to be disabled. Check with your employer for further information.

- Many children with disabilities become or remain eligible for Social Security benefits after their 18th birthday, even if s/he has a job.

- Your adult child may be able to deduct work-related expenses from his/her total income and continue to be eligible for public program benefits.
- Your adult child may also be able to save some of his/her income, benefits or other assets for a specific work related goal by developing a Plan for Achieving Self-Support (PASS) (see *Glossary*).
- Your adult child may continue to be eligible for Medicaid coverage even if s/he has a job and/or is no longer eligible for SSI payments.

An adult child or their parent should contact his/her employer, vocational counselor, local social security or Medicaid office for more information and eligibility requirements.

Legal Issues

Due to the complexity of legal issues, pending court cases and changing interpretations of federal laws, each state—and sometimes even different offices within the same state—can view their responsibilities differently. It is difficult to answer many of the legal issues around vocational training, education, financing and insurance at a national level and you should consult an advocate or a lawyer when you have questions. You can also consult the national or local bar association for referrals to lawyers who specialize in special health care needs. Some of the questions you may want to discuss with these professionals are:

☐ **What are the legal issues surrounding my child working?**

☐ **If my child works, does s/he have to keep his/her income below a certain amount to keep SSI or stay on Medicaid?**

☐ **If my child works, will that income be counted as separate from mine or my spouse's?**

☐ **How do I protect my child's holdings/earnings? How do I protect my family's assets?**

☐ **What is counted as income? Assets?**

☐ **How do trusts work? What do I need to know about estate planning?**

☐ **What if something happens to me or my spouse? Will my child need a guardian?**

CHAPTER 8

Recreation and Travel

Finding and Creating Recreational Opportunities

What recreational opportunities are there for my child and my family? How do I get information about recreational opportunities?

It is most important when looking for recreational opportunities to find activities that are interesting for your child and family and that have the supports available to make the activity enjoyable. Instead of looking at reasons why an activity is not possible, look for what is needed to make it achievable.

Recreational opportunities vary in communities, depending on what part of the country you live in, your particular town, your child's age and the type of activity you are looking for. Your child and family should be able to access most activities that are available to the general public. The passage of the Americans with Disabilities Act (ADA) and Section 504 should continue to make access easier. It prohibits the exclusion of a child with a disability from any service or type of program. (See ADA in the *Glossary* for more details.)

Places to check for recreational opportunities within your community include:

- local newspaper
- school systems
- local YMCA
- boys and girls clubs
- city recreation departments
- 4-H Club
- local gym
- civic organizations/churches and other religious organizations
- chamber of commerce
- neighbors, parents, teachers, professionals, and friends
- disability organizations, e.g. Association for Retarded Citizens or Easter Seals Society, may have specialized programs for children with certain disabilities/chronic illnesses.

Consider talking with the staff of community organizations, even if they have little or no experience working with children with special health needs. Once program directors discover that there is little or no change necessary in staffing, financing or programming, they usually will try to make the program accessible for your child. The bottom line is that they are nervous about trying something new, but if you can get a teacher, neighbor or friend to provide information and assistance when needed, recreation programs are usually willing to welcome your child.

For example, when one parent could not find a camp with adequately trained personnel for her child's needs, she arranged with a camp to have her child accompanied by a nurse. Another option may be to organize your own recreational program by linking up with other parents of children with special health needs and then asking the town or a local agency, like the YMCA, to provide funding, an instructor or location for the program. Volunteer staff can often be found through civic and religious organizations, local high schools and colleges.

When choosing a program, initial preparation with the provider is essential. You should discuss any issues with providers and include their concerns and possible solutions. Talk to anyone in the program who will have daily contact with your child and make sure they are as comfortable as possible with the situation, since they will also be serving as a role model for the other children.

Give your child and others involved a chance to grow and learn from each other. This creates a model for other community organizations to follow, and may lead to a more formalized program in the future.

Are there any laws that address recreational issues?

Know your child's rights under the Americans with Disabilities Act and Section 504 (see *Glossary*): no person may be excluded from any type of program on the basis of his/her disability unless compliance causes a program or company "serious financial hardship." Sometimes a program may be unaware of the law.

In addition, therapeutic recreation is one of the new related services recognized under IDEA: Individuals with Disabilities Education Act (PL 101-476) (see *Glossary*). Children receiving special education services are also entitled to:

- assessment of recreation and leisure skills, which may be included in the IEP
- use of therapeutic recreation to improve social, cognitive and physical abilities
- education or instruction to increase participation in leisure activities
- provision of recreation services in the least restrictive environment.

What are the advantages and disadvantages of programs that separate children with special needs from other children?

There are different ideas about what type of program would most benefit a child with special health needs. The following are some of the advantages of:

Integrated Programs:

- may have greater amount and variety of activities offered
- involve your child with many same-age peers in the community who don't have special needs
- improve your child's social and real life skills
- increase disability awareness
- promote confidence, self-esteem and friendships.

Separate or Special Programs:

- specifically designed to serve children with special needs
- possess the practical expertise and an accepting philosophy to work with children with a variety of abilities
- have more expertise in handling the physical, emotional, health and safety issues related to the children they serve
- provide an environment where a child may feel more comfortable surrounded by other children with the same abilities
- usually accept all children without negotiation and explanations that might be necessary in a program that is unfamiliar with your child's needs
- may already have adaptive or specialized recreational equipment
- provide greater opportunities for participation in team sports.

How do I make recreation a priority? There's so much work and planning involved, how do I break the routine of staying home?

With so many other things to think about—education, therapies, bills, etc.—recreation can often become the last priority. However, recreational activity is important because it:

- helps your child learn to interact with others
- helps your child maintain previously learned skills during periods of inactivity or vacation
- plays an important role in shaping a child's and family's identity
- brings a family closer together and helps to include siblings.

Although it often takes more time and effort to involve a child with special health needs in recreational activities, you should remember that you are not alone. Talk to other parents, local resources, such as parks and recreation departments, after-school programs and other community supports. Lastly, it is also important to remember that the fun and lasting memories from such outings sometimes help you to get you through more difficult times and help create a community network of support for you and your child.

What kinds of questions do I need to ask about safety issues before my child participates in a recreational program?

☐ How will I be informed of incidents or accidents?

☐ Is there adequate supervision? Who will be in charge?

☐ What is the training background of the staff?

☐ Are staff adequately trained and aware of my child's needs? Are they willing to learn?

☐ Do they have emergency plans? Do they know the quickest route to the local hospital?

☐ What kind of documentation do they require or provide?

☐ Is there a refrigerator (for any medications or formulas)?

Planning For Travel

Vacations and travel provide families with a change of pace from daily routines. Although parents who have children with special health care needs often feel that planning for a short trip or vacation may be a major task, many families have found that with advanced preparation it can be a worthwhile venture. Remember, vacations usually create many fond and warm memories for you and your child. To help you begin the planning process, the following is a list of suggested ideas and questions you should keep in mind or include in your travel planning.

What kind of planning and preparation do I need to do when planning a day trip/family vacation? What kinds of questions do I need to ask?

☐ What interests and activities do I and my child want to pursue?

☐ What is my child's doctor's opinion about traveling?

☐ How do I make my child and his/her equipment portable?

☐ Where is the nearest hospital or first aid station?

☐ Where can medications be refrigerated?

☐ Are there limitations on the kinds of equipment I can bring on a plane, bus or train?

☐ What kind of advance arrangements need to be made?

☐ Who do I need to inform ahead of time regarding my child and his/her equipment?

☐ What are my insurance restrictions and procedures for out-of-state coverage, including equipment?

☐ What kind of paperwork do I need when travelling?

☐ Do I need three-prong adaptors for medical equipment?

☐ Do I need to post an "Oxygen in use" sign on my car back window?

Generally, it is best to inform everyone your family will be interacting with: airlines, hotel, transportation, etc. It is also a good idea to bring letters from your child's doctors, indicating:

- function of each piece of equipment
- summaries of pertinent, current medical information
- procedures previously performed
- normal vital signs
- copies of prescriptions as backup.

Although the list of preparations and questions can seem overwhelming, many parents are surprised at the ease with which modifications can be made to accommodate their child's needs. Many of the recreational opportunities available to children in general are also available to children with special health needs and disabilities.

APPENDIX A Record Keeping

Parents of children with special health care needs have found it helpful to keep detailed records of their child's important records, doctor's visits, and equipment deliveries. Below is a list of some information that you may want to keep. Some parents feel more comfortable keeping all information, while others keep only a few records and updated notes. You will eventually find the best system for you. You may want to use a three-ring binder or folder and make the following sections:

Health Information

- copies of hospital discharge plans
- names, addresses and telephones of agencies (VNA, home care agency, respite, and case managers, etc.)
- dates of immunizations
- dates of surgical procedures and diagnostic tests
- allergies to drugs and other substances
- any untoward reactions to medical experiences (i.e. reactions to dye or experiences that your child may have found frightening)
- specialist and therapist reports
- names, telephone numbers and addresses of physicians/specialists
- birth certificate
- names of support groups
- any communicable diseases your child has had

Financing

- names, addresses and telephone numbers of insurance providers and their case managers
- copies of policies and other pertinent information
- dates of services, where it was provided and by whom
- notes of how insurance company responded to your claims
- Social Security number
- letters of medical necessity

Education

- copies of all IFSPs and IEPs
- copy of Health Care Plan (for a copy of a sample Health Care Plan, call Project School Care at (617) 735-6714
- names of school personnel and telephone numbers
- education evaluation reports (achievement tests, physical therapy reports, etc.)
- copies of written correspondence with school staff
- letters from your child's physician and doctors' orders
- notes and dates from all meetings with school personnel

Vocational

- high school transcript
- reports from vocational assessments
- employment experiences, dates, telephone numbers of agencies and contact people
- letters of recommendations
- copies of letters to any agencies

Don't Forget

- developmental milestones (first tries at walking, talking or using communication board)
- memorable moments
- lots of photographs
- keep a journal or diary

APPENDIX B: Resources

The best places to start for more information on most of the topics discussed in this booklet are your state departments of education and health. We've listed the address and telephone number of the state departments of health for you, as well as other associations and foundations that may be helpful. Other state agencies, listed in the telephone directory under STATE, include:

- department of education, division of special education
- vocational rehabilitation agency
- division of vocational education, office for special needs students
- mental health agency
- mental retardation program/services
- developmental disabilities program/services
- protection and advocacy agencies
- office of handicapped affairs
- coordinating council for Early Intervention
- state health department: division of children with special health needs.

You may also want to contact your local public library to see if they subscribe to Data Base Med-Line, a computerized database that has information covering medical publications about research, treatment, information and studies done on specific disorders, diseases and conditions. Fees vary.

State Health Department Division of Children with Special Health Needs

Alabama
Division of Rehabilitative and
Crippled Children's Services
2129 East South Boulevard
Montgomery, AL 36111-0586
(205)281-8780
(205)281-1973 FAX

Alaska
Program Manager Handicapped
Children's Program
Alaska Department of Health &
Social Services
1231 Gambell
Anchorage, AK 99501-4627
(907)274-7626
(907)586-1877 FAX

Arizona
Chief Office of Children's
Rehabilitative Services
Arizona Department of Health
1740 West Adams, Room #205
Phoenix, AZ 85007
(602)542-1860
(602)542-1887 FAX

Arkansas
Children's Medical Services
Department of Human Services
PO Box 1437
Little Rock, AR 72203
(501)682-2277
(501)682-6571 FAX

California
California Children's Services
State Department of Health
714 P Street, Room 323
Sacramento, CA 94234-7320
(916)322-2090

Colorado
Handicapped Children's Program
Colorado Department of Health
4210 East 11th Avenue
Denver, CO 80220
(303)331-8404
(303)320-1529 FAX

Connecticut
Bureau of Community Health Services
State Department of Health Services
150 Washington Street
Hartford, CT 06106
(203)566-4282
(203)566-8401 FAX

Division of Children with Special
Health Needs and Child/Adolescent
Health Bureau of Community Health
150 Washington Street
Hartford, CT 06106
(203)566-2057

Delaware
Child Health/CSHN
Division of Public Health
PO Box 637
Dover, DE 19903
(302)736-4786
(302)736-6617 FAX

District of Columbia
Handicapped Children's Unit
DC General Hospital, Building #10
19th and Massachusetts Avenue, SE
Washington, DC 20003
(202)675-5214

Florida
Children's Medical Services Program
Department of Health/Rehabilitative
Services
Building 5, Room 127
1323 Winewood Boulevard
Tallahassee, FL 32301
(904)487-2690
(904)488-3813 FAX

Georgia
Children's Health Services
Georgia Department of Human
Resources
Division of Physical Health
2600 Skyland Drive (Lower level)
Atlanta, GA 30319
(404)320-0529
(404)679-4781 FAX

Guam
Department of Public Health and
Social Services
PO Box 2816
Agana, Guam 96910
(671)734-2083

Hawaii
Children with Special Health
Care Needs Branch
Hawaii Department of Health
741 Sunset Avenue
Honolulu, HI 96816
(800)732-3197

School of Health Services Branch
Hawaii Department of Health
Honolulu, HI 96816
(800)732-2289

Idaho
Children with Special Health
Needs Program
Bureau of Maternal and Child Health
Idaho Department of Health/Welfare
450 West State Street
Boise, ID 83720
(208)334-5963
(208)334-5964 FAX

Illinois
Division of Specialized Care
for Children
University of Illinois at Chicago
2815 West Washington, Suite 300
PO Box 19481
Springfield, IL 62794-9481
(217)793-2340
(217)793-0773 FAX

Indiana
Children's Special Health Care
Services Division
Indiana State Board of Health
1330 W. Michigan Street
PO Box 1964
Indianapolis, IN 46206-1964
(317)633-8522
(317)232-4331 FAX

Iowa
Iowa Child Health Specialty Clinic
University of Iowa
Iowa City, IA 52242
(319)356-1118
(319)356-8284 FAX

Kansas
Services for Children with Special Health Care Needs
Kansas Department of Health & Environment
900 SW Jackson, 10th Floor
(913)296-1313
(913)296-6231 FAX

Kentucky
Commission for Handicapped Children
Kentucky Department of Human Resources
1405 East Burnett Avenue
Louisville, KY 40217
(502)588-3264
(502)588-4673 FAX

Louisiana
Handicapped Children's Services
Office of Public Health
Department of Health & Hospitals
PO Box 60630
New Orleans, LA 70160
(504)568-5055

Maine
Coordinated Care Service for Children with Special Health Needs
State House Station 11
151 Capitol Street
Augusta, ME 04333
(207)289-3311
(201)289-4172 FAX

Maryland
Division of CCS
Maryland Department of Health/Mental Hygiene
Mental Retardation/D D Administration
201 W. Preston Street, 4th Floor
Baltimore, MD 21201
(301)225-5580

Massachusetts
Division for CSHN
Parent/Child/Adolescent Health
Massachusetts Department of Public Health
150 Tremont Street, 4th Floor
Boston, MA 02111
(627)727-5812

Michigan
Children's Special Health Care Services
Bureau of Community Services
Michigan Department of Public Health
PO Box 30195
Lansing, MI 48909
(517)335-8961
(517)335-8560 FAX

Minnesota
Division of Maternal & Child Health
Minnesota Department of Health
717 Delaware Street SE
PO Box 9441
Minneapolis, MN 55440
(612)623-5166
(612)623-5043 FAX

Mississippi
Children's Medical Program
Mississippi Department of Health
PO Box 1700
Jackson, MS 39205-1700
(601)987-3965
(601)987-5560 FAX

Missouri
Division of Maternal, Child and Family Health
Missouri Department of Health
1738 E. Elm Street, PO Box 570
Jefferson City, MO 65102
(314)751-6174
(314)751-6010 FAX

Montana
Family & MCH Bureau
Montana Department of Health & Environmental Sciences
Cogswell Building
Helena, MT 69620
(406)444-4740
(406)444-2602 FAX

Nebraska
Medically Handicapped Children's Program
Nebraska Department of Social Services
301 Centennial Mall South, 5th Floor
Lincoln, NE 68509-5026
(402)471-9283
(402)471-9455 FAX

Special Services for Children & Adults
Nebraska Department of Social Services
301 Centennial Mall South, 5th Floor
Lincoln, NE 68509-5026
(402)471-9345
(402)471-9455 FAX

Nevada
MCH/CSHCS
Nevada State Health Division
Room 205
505 East King Street
Carson City, NV 89710
(702)687-4885

New Hampshire
Office of Family & Community Health
New Hampshire Division of Public Health Services
6 Hazen Drive
Concord, NH 03301-6527
(603)271-4726
(603)271-3745 FAX

Bureau of Special Medical Services
New Hampshire Division of Public Health Services
6 Hazen Drive
Concord, NH 03301-6527
(603)271-4596
(603)271-3745 FAX

New Jersey
Division of Family Health Services
New Jersey Department of Health
CN 364
Trenton, NJ 08225-0364
(609)292-4093

Special Child Health Services Program
New Jersey Department of Health
CN 364
363 W. State Street
Trenton, NJ 08225-0364
(609)292-5676
(609)292-3580 FAX

New Mexico
Children's Medical Services
Department of Health & Environment
PO Box 968
Santa Fe, NM 87504-0968
(505)827-2350

New York
Bureau of Child/Adolescent Health
New York Department of Health
Corning Tower Building, Room 780
Empire State Plaza
Albany, NY 12237
(518)474-2084
(518)474-4471 FAX

North Carolina
Children and Youth Section
North Carolina Department of Environment, Health, and Natural Resources
PO Box 27687
Raleigh, NC 27611-7687
(919)733-7437
(919)733-0488 FAX

North Dakota
Crippled Children's Services
North Dakota Department of Human
State Capitol Building
Judicial Wing
600 E. Boulevard Avenue
Bismarck, ND 58505
(701)224-2436
(701)224-2359 FAX

Ohio
Division of Maternal & Child Health
Ohio Department of Health
246 North High Street
PO Box 118
Columbus, OH 43266-0118
(614)466-3263
(614)644-8526 FAX

Oklahoma
Children's Medical Services Division
4545 N. Lincoln Blvd., 4th floor
Oklahoma City, OK 73103
(405)557-2539

Oregon
Child Development/Rehabilitation Center
Oregon Health Sciences University
PO Box 574
Portland, OR 99207
(503)494-8362
(503)279-4447 FAX

Pennsylvania
Division of Maternal & Child Health
Pennsylvania Department of Health
Health & Welfare Building
PO Box 90, Room 725
Harrisburg, PA 17108
(717)787-7192

Division of Maternal & Child Health
Pennsylvania Department of Health
PO Box 90, Room 714
Harrisburg, PA 17108
(717)783-5436

Puerto Rico
MCH & Children with Special Health Needs
Department of Health
Commonwealth of Puerto Rico
Call Box 70184
San Juan, PR 00936
(809)767-0870
(809)767-1945 FAX

Rhode Island
Services for Handicapped Children
Rhode Island Department of Health
Three Capitol Hill
Providence, RI 02908-5098
(401)277-2312

South Carolina
Division of Children's Rehabilitative Services
South Carolina Department of Health & Environmental Control
Robert Mills Complex, Box 101106
2600 Bull Street
Columbia, SC 29211
(803)737-4050
(803)737-4078 FAX

South Dakota
MCH/CSHS Programs
South Dakota Department of Health
118 W. Capitol
Pierre, SD 57501
(605)773-3737
(605)773-3684

Tennessee
Children's Special Services
Tennessee Department of Health and Environment
525 Cordell Hull Building
Nashville, TN 37247-4701
(615)741-7353

Texas
Bureau of Chronically Ill & Disabled Children Services
Texas Department of Health
1100 West 49th Street
Austin, TX 78756-3179
(512)458-7355

Utah
Children's Special Health Services Bureau
Utah Department of Health
Cannon Building
288 North 1460 West
Salt Lake City, UT 84116-0650
(801)538-6957
(801)538-6510 FAX

Child Health Bureau
Utah Department of Health
Cannon Building-Box 16650
288 North 1460 West
Salt Lake City, UT 84116-0650
(801)538-6140
(801)538-6510 FAX

Vermont
Handicapped Children's Services
Vermont Department of Health
1193 North Avenue, PO Box 70
Burlington, VT 05401
(802)863-7338

Virginia
Children's Specialty Services
Bureau of MCH
Virginia Department of Health
1500 East Main Street
Room 135, PO Box 2448
Richmond, VA 23218
(804)786-7367
(804)371-6031 FAX

Washington
Children with Special Health Needs
Division of Parent Child Health Services
Department of Health
Mail Stop LC-11A
Olympia, WA 98504
(206)753-0908
(206)586-3890 FAX

West Virginia
Division of Handicapped Children
West Virginia Department of Health/Human Services
1116 Quarrier Street
Charleston, WV 25301
(304)348-6330
(304)348-2183 FAX

Wisconsin
Wisconsin Division of Health
PO Box 309
Madison, WI 53701
(609)266-3886
(608)267-1052 FAX

Wyoming
Children's Health Services
Division of Health & Medical Services
Wyoming Department of Health
Hathaway Building
Cheyenne, WY 82002-0710
(307)777-7941
(307)777-5402 FAX

General

ABLEDATA
8455 Colesville Road
Suite 935
Silver Spring, MD 20910
(800)346-2742 Voice and TDD

ACCH: Association for the Care of Children's Health
7910 Woodmont Ave
Suite 300
Bethesda, MD 20814
(301)654-6549

Administration on Developmental Disabilities
200 Independence Avenue, SW
Washington, DC 20201
(202)245-2890

American Association of University Affiliated Programs for Persons with Developmental Disabilities
Suite 410
8630 Senton Street
Silver Spring, MD 20910
(301)588-8252

American Association on Mental Retardation
1719 Kalorama Rd NW
Washington, DC 20009-2684
(202)387-1968
(800)424-3688

American Foundation for the Blind
1615 M Street NW
Suite 250
Washington, DC 20036
(202)457-1487

Association for Retarded Citizens
500 E. Border Street
Third Floor
Arlington, TX 76010
(817)261-6003

Child and Adolescent Family Support Branch
National Institute of Mental Health (NIMH)
Room 11C09
5600 Fishers Lane
Rockville, MD 20857
(301)443-1333

Children's Defense Fund
25 E Street NW
Washington, DC 20001
(202)628-8787

ERIC Clearinghouse on Handicapped and Gifted Children
The Council for Exceptional Children
1920 Association Drive
Reston, VA 22091
(703)620-3660

Exceptional Parent Magazine
1170 Commonwealth Avenue
Boston, MA 02134-9942
(800)852-2884

Family Resource Coalition
200 South Michigan Ave., Suite 1520
Chicago, IL 60604
(312)341-0900
(312)341-9361 FAX

Human Services Research Institute
2336 Massachusetts Avenue
Cambridge, MA 01240
(617) 876-0426

Learner Managed Designs, Inc.
2201 K West 25th Street
Lawrence, KS 66047
(913)842-9088
(Professional training resources, books, software and videos on a variety of topics.)

National Association of Developmental Disabilities Councils
1234 Massachusetts Avenue, NW
Suite 103
Washington, DC 20005
(202)347-1234

National Center for Youth with Disabilities
Box 721 UMHC
Harvard Street at East River Road
Minneapolis, MN 55455
(612)626-2825
(800)333-6293
(612)624-3939 Voice & TDD

National Easter Seal Society
1350 New York Avenue, NW
Suite 415
Washington, DC 20005
(800)221-6827
(202)347-3066

National Information Center for Children and Youth with Disabilities (NICHCY)
P.O. Box 1492
Washington, DC 20013
(800)999-5599
(703)893-6061
State resource lists and other information.

National Information Clearinghouse
Center for Developmental Disabilities
University of South Carolina
Benson Building, 1st Floor
Columbia, SC 29208
(800)922-9234, ext. 201
(800) 922-1107 in SC

National Institute on Disability and Rehabilitation Research
(202)732-1139
(202)732-5316 TDD

National Organization on Disability
910 16th Street NW
Suite 600
Washington, DC 20006
(202)293-5960
(800)248-2253

National Rehabilitation Information Center
8455 Colesville Road
Suite 935
Silver Springs, MD 20910-3319
(301)588-9284 Voice/TDD
(301)587-1967 FAX
(800)346-2742

National Resource Institute on Children with Handicaps (NRICH)
University of Washington
Mail Stop WJ-10
Seattle, WA 98195
(206)543-2254

The Association for Persons with Severe Handicaps (TASH)
7010 Roosevelt Way, N.E.
Seattle, WA 98115
(206)523-8446

The Rural Disability Information Service
MONTECH Rural Institute on Disabilities
University of Montana
634 Eddy Avenue
Missoula, MT 59812
(406)243-5773

United Cerebral Palsy Association Inc.
1522 K Street, NW
Suite 1112
Washington, DC 20005
(800)872-1827
(202)842-3519

U.S. Department of Transportation
(202)366-9306 or 4011
(202)755-7687 or 366-2979 TDD

Health/Professional Associations

Alliance of Genetic Support Groups
1001 22nd Street, N.W., Suite 800
Washington, DC 20037
(800)336-GENE
(202)331-0942
(202)293-0479 FAX

American Association on Mental Retardation
(800)424-3688
(202)387-1968 (within Washington, DC)

American Federation of Home Health Agencies
PO Box
Brunswick, GA 31520
(301)588-6300
(800)777-6876

American Physical Therapy Association Inc.
18 Tremont Street, Suite 1010
Boston, MA 02108
(617)523-4285

Association of Birth Defect Children (ABDC)
5400 Diplomat Circle, Suite 270
Orlando, FL 32810
(407)629-1466

AT&T National Special Needs Center
2001 Rt 46, Suite 310
Parsippany, NJ 07054
(800)833-3232

Caring Magazine
National Association for Home Care
519 C Street NE/Stanton Park
Washington, DC 20002
(202)542-8600

Hospice Association of America
519 C Street, NE
Washington, DC 20002
(202)547-5263

Joint Commission on Accreditation of Hospitals
875 North Michigan Avenue
Chicago, IL 60611
(312)642-6061

March of Dimes Birth Defects Foundation
1275 Mamaroneck Avenue
White Plains, NY 10605
(914)428-7100

NAIC: National AIDS Information Clearinghouse
P.O. Box 6003
Rockville, MD 20850
(800)243-7012 TTY/TDD
(301)738-6616 FAX

National AIDS Hotline
(800)342-AIDS
(800)344-SIDA (Spanish access)
(800)AIDS-TTY (Deaf access)

National Association for Home Care
519 C Street, NE
Washington, DC 20002
(202)547-5263

National Association for the Deaf
(202)651-5373 Voice/TDD

National Association of Medical Equipment Suppliers
625 Slaters Lane, Suite 200
Alexandria, VA 22314-1171
(703)836-6263

National Association of School Nurses
P.O. Box 1300
Scarborough, ME 04070-1300
(207)883-2117

National Association of Social Workers
750 1st Street, NE
Washington, DC 20002
(800)638-8799

National Center for Education in Maternal and Child Health
520 Prospect Street, NW
Washington, DC 20057
(202)625-8400

National Maternal and Child Health Clearinghouse (NMCHC)
38th and R Streets, NW
Washington, DC 20057
(202)625-8410

National Easter Seal Society
70 East Lake Street
Chicago, IL 60601
(312)726-6200
(800)221-6827

National Head Injury Foundation, Inc.
333 Turnpike Road
Southborough, MA 01772
(508)485-9950

National Health Information Center
P.O. Box 1133
Washington, DC 20013-1133
(800)336-4797

National Homecaring Council
235 Park Avenue South
New York, NY 10003
(212)674-4990

National Hospice Federation
1901 Moore Street, Suite 901
Arlington, VA 22209
(703)243-5900

National Information Center for Orphan Drugs and Rare Diseases (NICODARD)
P.O. Box 1133
Washington, DC 20013-1133
(800)456-3505

National Institutes of Health
9000 Rockville Pike
Bethesda, MD 20892
(301)496-4000

National League for Nursing
American Public Health Association
10 Columbus Circle
New York, NY 10019
(212)582-1022

National Organization for Rare Disorders (NORD)
P.O. Box 8923
New Fairfield, CT 06812
(203)746-6518

National Pediatric HIV Resource Center
Children's Hospital of New Jersey
15 S. Ninth Street
Newark, NJ 07107
(201)268-8251
(800)362-0071
(201)485-7769 FAX

National Spinal Cord Injury Association
369 Elliot Street
Newton Upper Falls, MA 02164

Respite Care
Texas Respite Resource Network (TRRN)
National Clearinghouse
PO Box 7330
Station A
San Antonio, TX 78207-3198
(512)228-2794

Special Connections
P.O. Box 6702
Holliston, MA 01746
(800)634-LINK
Maintains a database for new and used equipment.

Spina Bifida Association of America
4590 MacArthur Boulevard, NW
Suite 250
Washington, DC 20007
(202)944-3285

The Kids on the Block, Inc.
9385-C Gerwig Lane
Columbia, MD 21046
(301)290-9095
(800)368-Kids

United Cerebral Palsy Association
1522 K Street, NW
National Office or Community Services Division
Suite 1112
Washington, DC 20005
(202)842-1266
(800)872-5827 (except Washington, DC)

United Ostomy Association, Inc.
36 Executive Park, Suite 120
Irvine, CA 92714
(714)660-8624

Voluntary Hospitals of America, Inc.
50 17th Street, NW, Suite 300
Washington, DC 20036
(202)822-9750

Parent groups

American Self-Help Clearinghouse
Saint Clares-Riverside Medical Center
Denville, NJ 07834
(201)625-7101
(201)625-9053 TDD

Exceptional Parent Magazine
1170 Commonwealth Avenue
Boston, MA 02134-9942
(800)852-2884
Federation for Children with Special Needs
95 Berkeley Street, Suite 104
Boston, MA 02116
(800) 331-0688 (Massachusetts only)
(617) 482-2915
The Federation operates CAPP / National Parent Resource Center. For more information, contact the regional office nearest you.

Central Office
CAPP/Center
Federation for Children with Special Needs
95 Berkeley Street, Suite 104
Boston, MA 02116
(617)482-2915

Midwest Regional Center
PACER Center
4826 Chicago Avenue
Minneapolis, MN 55417
(612)827-2966

Northeast Regional Center
Parent Information Center
P.O. Box 1422
Concord, NH 03301
(603)224-0402

South Regional Center
PEP, Georgia ARC
1851 Ram Runway #104
College Park, GA 30337
(404)761-3150

West Regional Center
Washington PAVE
12208 Pacific Hwy, SW
Tacoma, WA 98499
(206)588-1741

National Clearinghouse on Family Support and Children's Mental Health
Portland State University
PO Box 751
Portland, OR 97207
(503)231-5781

National Parent Network on Disabilities
1600 Prince Street, Suite 115
Alexandria, VA 22314
(703)684-6763

Parent Care Inc.
9041 Colgate Street
Indianapolis, IN 46268-1210
(312)872-9913
Parent Education Advocacy Training Center (PEATC)
228 S. Pitt Street, Room 300
Alexandria, VA 22314

Pathfinder Resources, Inc.
2324 University Avenue W.
Suite 105
St. Paul, MN 55114
(612)647-6905
(612)647-6908 FAX

SKIP, Inc. / Sick Kids (Need)
Involved People
National Headquarters
990 Second Avenue
New York, NY 10022
(212)421-9160

Education/Vocational

American Vocational Association
(AVA)
1410 King Street
Alexandria, VA 22314
(703)683-3111
(800)826-9972

Apple Computer Office for Special
Education Material
(800)732-3131 x275

Association for Children and Adults
with Learning Disabilities
4156 Library Road
Pittsburgh, PA 15234
(412)341-1515

AT&T Computers (General Sales)
(800)247-1212

Center for Special Education
Technology
c/o Council for Exceptional Children
(800)873-8255

Clearinghouse on Disability Information
Office of Special Education &
Rehabilitation Services (OSERS)
Room 3132
Switzer Building
330 C Street SW
Washington, DC 20202-2524

Commission on Certification of
Work Adjustment and Vocational
Evaluation Specialists (CCWAVES)
1835 Rohlwing Road
Rolling Meadows, IL 60008

Council for Exceptional Children
(CEC)
1920 Association Drive
Reston. VA 22091
(703)620-3660 Voice & TDD
(703)264-9494 FAX

Council of State Administrators of
Vocational Rehabilitation
PO Box 3776
Washington, DC 20007
(202)638-4634

Disability Rights Education and
Defense Fund
(800)466-4232 Voice/TDD
(510)644-2555 Voice
(510)644-2629 TDD

Division of Career Development (DCD)
1920 Association Drive
Reston, VA 22091-1589
(703)620-3660

Dole Foundation for the Employment
of Persons with Disabilities
1819 H Street, NW, Suite 850
Washington, DC 20006
(202)457-0318

ED-LINC
c/o Linc Associates
6065 Franatz Road, Suite 205
Dublin, OH 43017
(614)793-0698

Equal Employment Opportunity
Commission
(800)669-3362 Voice
(800)800-3302 TDD

ERIC Clearinghouse on Adult Career
and Vocational Education
1960 Kenny Road
Columbus, OH 43210
(800)848-4815

Higher Education & Adult Training
of People with Disabilities
(HEATH Center)
1 DuPont Circle, Suite 800
Washington, DC 20036
(800)54-HEATH
(202)939-9320 (in Washington, DC)

IBM Computer Special Needs
Information Referral Center
PO Box 2150
Atlanta, GA 30301-2150
(800)IBM-2133

Job Accommodation Network (JAN)
West Virginia University
809 Allen Hale, PO Box 6123
Morgantown, WV 26506-6123
(800)526-7234
(800)ADA-work
(800)526-4698 (in VA)

Job Opportunities for the Blind (JOB)
1800 Johnson Street
Baltimore, MD 21230
(800)638-7518

National Association of Rehabilitation Facilities
PO Box 17675
Washington, DC 20041
(703)648-9300

National Association of State Directors of Special Education
1800 Diagonal Road, Suite 320
Alexandria, VA 22314
(703)519-3800

National Center for Learning Disabilities
99 Park Avenue
New York, NY 10016
(212)687-7211

National Center for Youth with Disabilities (NYCD)
University of Minnesota
UMHC, Box 721
Minneapolis, MN 55455
(800)333-6293 Voice
(612)624-3939 TDD

National Clearinghouse for Bilingual Education (NCBE)
1118 22nd Street NW
Washington, DC 20037
(800)321-6233
(202)467-0867

National Clearinghouse on Post Secondary Education for Individuals with Disabilities (HEATH Resource Center)
One Dupont Circle NW
Suite 800
Washington, DC 20036-1193
(800)544-3284 Voice/TDD
(202)939-9320

National Committee for Citizens in Education
900 2nd Street, NE, Suite 8
Washington, DC 20002
(202)408-0447
(800)NETWORK

National Lekotek Center
2100 Ridge Avenue
Evanston, IL 60204
(708)328-0001

National Organization on Disability
(800)248-ABLE

National Rehabilitation Association
1910 Association Drive
Reston, VA 22091
(703)715-9090
(703)715-9209 TDD

National Rehabilitation Information Center (NARIC)
8455 Colesville Road, Suite 935
Silver Springs, MD 20910-3319
(800)34-NARIC
(301)588-9284

Office of Special Education and Rehabilitation, Apple Computer, Inc.
20525 Mariani Avenue, MS 43S
Cupertino, CA 95014
(408)974-7910
(408)974-7911 TDD

Office of Special Education and Rehabilitative Services (OSERS)
Room 3018 Switzer Building
330 C St SW
Washington, DC 20202-2524
(202)732-1723

Office of Vocational & Adult Education
U.S. Dept. of Education
Policy Analysis Staff
Room 4525, Switzer Building
330 C Street SW
Washington, DC 20202

President's Committee on the Employment of People with Disabilities
1331 F Street NW
Suite 300
Washington, DC 20004-1107
(202)376-6200 Voice
(202)376-6205 TDD

Project School Care
Children's Hospital
Gardner 614
300 Longwood Avenue
Boston, MA 02115
(617)735-6714

RESNA
RESNA Technical Assistance Project
Suite 700
1101 Connecticut Avenue NW
Washington, DC 20036
(202)857-1140

Resource Access Project (RAP)
240 Col. Wolfe School
403 E. Healey
Champaign, IL 61820
(217)333-3876
Network for Head Start.

SPECIALNET
GTE Education Services, Inc.
2021 K Street, NW
Suite 215
Washington, DC 20006
(202)835-7300

The American Council on Rural Special Education (ACRES)
Miller Hall 359
Western Washington University
Bellingham, Washington 98225

Individuals with Disabilities
S-151 Waisman Center
1500 Highland Avenue
Madison, WI 53705
(608)262-6966 Voice
(608)263-5408 TDD

Financing

Federal Hill-Burton Free Care Program
Department of Health & Human Services
5600 Fishers Lane
11-25 Park Lawn Building
Division of Facilities Compliance
Rockville, MD 20857
(800)638-0742
(800)492-0359 (in MD)

Health Care Financing Administration
U.S. Department of Health & Human Services
(800)638-6833

Health Insurance Association of America
1001 Pennsylvania Avenue, NW
5th Floor South
Washington, DC 20004-2599
(202)624-2000

National Association of Insurance Commissioners
120 W 12th Street, Suite 1100
Kansas City, MO 64105
(816)842-3600

National Early Childhood Technical Assistance System (NEC*TAS)
University of North Carolina at Chapel Hill
CB# 8040
500 NCNB Plaza
Chapel Hill, NC 27599
(919)962-2001

Social Security Administration
(800) 772-1213

State Medicaid Directors Association
810 First Street NE, Suite 500
Washington, DC 20002
(202)682-0100

Recreation

Amazing Golfer
(800)3-Golfer

American Alliance for Health, Physical Education, Recreation and Dance
2775 South Quincy Street, Suite 300
Arlington, VA 22206
(703)476-3400

National Handicapped Sports and Recreational Association
451 Hungerford Drive, Suite 100
Rockville, MD 20850
(301)217-0960 Voice
(301)217-0963 TDD

National Institute of Arts & Disabilities (NIAD)
2775 South Quincy Street, Suite 300
Arlington, VA
(510)620-0290
National Parks Service

Department of Special Programs and Populations
Department of the Interior
18th and C Streets, NW
Washington, DC 20240
(202)343-3674

National Therapeutic Recreation Society
2775 South Quincy Street, Suite 300
Arlington, VA 22206
(703)820-4940

North American Riding for the Handicapped Association, Inc.
(800)369-7433

Very Special Arts
Education Office
John F. Kennedy Center for the Performing Arts
Washington, DC 20566
(202)662-8899

Legal

Center for Law and Education
Larsen Hall, 6th Floor
14 Appian Way
Cambridge, MA 02138
(617)495-4666

Child Welfare League of America, Inc. (CWLA)
220 First St, NW, Suite 310
Washington, DC 20001-2085
(202)638-2952

Clearinghouse on Disability Information
Office of Special Education & Rehabilitative Services
U.S. Department of Education
Room 3132, Switzer Building
Washington, DC 20202-2524
(202)732-1241

DREDF/Disability Rights Education and Defense Fund, Inc.
2212 6th Street
Berkeley, CA 94710
(415)644-2555

For general information about the ADA:
Department of Justice funded ADA Technical Assistance Unit of the Disability Rights Education and Defense Fund
2212 6th Street
Berkeley, CA 94710
(800)466-4232 Voice
(800)466-4ADA TDD

Information about ADA Requirements for accessibility contact:
Architectural and Transportation Barriers Compliance Board
1111 18th Street, NW, Suite 501
Washington, DC 20036
(800)USA-ABLE Voice and TDD

Information about ADA Requirements for employment:
Equal Employment Opportunity Commission
1801 L Street, NW
Washington, DC 20507
(800)669-EEOC Voice
(800)800-3302 TDD

Information about ADA requirements for public accommodations and state/local government services:
Department of Justice (DOJ)
Office of Americans with Disabilities Act
Civil Rights Division
P.O. Box 66118
Washington, DC 20035-6118
(202)514-0301 Voice
(202)514-0381 TDD

Information about ADA requirements on transportation:
Department of Transportation (DOT)
400 Seventh Street SW
Washington, DC 20590
(202)366-9305 Voice
(202)755-7687 TDD

Mental Health Law Project
1101 15th Street, NW, Suite 1212
Washington, DC 20005
(202)467-5730

National Association of Protection and Advocacy Systems
900 Second Street NE, Suite 211
Washington, DC 20002
(202)408-9514

National Association of Protection and Advocacy Systems (NAPAS)
900 2nd Street NE, Suite 211
Washington, DC 20002
(202)408-9514

National Center for Law and the Deaf
(202)651-5373 Voice/TDD

Office of Civil Rights, National Office
Department of Education
400 Maryland Avenue SW
Switzer Building, Room 5000
Washington, DC 20202
(202)708-5366

Office of Civil Rights, Region I (New England)
U.S. Department of Education
John W. McCormack Post Office and Courthouse
Room 222, 01-0061
Boston, MA 02109-4557
(617)223-9662 TDD
(617)223-9695

Office of Civil Rights, Region II (NJ, NY, Puerto Rico, Virgin Islands)
U.S. Department of Education
26 Federal Plaza
33rd Floor, Room 33-130, 02-1010
New York, NY 10278-0082
(212)264-4633
(212)264-9464 TDD

Office of Civil Rights, Region III (DE, DC, MD, PA, VA, WV)
U.S. Department of Education
3535 Market Street
Room 6300, 03-2010
Philadelphia, PA 19102-3326

Office of Civil Rights, Region IV (AL, FL, GA, KY, MS, NC, SC, TN)
U.S. Department of Education
P.O. Box 2048, 04-3010
Atlanta, GA 30301-2048
(404)331-2954
(404)331-7816 TDD

Office of Civil Rights, Region V (IL, IN, MI, MN, OH, WI)
U.S. Department of Education
401 South State Street, Room 700C, 05-4010
Chicago, IL 606005-1202
(312)886-3456
(312)353-2541 TDD

Office of Civil Rights, Region VI (LA, NM, OK, TX, AR)
U.S. Department of Education
1200 Main Tower Building, Suite 2260, 06-5010
Dallas, TX 75202-9998
(214)767-3959
(214)767-3639 TDD

Office of Civil Rights, Region VII (IA, KS, MO, NE)
U.S. Department of Education
10220 N. Executive Hills Boulevard, 8th Floor
Kansas City, MO 64153-1367
(816)891-8026
(816)374-6461 TDD

Office of Civil Rights, Region VIII (CO, MT, ND, SD, UT, WY)
U.S. Department of Education
Federal Building, Suite 310, 08-7010
Denver, CO 80204-3582
(303)844-5695
(303)844-3417 TDD

Office of Civil Rights, Region IX (AZ, CA, HI, NV, Guam, Trust Territory of the Pacific Islands, American Somoa)
U.S. Department of Education
Old Federal Building
50 United Nations Plaza, Room 239, 09-8010
San Francisco, CA 94102-4102
(415)556-7000
(415)556-6806 TDD

Office of Civil Rights, Region X (AK, ID, OR, WA)
U.S. Department of Education
915 Second Avenue, Room 3310, 10-9010
Seattle, WA 98174-1099
(206)553-6811
(206)553-4542 TDD

Special Advisor on Disability Issues
U.S. Department of Housing & Urban Development
451 7th Street SW
Washington, DC 20410
(202)426-6030

Task Force on the Rights and Empowerment of Americans with Disabilities
907 6th St SSW, Suite 516C
Washington, DC 20024
(202)488-7684
(202)484-1370 TDD

U.S. Department of Justice
Civil Rights Division
Coordination & Review Section
PO Box 66118
Washington, DC 20035-6118
(202)514-0301 Voice
(202)514-0381/83 TDD

APPENDIX C Suggested Readings

Disability. 1992.
(Publication No. 05-10029)
Federal Social Security Office.
(800) 772-1213

Paying the Bills. 1992.
Parent Members of New England Serve
Regional Task Force on Health Care
Financing.

SSI 1992.
(Publication No. 05-11000).
Federal Social Security Office
(800) 772-1213

Children Assisted by Medical Technology in Educational Settings: Resources for Training. 1991.
Project School Care
Gardner 610
Children's Hospital
300 Longwood Avenue
Boston, MA 02115

Vocational Preparation and Employment of Students with Physical and Multiple Disabilities. 1991.
Paul H. Brookes Publishing Co., Inc.
P.O. Box 10524
Baltimore, MD 21285-0624

The Effective Driver of Handicapped Students. 1990.
Korn G., Korn JA, Kingston, NH:
SAFEWAY Training & Transportation
Services, Inc. (603)642-3642

How to Get Quality Care for a Child with Special Health Needs. A guide to health services and how to pay for them. 1990.
Georgianna Larson and Judith A. Kahn
Lifeline Press
2500 University Avenue West
St. Paul, MN 55114

Negotiating the Special Education Maze: A Guide for Parents and Teachers. 1990.
Woodbine House
5615 Fishers Lane
Rockville, MD 20852

Roadmap to Transition for Young Adults with Severe Disabilities. 1990.
ERIC Clearinghouse on Handicapped
and Gifted Children
1920 Association Drive
Reston, VA 22091

The Self-Help Sourcebook: Finding and Forming Mutual Aid Self-Help Groups. 3rd edition. 1990.
St. Clares-Riverside Medical Center
Denville, NJ 07834
Edited by Edward J. Madara and
Abigail Meese

The Workspace Workbook: An Illustrated Guide to Job Accommodation and Assistive Technology. 1990.
Publications Department
National Easter Seal Society
East Lake Street, Chicago, IL 60601

Assistive Technology Sourcebook. 1989.
Association for the Advancement of
Rehabilitation Technology (RESNA)
1101 Connecticut Avenue, NW,
Suite 700
Washington, DC 20036

Becoming Informed Consumers: A National Survey of Parents' Experience with Respite Services. 1989.
Human Services Group
2336 Massachusetts Avenue
Cambridge, MA 02140

Children Assisted by Medical Technology in Educational Settings: Guidelines for Care. 1989.
Project School Care
Gardner 610
Children's Hospital
300 Longwood Avenue
Boston, MA 02115

Colleges That Enable: A Guide to Support Services Offered to Physically Disabled Students on 40 U.S. Campuses. 1989.
Jason Tweed
4B Tanglewood Drive
Reading, PA 19607

How to Obtain Funding for Augmentative Communication Devices. 1989.
Prentke Romich Co.
1022 Heyl Road
Wooster, OH 44691

Respite Services: A National Survey of Parents' Experiences. The Exceptional Parent. 1989.
Psy-Ed Corporation
1170 Commonwealth Avenue
Boston, MA 02134

Campus Daze: Easing the Transition from High School to College. 1988.
Octameron Associates
PO Box 3437
Alexandria, VA 22302
(cost $3.00)

Choices and Empowerment Towards Adulthood: A Self-Advocacy Manual for Students-in-Transition. 1988.
Self-Advocacy Training Project
Disabled in Action of Baltimore
3000 Chestnut Avenue
Baltimore, MD 21211

Kaleidoscope: A Spectrum of Articles Focusing on Families. 1988.
Kaleidoscope
Connecticut's University Affiliated
Program on Developmental Disabilities
The University of Connecticut
991 Main Street
East Hartford, CT 06108

Managing the School Age Child with a Chronic Health Condition. 1988.
Georgianna Larson, ed.
Pathfinder Resources
2324 University Avenue W.
Minneapolis, MN 55114

Parent Written Care Plans: Instructions for the Respite Setting. The Exceptional Parent. 1988.
Psy-Ed Corporation
1170 Commonwealth Avenue
Boston, MA 02134

Quality Health Care for People with Developmental Disabilities: A Guide for Parents and Other Caregivers. 1988.
Kathleen Pfaffinger and Richard P. Nelson
Minnesota University Affiliated
Program on Developmental Disabilities
University of Minnesota
6 [illegible]ee Hall
150 Pillsbury Drive S.E.
Minneapolis, MN 55455

Respite Care: An Annotated Bibliography. 1988.
Families as Allies Project
Research & Training Center to
Improve Services for Seriously
Emotionally Handicapped Children
and their Families
Portland State University
P.O. Box 751
Portland, OR 97207-0751

Successful Transition from School to Work and Adult Life: A Handbook for Students, Parents, Teachers and Advocates. 1988.
Self-Advocacy Training Project
Disabled in Action of Baltimore
3000 Chestnut Avenue
Baltimore, MD 21211

Understanding Your Health Insurance Options. A Guide for Families Who Have Children With Special Health Care Needs. 1988.
Margaret A. McManus
McManus Health Policy Inc.
3615 Wisconsin Avenue NW
Washington DC 20016
(202)895-1580

A Parent Guide for Doctors Visits. 1987.
Connecticut Developmental Disabilities Council.
90 Pitkin Street
E. Hartford, CT 06108

Funding Technology: Ways Through the Maze. The Exceptional Parent. 1987
Psy-Ed Corporation
1170 Commonwealth Avenue, third floor
Boston, MA 02134

How to Develop a Community Network. 1987.
Pathfinder
2324 University Avenue W.
St. Paul, MN 55114

Making Your Medical Decisions. 1987.
Bowen Hosford
Harper and Row
Keystone Industrial Park
Scranton, PA 18512

Directory of College Facilities and Services for the Disabled. (2nd ed.) 1986.
Oryx Press
2214 North Central at Encanto
Phoenix, AZ 85004-1483

Insurance Can Help Pay for Adaptive Equipment. The Exceptional Parent. 1986. Psy-Ed Corporation
1170 Commonwealth Avenue
Third Floor
Boston, MA 02134

Enhancing Transition from School to the Workplace for Handicapped Youth: The Role of Special Education. 1985.
Office of Career Development for
Special Populations
College of Education
University of Illinois at Urbana
Champaign
1310 S. Sixth Street
Champaign, IL 61820

How to Get Services By Being Assertive. 1985.
Charlotte Des Jardins
Coordinating Council for Handicapped
Children
220 South State
Chicago, IL 60604

The Respite Care Manual. 1984.
Temporary Care Services, Inc.
P.O. Box 542
Cambridge, MA 02238

Health Care Coverage and Your Disabled Child: A Guide for Parents. 1983.
United Cerebral Palsy of Minnesota
1821 University Avenue
St. Paul, MN 55014

Alternatives: A Family Guide to Legal and Financial Planning for the Disabled
Mark L. Russell
First Publications, Inc.
Box 5072
Evanston, IL 60204

RESNA
Technical Assistance Project
1101 Connecticut Avenue, NW
Suite 700
Washington, DC 20036
(202)857-1140

Competitive Employment: Issues and Strategies
F.R. Rusch (Ed.)
Paul H. Brookes Publishing Company
P.O. Box 10624
Baltimore, MD 21285

Employers and Parents Taking Action: Transitional Work Opportunities for Disabled Youth
Project Coordinator
Regional Information Exchange
Human Interaction Research Institute
1845 Sawtelel Blvd.
Los Angeles, Ca 90025

Financial Planning for the Handicapped
Don P. Holden and Charles Thomas
2600 South First Street
Springfield, IL 62717

Getting Employed, Staying Employed: Job Development and Training for Persons with Severe Handicaps
Caven S. McLoughlin, J. Bradley
Garner, and Michael Callahan
Paul H. Brookes Publishing Co.
PO Box 10624
Baltimore, MD 21285

How to Provide for their Future
Association for Retarded Citizens of the U.S.
PO Box 6109
Arlington, TX 76011

Life After School for Children with Disabilities: Answers to Questions Parents Ask About Employment and Financial Assistance
National Association of State Directors of Special Education
202 1 K Street
Northwest, Suite 315
Washington, DC 20006
(202)296-1800

Meeting the Medical Bills (videotape)
National Center for Clinical Infant Programs
2000 14th Street N, Suite 380
Arlington, VA 22201-2500
(703)528-4300

Pathways to Employment for Developmentally Disabled Adults
W. Kiernan and J. Stark, Eds.
Paul H. Brookes Publishing Company
PO Box 10624
Baltimore, MD 21285

Pocket Guide to Federal Help for
Individuals with Disabilities
Clearinghouse on Disability
Information
US Dept. of Education
Room 3132 Switzer Building
Washington, DC 20202-2524
(202)732-1241, 1245, 1723

Social Security and SSI Benefits for
Children with Disabilities
(Publication No. 05-10026).
Federal Social Security Office
(800) 772-1213

Toward Independence - An Assessment
of Federal Laws and Programs
Affecting Persons with Disabilities -
with Legislative Recommendations
National Council on the Handicapped,
from Superintendent of Documents
Washington, DC 20402
#052-03-01022-4

Understanding Social Security
(Publication No. 05-10024).
Federal Social Security Office
(800) 772-1213

Augmentative and Alternative
Communication Journal
Williams & Wilkins
P.O. Box 64025
Baltimore, MD 21264
(301)528-4000
(800)638-6423

Journal of Special Education
Technology
Peabody College
Vanderbilt University
Box 328
Nashville, TN 37203
(615)322-8150

The Computer Monitor
Parent Advocacy Coalition for
Educational Rights
Computer Resource Center
4826 Chicago Avenue, South
Minneapolis, MN 55417-1055
(612)827-2966

APPENDIX D Glossary

Activities of Daily Living (ADL) - A term used by some health and home care providers to describe personal care, such as bathing, toileting, eating, mobility, simple health care procedures, and occasionally, housekeeping activities.

Advocate - An advocate is someone who can listen to your problems and ideas and help you make decisions or find solutions.

Allowed Charges - Charges by a health provider, which qualify as covered expenses and therefore the program will pay in whole or in part, minus any deductible, co-payment, or table of allowance included in the program.

Americans with Disabilities Act (ADA) (PL101-336) - Passed in 1990 to supplement civil rights legislation enacted under the Rehabilitation Act, ADA prohibits discrimination against individuals with disabilities. This act applies to all employers, including state and local government, with 25 or more employees after July 26, 1992, and all employers with 15 or more employees after July 26, 1994. This law applies to both adults and children. Places such as hotels, auditoriums, grocery stores, retail stores, public transportation terminals, zoos, museums, parks, schools and day care centers are just some of the businesses/ services covered under the new law.

Balance Billing - Where someone bills you for the remainder of a cost not paid for by your insurance provider.

Case Manager - A person who works with the family to plan for services and who communicates with many service providers. A case manager could be a social worker, a nurse, an insurance representative, or a professional from a home care company. A case manager tries to oversee and bring together the many parts of the care your child needs.

Certified Nurse's Aide - Assists in nursing care by performing basic unskilled tasks and procedures. They are certified and have more training and documented skills than an uncertified nurse's aide or assistant has. A Certified Nurse's Aide is trained and supervised by a Registered Nurse.

Classroom Aide - A person hired by the school system to help the teacher in the classroom. Your child might have a one-on-one classroom aide if your child needs close, individual attention for learning.

Co-Insurance - A provision of a program in which the insured person shares in the cost of covered services on a percentage basis. A typical co-insurance arrangement is 80%-20%. This means the carrier will pay 80% of the benefit of the covered health service and the patient will pay 20%.

Confidentiality - Your child's records and information will only be shared with people directly involved in your child's care, i.e., the health care team.

Discharge Planning/Continuing Care - A hospital department, staffed by professionals familiar with your community's health resources. In some hospitals, your child's main nurse may do the discharge planning if the hospital does not have a separate staff for this service. The main goals of discharge are to help the health care team create a plan for your child's health care after s/he leaves the hospital and to make sure your child has the resources in place in the community that s/he needs.

Durable Medical Equipment - Health care equipment that can be used over and over again (e.g. hospital beds, ventilators, I.V. poles, wheelchairs, walkers).

Early Intervention - Any services or programs, for children 3 and under, created to improve the development of a child who is considered at risk, disabled or disadvantaged. These services are meant to help decrease or eliminate the disabilities or risks as the child grows older.

Estate Planning - The process of creating a formal document that outlines who you want your property to go to. This process is best done with the help of professionals, such as a lawyer or accountant.

Family Educational Rights and Privacy Act, 20 USC 1232 (g)(4)(B) - Protects a student's right to privacy by requiring school records to be kept private.

Handicapped - Any person who has a physical or mental impairment that substantially limits one or more major life activities, who has a record of such an impairment, or who is regarded as having such an impairment. (Based on Rehabilitation Act of 1973.)

Home Health Aide - Staff who may help with a person's personal hygiene, meal preparation, perform light housekeeping, or provide health-related assistance, such as taking vital signs. Some home health aides are employees of home health or home nursing agencies and are trained by that agency. Some people may not have formal training, but may have many years of experience in working with people in their homes.

Home Health Care - Includes a wide range of physician-directed services, including nursing, respiratory, physical and occupational therapy, which are provided in patients' homes. Home health care is meant to help a person maintain health and minimize the effects of disability or illness.

Home Nursing Care - Is one form of home health care. Home nursing care can only be provided by a licensed nurse, either LPN or RN.

IDEA: Individuals with Disabilities Education Act (PL 101-476) - is based upon the Education for All Handicapped Children Act (PL 94-142). A student must be enrolled in special education in order to receive the services mandated by IDEA. Students with a wide range of disabilities may be eligible for special education and related services. These disabilities include: speech impairment, severe vision and hearing problems, learning disabilities, mental retardation, emotional problems, physical disabilities and other health impairments. There is state to state variation in the way in which a child qualifies for special education services, but in general, if a child has a disability that makes it hard for him/her to obtain education without extra services, s/he is eligible for an evaluation to determine what services need to be provided.

Individual Education Plan - Is a special education service plan for your child's school program and is required for all students receiving special education services. The IEP outlines your child's educational goals and any services/assistance your child needs to meet those goals.

Insurance Provider - Both private insurance companies/plans, including HMOs and PPOs, and public programs, like Medicaid, unless otherwise indicated.

Interagency Coordinating Committee - Mandated by PL 99-457 for each state. It is a lead agency made up of parents, legislators and state agency representatives.

Least Restrictive Environment - Generally, this means that a child with special needs is educated as much as possible with children who do not have special needs. The school program should still meet all of the child's education needs. You may hear teachers, principals, or special education directors mention words such as "mainstreaming," "integration," and "inclusion" when they talk about making suggestions for your child's education program and having your child in the least restrictive environment. Be sure you ask the school staff exactly what they mean when they use those terms.

Licensed Practical Nurse (LPN) - A graduate of an approved educational program who has qualified under the necessary state licensure regulations. May administer care under the direction of a licensed physician or registered nurse.

Medicaid (Title XIX) - A joint state-federal health insurance program administrated by the states' health department or public welfare department under the Health Care Financing Administration (HCFA). Medicaid makes payments for approved health services that hospitals, health agencies and private practitioners provide to people who qualify for Medicaid. A person usually qualifies for Medicaid if his/her income is not more than the maximum welfare benefits, s/he is disabled and has limited assets, or s/he spent a certain percentage of his/her income and/or assets on medical expenses.

Medicaid Spenddown - Allows you to become eligible for Medicaid as a medically needy individual by spending sufficient income and/or assets on medical expenses.

Medicaid Waivers - Allows people who might not otherwise qualify for Medicaid, due to income and asset rules, to receive assistance. These waivers pay for services provided in the home for people who would otherwise need to receive their health care in the hospital or other institutional setting.

Medicare - Federal program administered by the Health Care Financing Administration (HCFA). Medicare generally applies to people over 65, but also covers people under 65 who have been entitled to social security benefits (SSDI) for 2 years. The Medicare program also covers children with chronic renal disease who need a kidney transplant or maintenance dialysis.

Occupational Therapy (OT) - Activities that concentrate on helping a child with fine motor skills and perceptual abilities (e.g. bathing, feeding, directing a wheelchair, rolling a ball, finger painting) and adaptations on equipment.

Personal Care Attendant - May be employees of a home health agency or may be hired privately. They assist the person with activities such as dressing, general homemaking duties, and moving in and out of bed, chairs and the bathroom.

Physical Therapy (PT) - Activities or routines to help a child improve movement skills through exercise, whirlpool and other methods.

PL 93-112 (Section 504 of Rehabilitation Act of 1973) - Federal legislation passed to protect the civil rights of persons with disabilities. Its definition of handicapped is the basis for later statutes regarding rights and eligibility for services. It also prohibits discrimination against individuals solely on the basis of physical impairment, in federally assisted or run programs, including any health or social program supported by federal dollars. The law is also aimed at schools, in an attempt to prevent them from excluding or restricting an educational program for students with health impairments.

PL 99-457 (The Education of the Handicapped Act Amendments of 1986) - Congress passed The Education of the Handicapped Act Amendment (PL 99-457) to address the needs of young children with disabilities. PL 99-457 consists of two parts: Title I, the so-called Part H (which addresses the child from zero through 2 years 11 months), and Title II, the extension of special education services to the 3 to 5 age group.

Title I (Part H) of PL 99-457 calls on states to coordinate Early Intervention services for infants and toddlers and to create a plan for how the services are to be implemented.

Title II of PL 99-457 extends the provisions of PL 94-142 to children aged 3 to 5. This part of the program is run by state departments of education. The educational services may be provided in small integrated groups, in separate programs or through home-based services. Eligibility requirements for different services vary greatly from state to state.

Plan to Achieve Self-support (PASS) - A federal program designed to help individuals achieve self-support. It allows someone to set aside some of their earned income or SSDI benefits to save for an item that will help them achieve self-support. This program has not been accepted in all states and you should consult your local social security office for your state's regulations.

Pre-existing Condition - A health condition that a person has before becoming eligible for health insurance. Your policy should list these conditions in writing and you should talk to someone at the insurance company to make sure you know exactly what the list is. Sometimes the insurance will not pay for care of the pre-existing condition or you may have to wait a certain amount of time before the insurance pays for care.

Registered Nurse (RN) - A graduate of an accredited school of nursing who has passed a licensing examination and is registered to practice in a particular state.

Respite Care - Care for a limited time, in which a family gets a "break" from caring for their child with special health care needs.

Social Security Disability Income - Ordinarily, any child under age 18 can receive payments if s/he receives Social Security survivors benefits or is the son or daughter of someone receiving Social Security retirement or disability benefits. If a child has a disability that began prior to age 22, s/he can continue receiving these benefits well into his/her adult years. This is called "disabled adult child's benefits." A disabled child, upon turning 18, can also become eligible for payments if s/he has earned the minimum number of work credit hours.

Speech Therapy - Activities or routines to help a child improve communication skills.

State Health Department - Each state has a health department, often called Department of Public Health, whose staff educate the public about many health issues. They have many health-related resources and in some states, may have case managers available to help you organize your child's care.

State Mental Health Agency - Each state has a state mental health agency, often called the Department of Mental Health, with staff who educate the public about emotional and mental health topics.

Supplemental Insurance - When you buy another insurance policy to try to cover the cost of services that your current insurance coverage will not pay for.

Supplemental Security Income Program (SSI) - A cash assistance federal program that pay benefits to disabled children under age 18 whose families have limited income or resources.

Team Meeting (educational) - Team members always include persons from family and school and may include health care and community service staff. Meetings are held to plan goals, objectives and services listed in the student's IEP.

Visiting Nurse Association (VNA) - An organization staffed by community nurses who come into the home for short periods of time. They do assessments, follow-up care, and can help do certain nursing procedures. They may also provide home health services.

Vocational Rehabilitation - A nationwide federal/state program that helps eligible individuals with disabilities with employment issues and in finding work. Individuals are generally assigned a counselor who will help the person through the process. The individual may have to pay some of the cost of services depending on the local agency and the individual's financial situation.

Vocational Training - Training to help prepare students to work in a particular job or occupation.

Waiting Period - Health plans may provide benefits or coverage for an illness only after a certain amount of time has passed after you sign up for the plan. Waiting for that time to pass before you receive your benefits is called the waiting period.

Project School Care, directed by Judith S. Palfrey M.D., is a program of Children's Hospital, Boston established to document and foster access to educational opportunities for children with special health care needs, particularly children who are assisted by medical technology.

Project School Care offers services in consultations, training and information in Massachusetts and nationally.

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(617)735-6714
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