

Coordinated Care Record



Developed by:
University of Illinois at Chicago
Division of Specialized Care for Children

Table of Contents

Acknowledgments	i
Parent to Parent Letter	ii
Joys.....	iv
Introduction	vi
I. Home Medical Record	
Introduction	I-1
Tips.....	I-1
Home Medical Record Forms	I-5
• Identification Numbers (Form CCR.38)	
• Blank Calendar (Form CCR.2A)	
• Appointment Calendar (Form CCR.2B)	
• Physicians/Therapists/Dentists (Form CCR.4)	
• (or other professionals involved in child’s care)	
Diagnosis/Medications/Hospitalizations	
• Diagnosis (Form CCR.6)	
• Medications (Form CCR.28)	
• Hospitalizations (Form CCR.30)	
Medical History	
• Birth History (Form CCR.10)	
• Family History (Form CCR.12)	
• Feeding History (Form CCR.24)	
• Growth and Development Record (Form CCR.26)	
• Growth Charts	
Routine Health Care	
• Routine Health Care (Form CCR.13)	
• Child’s Illness/Infection/Injury Record (Form CCR.14)	
• Immunization and Allergy Record (Form CCR.20)	
• Dental Record (Form CCR.22)	
Specialized Health Care	
• Equipment/Supplies Sheet (Form CCR.32)	
• Tests and X-Rays (Form CCR.36)	
• (CT Scans, Chest X-Rays, EKG, Echo, Stress Test, Lab Work)	
• Notes (Form CCR.40)	
• Words and Their Meanings (Form CCR.8)	
• Medical Specialties and Specialists	
II. Funding	
Introduction	II-1
Tips	II-1
Private Insurance.....	II-3
Public Insurance.....	II-4
• Medicaid.....	II-4

• Medicare	II-5
• Division of Specialized Care for Children (DSCC)	II-5
• Comprehensive Health Insurance Plan (CHIP)	II-6
• Supplemental Security Income (SSI)	II-6
• Department of Rehabilitation Services (DORS).....	II-6
Other Possible Funding Resources	II-6
Insurance Terms Glossary	II-8
Worksheets.....	II-13
General Insurance Information.....	II-14
• Your Child’s Insurance Information (Form CCR.44)	
• Private Insurance Worksheet (Form CCR.46)	
• Public Insurance Worksheet (Form CCR.48)	
• Income Tax Expense Record (Form CCR.50)	
• Medical Travel Expense (Form CCR.52)	
• Notes (Form CCR.40)	
Funding Assistance Forms and Eligibility Letters	II-16
III. Early Intervention/Education/Vocation	
Introduction	III-1
Tips	III-2
Worksheets.....	III-5
• Education Information (Form CCR.54)	
• Education Record (Form CCR.56)	
• Notes (Form CCR.40)	
Child’s Educational Plan and School Reports	III-6
IV. Rights	
Introduction	IV-1
Obtaining Medical Records	IV-1
Appeals.....	IV-3
• Release of Information Form (Form CCR.58)	
• Notes (Form CCR.40)	
V. Other	
Introduction	V-1
Tips	V-1
Recommended Reading.....	V-5
Resources.....	V-9

Acknowledgments

This workbook was developed to help families organize the considerable and sometimes confusing array of information existing about their child with special health care needs. It can also be used to help coordinate and bring together the many services and providers of care involved in the child's life. The idea for the workbook came from the staff of the Division of Specialized Care for Children, however, it could never have been brought into being without the dedicated efforts of parents and care providers who reviewed, criticized and often rewrote its content. There is not sufficient room to recognize everyone who helped to make this idea a reality but it would be wrong for the Division not to acknowledge and thank the following persons for their very special commitment and contributions.

Wanda J. Thompson, Assistant Director for Program Support
Ron Renshaw, Program Support Specialist
Josie Negro, Project Secretary
Mitzi Adams, Parent
Scott and Shari Duros, Parents
Christine Felde, Parent
Natalie Fischer, Speech and Hearing Consultant
Dixie Gasparini, Parent
Christine Griffith, Nursing Consultant II
Donna Peterson, Nursing Consultant II
Jim Turner, Medical Social Consultant II
Kathleen Wittmeyer, Nursing Consultant II

Robert F. Biehl, M.D., M.P.H.
Director

Dear Parents,

You are the parents of an exceptional child. We are, too, and we've been working on this handbook in an effort to develop a tool which you can hang on to as you begin to manage the care and development of your child.

Raising children is a hard job. When you have a child with a handicap of any kind, you are going to be faced with many important issues in dealing with the care of your child. There are some 300,000 infants born every year with some type of birth defect. There are also many children who become the victims of trauma. This certainly means that you are not alone. You will need immense energy, self-knowledge and dedication as a parent. You will learn a lot about yourself - mainly, that you are strong and you can endure. Reactions of anger, fear, guilt, denial and grief are all very normal at this time. Don't ever hesitate to ask for help.

Let us share a few basic hints with you:

1. Always be aware that you as parents are, in fact, case managers of your child's care.
2. Trust your instincts when it comes to the care of your child.
3. Learn to be assertive.

This is advice from parents who have had many experiences. Here are some personal notes:

Mitzi: Although there will be times you'll feel you can't go on, there will also be times of happiness, fun and laughter. The sad tears you cry now will be happy tears as this special child of yours will bring a whole new meaning to your life. You will cherish those smiles and hugs. This little human being loves, needs and depends on you, and will complete your life in ways you never dreamed possible.

I sincerely hope you find this handbook useful many times; but, I'm sure that if even just once you may find some guidance and comfort, we will all feel richly rewarded. I wish you well.

Christine: As I was watching George Bush's inauguration with my five year old son, he said, "Mommy, I don't like Mrs. Bush's white hair." "Well," I answered, "I read a story about her, and it said her hair turned white when her little girl was very sick and died." My son thought this over for several minutes and asked, "Mommy, if Mrs. Bush gets very very happy now will her hair turn brown again?"

"No, Eric, some things cannot be changed."

Your life is changed now too. Everything is quite different. Some things are more difficult and some things are more special. Grow with all of this. Don't be afraid to ask for help in this management role. It is a job that can be learned. It can be done!

In working on this handbook our group came across this quote from Kahlil Gibran:

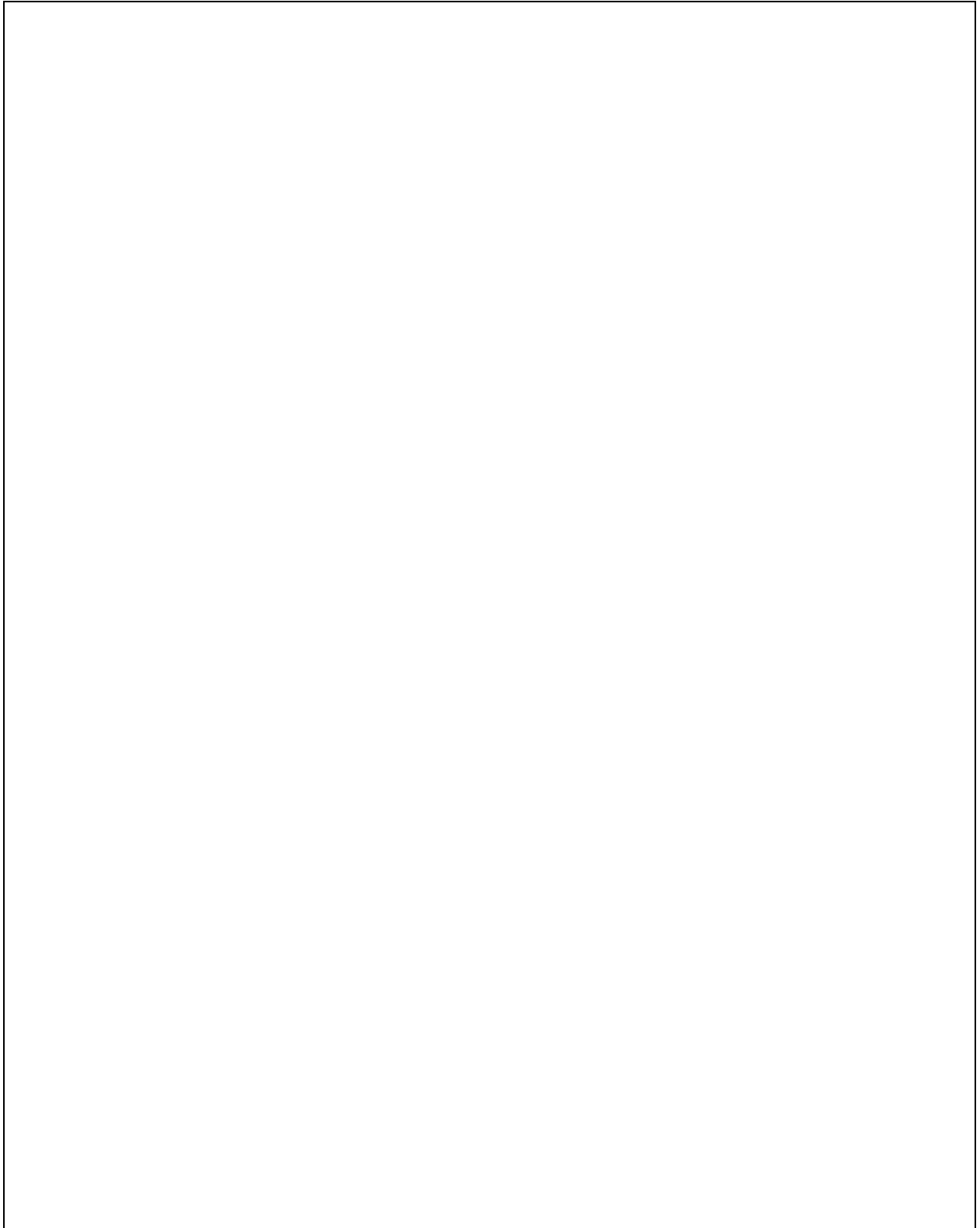
The deeper that sorrow carves in your being, the more joy you can contain.

May your joy sustain you!

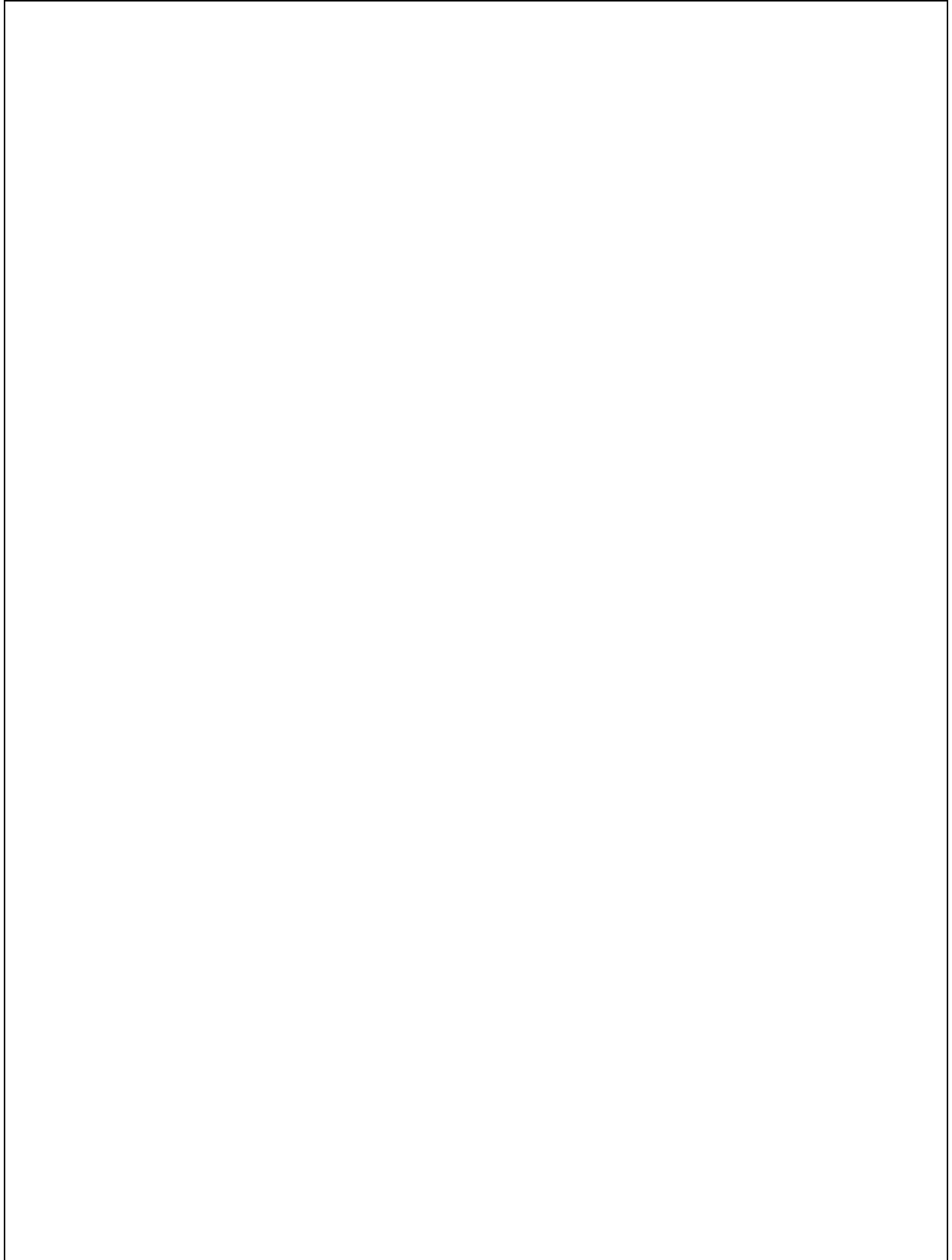
With great respect and love, we are
Mitzi Adams, mother of Trevor
Shari and Scott Duros, parents of Staci and Scott
Christine Felde, mother of Kara
Dixie Gasparini, mother of Ashley

Joys

Use these pages to record your special joys or your child's special accomplishments. Include photos if you like.

A large, empty rectangular box with a thin black border, intended for recording special joys or accomplishments. The box is currently blank.

Joys



Introduction

Your child with special health care needs faces challenges in many areas: medical, social, educational and vocational. Professionals in each of these fields can provide assistance within their own areas of knowledge, but you, as your child's parents, cannot leave the management of your child's care totally in the hands of the professionals. You must also become a part of the team caring for your child. This Coordinated Care Record has been designed to help you become a full member of your child's special health care team.

As parents, you know your child best. You live with your child and see him or her in all areas of life, at home, at school, at the doctor's office, etc. Also, as parents, you have only your child's interests at heart, so you are in a good position to advocate for your child. The services and providers of service will change throughout your child's life, but you will most likely remain as the constant in his or her life, the ones most familiar with your child and his or her history.

Health care and other services for your child will be most helpful when these services are made available in such a way that you have the maximum possible involvement. You can achieve this level of involvement only by becoming an equal partner with the professionals who are offering the services required by your child.

In order for you to become equal partners with professionals in caring for your child, you need to become educated consumers of whatever it is your child is receiving. If it is medical care, education, financial assistance or any other type of service, you need to learn about that service, who provides it, how you get it, and what your responsibilities are. The purpose of this workbook is to give you some guidelines to use as you become educated consumers. Another purpose is to supply you with a framework to help you gather information and coordinate care for your child.

You will be learning about different kinds of programs and services throughout your

child's life. You will meet people from many agencies, with a variety of backgrounds: doctors, nurses, teachers, social workers, etc. You will learn to ask the right kinds of questions to get the information you need to make decisions about your child's care. You will learn how to be a member of a team working for the betterment of your child. Skills you will learn include communicating, negotiating, coordinating, and coping, just to mention a few. This workbook will give you guidelines in the form of "Tips," worksheets to help organize information about your child, and a place to keep specific reports or papers important to your child's care.

The titles and order of the workbook sections were recommended by our parent advisers. They told us that parents worry first about what is wrong with their child and how to treat it. Therefore, the first section is a place to keep health and medical information. The worksheets reflect questions most often asked by health professionals or information most often required.

The next thing parents worry about is "how am I going to pay for this?" The second section addresses funding. The "Tips" discuss types of funding available to help pay for bills. The worksheets will help you identify your child's specific insurance coverage. There is also space for you to keep information about your eligibility and funding from the state's Division of Specialized Care for Children.

The third thing parents worry about is their child's education and whether they will be able to support themselves as adults. "Tips" include some general information about educational and vocational programs in Illinois. The worksheets are designed to help you identify and record the educational or vocational programs your child is involved in. A space is included for you to keep copies of important educational plans or school reports.

While we hope children will receive the services they need and parents and professionals will be able to work together as

teams, we realize this is not always the case. The section titled "Rights" contains information about your rights and what to do to assert those rights.

The last section is entitled "Other" because there was a lot of information the committee wanted to share with parents but it did not fit neatly into any of the other sections. So this section is just that - "Other."

Each section of the Coordinated Care Record includes pages for notes you may wish to

make. Also, you will be able to add pages to any of the sections, if you like. Use the Coordinated Care Record in the manner that you feel will make it the most helpful in meeting your personal needs.

The Division of Specialized Care for Children is committed to supporting the principles of family-centered, community-based, coordinated care. This workbook is a result of that commitment. We hope it will help you in your endeavors to obtain the best possible care and services for your child.

Home Medical Record

Introduction

Your child has a special health care need. Medical appointments are a part of your life. You may be involved with one or with many physicians. Your child may require additional services recommended by the physician, such as occupational or physical therapy. Laboratory studies, x-rays or other specialized testing may be recommended to assist the physician in learning more about your child's medical condition. Over the course of time you will find that you need to keep track of information regarding the medical services your child receives. This information will be useful when you take your child to a new physician, when your child becomes involved in a school program, or for some other reason you need to share information about your child's medical history. It may also assist you in keeping track of his or her progress, in order that you can gain an overall perspective on your child's medical care.

Tips

- Sometimes a physician may mention a possible diagnosis for your child's medical condition. Be sure that you understand whether a diagnosis is only suspected or is actually confirmed.
- Don't hesitate to ask questions.
- If—between visits—you think of questions you would like answered by your child's physician, write them down and take them with you to the next appointment.
- If you are not able to understand the medical language used by your child's physician or other professionals, ask them to explain it. If you do not have the opportunity to ask, obtain a medical dictionary to use as a reference book, or use a medical dictionary at your local library.
- There may be more than one medical treatment option for your child's condition. Ask what the options are and what can be expected from each option. Then decide which treatment you think will be best for your child.
- Ask if a second opinion would be helpful, if you are uncomfortable or confused about the diagnosis or treatment and uncertain about the correct decision as a parent.
- While second opinions can be helpful, be careful you do not become a medical "shopper," hunting for the doctor who says what you want to hear.
- Be sure you know what the specialist expects you to do next and what you can expect the specialist to do. Write those expectations down in the plan section of this book (CCR.42).
- Ask the specialist to whom he or she will send medical reports. Make a list of persons to whom you would like to have reports sent. Be sure that your child's pediatrician or your family doctor receives copies of reports from specialists, therapists, etc.
- If your child is seen by more than one specialist, be sure that they are each aware of the others involvement and that they share reports.
- When your child is referred to another doctor or specialist, ask about the purpose of the referral. Also find out what will be involved in the specialist's examination (such as lab work and x-rays). Ask about the reports the specialist will want to see

and take them with you or ask (in writing that they be sent).

- Most physicians and hospital social service departments who work with "special needs" children and their families are aware that other, non-medical services are sometimes needed (for example, counseling services for financial support) and will be able to help with referrals for such services when they recognize the need or when parents request such assistance. Don't hesitate to ask them to explain other services which you may be eligible to receive.
- Have the physician tell you the name of any medication that is prescribed. Then, be sure that this is the same medication that the pharmacist is providing. Handwriting can occasionally be misinterpreted.
- Ask the physician, nurse or pharmacist to explain to you any side effects of medications prescribed or situations in which a specific medication should not be used.
- Check to make sure that all prescriptions are filled correctly by reading the label and looking at the medicine's color and consistency. Check the size, shape and color of pills, if they have previously been prescribed, to see if they appear to be the same. If an error has been made, contact the pharmacist immediately.
- Learn how to change milliliters (ml) into teaspoon measurements (1 teaspoon = 5 ml or 5 cc). This will be helpful when liquid medication is prescribed.
- When possible, use the same pharmacist or pharmacy to fill all your child's prescriptions. This will permit the pharmacist to check readily to see what other medications your child is taking or has taken in the past and alert you and the doctor to possible medication interactions.

He or she can also become familiar with any problems your child has with taking medication (such as reactions).

- Become familiar with any medication prescribed for your child, its purpose, side effects, etc. Pharmacists are required to provide printed information regarding the medications they dispense. Be sure to read what is provided and ask the pharmacist any questions you may have about the medication.
- Check with physicians, nurses and therapists to learn if there is any equipment that could assist with your child's care or development at home.
- Obtain maintenance information on any special equipment that your child uses.
- When replacing equipment, be sure that the replacement item is the same as the original. Be sure that the equipment dealer provides a replacement item that meets the specifications of the original.
- Ask other parents about helpful tips they may have.

Medical Records

- It is not usually necessary to have copies of all reports at home, but it may be helpful to obtain diagnostic and surgical reports to take to new physicians any time care is being transferred. As your child's guardian you have the right to request copies of operative reports, hospital discharge summaries, and test results. You will usually need to sign a release or make a written request to obtain them. A sample request form has been included in the "Rights" section of this notebook (Form CCR.58). At times there will be a fee to cover the copying costs, so be sure to ask first! Some parents ask their family physician/pediatrician to obtain the reports and then have copies made at a lesser fee (or at no charge).

Pictures/Diagrams

- If your child has a birth defect or structural malformation, consider keeping a diagram of it in this section. You may wish to copy pictures from medical books at your local library or obtain pamphlets from national organizations pertaining to your child's diagnosis. Given an illustration of the normal structure, your physician should be able to draw in any variations to show your child's particular problem.
- If you do not have access to pictures of normal structures (anatomy) or common defects, perhaps your doctor could draw an illustration of your child's condition freehand. If your child's medical problem is something that can be seen, it may be useful to take photographs of your child before and after treatment.

Things To Take To An Appointment

- Birth/Development and Family History: You may wish to take the appropriate pages from this book each time your child sees a physician for the first time or when he or she is being admitted to the hospital.
- List of all medications and the dosages your child is currently taking. Also list any allergies or negative reactions your child has had to medications in the past.
- List of questions and concerns (you may want to make your own list of questions to keep in this book). Leave room to write in the doctor's answers! Include questions your child may have about his or her condition.
- Information about insurance coverage and other payment sources.
- Amusements, snacks, and loose change to entertain your child while in the waiting area.

- Consider taking a neighbor, friend, or baby-sitter to watch your child if you plan to speak privately or at length with the physician after your child has been examined.

What To Do If Your Child Is Hospitalized

- Prepare an information sheet about your child, including a list of favorite foods, bowel and sleeping habits, most enjoyed activities, etc. (Include the words your child uses for urinating and bowel movements.)
- Be sure that your insurance company, HMO, PPO or other third party payor has been notified and that precertification has been done (when required). If the Division of Specialized Care for Children is involved with your child, be sure to notify DSCC.
- When possible, staying with your child is a good idea. Most hospitals allow parents to stay 24 hours a day, if the child's medical condition permits it. If you cannot stay with your child in the hospital, visit regularly and as frequently as possible.
- At the end of a visit, be sure to make your child aware that you are leaving. For younger children this may be upsetting, but if you depart without saying good-bye, this can make the child feel alone and mistrustful of you when he or she realizes you are gone.

- Speak to the hospital staff who will be involved with your child's care. Share your observations and concerns with them. This will help them understand your child better and also help them be more sensitive to your needs, as well as those of your child.
- Though infants or very young children may not be able to discuss hospitalization, it is helpful to prepare older children for the experience. Let the child know whether you will be able to stay with him or her overnight, how often you will visit, what his or her room will be like, and what kind of examinations and treatment he or she will experience. Your child may not be able to absorb all this information at once, so give it in small amounts, repeat it as often as seems necessary over the course of several days and be ready to answer any questions. Many hospitals have orientation programs for children.
- If hospital regulations permit it, bring along your child's favorite toy, such as a stuffed animal, or a blanket. This will help your child feel more secure. If your child will have oxygen, check with a nurse about toys that are safe in oxygen delivery systems.
- Prior to your child's discharge, be sure to ask for written instructions from your child's hospital care staff (nurses, dietitians or therapists). Keep the instructions in this notebook. Have the hospital care staff observe you performing any special care that will need to be continued when your child returns home, to be sure that you are doing it properly.
- Children, especially younger ones, may be unusually clinging or tearful during or following hospitalization. Learn to anticipate this and recognize it as a normal emotional response of a child to separation from his or her family.

Home Medical Record Forms

IDENTIFICATION NUMBERS

Child's Name _____ Child's Social Security Number _____

Father's Social Security Number _____ Mother's Social Security Number _____

DSCC Registration Number _____ IDPA (Public Aid Number) _____

Agency _____ ID Number _____

Agency _____ ID Number _____

Insurance Policy Name _____ Policy Number _____

Insurance Policy Name _____ Policy Number _____

Hospital Name _____ ID Number _____

Hospital Name _____ ID Number _____

Hospital Name _____ ID Number _____

Clinic Name _____ ID Number _____

Clinic Name _____ ID Number _____

MONTH _____

SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY

TIP: Make copies of this blank page for future months or call your DSCC consultant for more copies.

PHYSICIANS/THERAPISTS/DENTISTS
(or other professionals involved in child's care)

NAME	SPECIALTY	ADDRESS	PHONE NUMBER	DATES CARE BEGAN & ENDED

TIP: Fill out this form and take it with you to visits with physicians and other specialists working with your child. **(Be sure to include pediatrician or family doctor.)** You can ask that reports be sent to the persons listed on this form. This will save you time and effort when you are asked who will need copies of reports.

Diagnosis/Medications
Hospitalizations

DIAGNOSIS

Child's Name: _____ Birthdate: _____

<p>Diagnosis: _____</p> <p>Abbreviation: _____</p> <p>Also Called: _____</p> <p>Doctor(s) Who Diagnosed: _____</p> <p>Specialty of Doctor(s): _____</p> <p>Date(s) Diagnosed: _____</p>	<p>Diagnosis: _____</p> <p>Abbreviation: _____</p> <p>Also Called: _____</p> <p>Doctor(s) Who Diagnosed: _____</p> <p>Specialty of Doctor(s): _____</p> <p>Date(s) Diagnosed: _____</p>
<p>Diagnosis: _____</p> <p>Abbreviation: _____</p> <p>Also Called: _____</p> <p>Doctor(s) Who Diagnosed: _____</p> <p>Specialty of Doctor(s): _____</p> <p>Date(s) Diagnosed: _____</p>	<p>Diagnosis: _____</p> <p>Abbreviation: _____</p> <p>Also Called: _____</p> <p>Doctor(s) Who Diagnosed: _____</p> <p>Specialty of Doctor(s): _____</p> <p>Date(s) Diagnosed: _____</p>
<p>Diagnosis: _____</p> <p>Abbreviation: _____</p> <p>Also Called: _____</p> <p>Doctor(s) Who Diagnosed: _____</p> <p>Specialty of Doctor(s): _____</p> <p>Date(s) Diagnosed: _____</p>	<p>Diagnosis: _____</p> <p>Abbreviation: _____</p> <p>Also Called: _____</p> <p>Doctor(s) Who Diagnosed: _____</p> <p>Specialty of Doctor(s): _____</p> <p>Date(s) Diagnosed: _____</p>

MEDICATIONS

NAME OF MEDICATION*	PRESCRIBED BY	PURPOSE OF MEDICATION	DATE BEGAN	DATE ENDED	CAUTIONS	RESPONSE

*TIP: Ask you doctor, doctor's nurse, or pharmacist for information about this medication.

HOSPITALIZATIONS

DATE	NAME AND COMPLETE ADDRESS OF HOSPITAL	ATTENDING PHYSICIAN/ SURGEON	REASON FOR ADMISSION/ TYPE OF SURGERY	OUTCOME

TIP:

Medical History

BIRTH HISTORY

Child's Name: _____ Date of Birth: _____ Birthweight: _____ Length: _____

Child's order of birth (*first child, second child, third child, etc.*) _____

Doctor/Obstetrician: _____

Address: _____

Telephone: _____

How many months pregnant were you when you first saw a doctor? _____

How many times did you see the doctor during your pregnancy? _____

Name of hospital where child was born: _____

Address: _____

Telephone: _____

Child was in the hospital from _____ to _____
date *date*

Name of child's primary doctor in the hospital: _____

Specialty: _____

Address: _____

Telephone: _____

Child's APGAR Scores: _____ 1 minute _____ 5 minutes

Name of hospital child was transferred to: _____

Address: _____

Telephone: _____

Reason for transfer: _____

Child was in this hospital from _____ to _____
date *date*

Name of child's doctor: _____

Specialty: _____

Address: _____

Telephone: _____

Drugs/medication taken by mother before/during pregnancy:

1. _____
2. _____
3. _____
4. _____

Mother's illnesses during pregnancy:

1. _____
2. _____
3. _____
4. _____

Was baby full term (9 months)? Yes ___ No ___ If no, weeks of gestation _____

Length of Labor: _____

Type of delivery: Normal ___ Breech ___ Precipitate ___ Caesarean ___

Child's condition at birth: _____

Child's problems following birth: _____

Did mother have problems with other pregnancies? _____

FAMILY HISTORY

Child's Name: _____

Does anyone else in family have a similar condition to the child? _____

Do any relatives or members of your immediate family have the following condition (list relationship to child):

1. Diabetes _____
2. Heart Problems _____
3. Hearing Impairment _____
4. Vision Impairment _____
5. Allergies/Asthma _____
6. Seizure Disorder _____
7. Cerebral Palsy _____
8. Mental Retardation _____
9. Cleft Palate _____
10. Birth Defects _____

Have you, or has anyone in your family, had genetic counseling? _____

TIP: Family medical history forms may contain references to "maternal" or "paternal" relatives. "Maternal" means on the mother's side of the family; "paternal" means on the father's side of the family.

Feeding History

Food is essential for our bodies to function. Some children with special health care needs must have changes made in their diet so they can grow and develop. The changes may be in either the type of food they eat or the way they eat it. Keeping track of them is important for parents. If your child should ever have a problem with feeding, your doctor will want to know about your child's feeding history.

Child's Name: _____

When your baby came home from the hospital, what type of food did he/she eat?

- _____ Breast milk
- _____ Regular formula (what brand, color of can) _____
- _____ Special formula (what brand, color of can) _____
- _____ Homemade (list ingredients) _____

If your baby's feeding habits changed, what was the change and why:

- _____ Breast to bottle
Child's age _____
Why? _____
- _____ Formula change
Child's age _____
What was the change? _____
Why? _____
- _____ Bottle to cup
Child's age _____
Why? _____
- _____ Started solid food
Child's age _____
Why? _____
- _____ Other changes
Describe the change _____

Growth and Development Record

All children grow and develop. Children with special health care needs may grow and develop at a rate different from other children. It is important to keep a record of your child's physical growth and his or her skill development. This way you and your child's care providers can learn what is normal for your child.

Growth is an increase in body size. You will be given growth charts by your DSCC consultant or by your child's doctor. You can record your child's growth each time he or she is measured and record it on the charts. Put the charts behind this form.

The term "development" refers to an increase in skill and function. This is how well your child is learning to move, talk, and take care of himself or herself.

Child's Name: _____

Important skills to remember - list dates your child:

held up head _____

smiled _____

rolled over _____

sat without support _____

crawled _____

walked without support _____

spoke first word _____

spoke sentences _____

toilet trained bladder _____

toilet trained bowel _____

Many doctors or their nurses perform development screenings. Public health nurses or some community programs perform them as well. These screenings record what skills your child is able to achieve. If your child has a developmental screening done, request a copy and file it behind this page.

Be sure to ask how your child's special health care need will impact on his or her growth and development.

Ask about special programs in the community to help with your child's developmental needs. If your child is under the age of three, ask specifically for the name of the local birth to three program. If your child is over the age of three, ask about services from the local public school. You can learn more about this in the Education Section of this record (see side tabs).

Routine Health Care

Routine Health Care

In addition to the specialized medical care required for your child's special health care needs, it is very important for your child to have a source of routine health care, too. Some specialists do check on the child's general health and provide medical care for illnesses not related to the special health care need; some do not.

If your medical specialist is not going to provide routine health care, you will need a pediatrician or family doctor for your child. You will need to make regular appointments for check-ups and immunizations. The doctor will tell you how often your child needs to be seen. Some pediatricians or family doctors will also help coordinate specialty medical care. This can be very helpful, especially if your child sees more than one specialist. It is very important for your pediatrician or family doctor to receive a copy of the reports from all the specialists treating your child. It is also important for the specialists to know what your pediatrician or family doctor recommends. You will need to be sure they are sharing information. It may be helpful for you to keep copies of reports in this Coordinated Care Record and take it with you to your doctor appointments.

In some communities, routine health care is available at public health departments or community health centers. Some places only provide "well child care" which is regular check-ups and immunizations. They cannot take care of sick children. If you receive check-ups and immunizations from a clinic, be sure to ask if they will also provide care if your child should become sick. If not, ask them to help you find a doctor who will.

You may wish to use the space below to record the names and addresses of the pediatrician, family doctor or clinics where your child receives routine health care.

Pediatrician/Family Doctor

Name: _____

Address: _____
Street *City* *Zip*

Phone: _____

Community Health Clinic - Well Child Clinic

Name: _____

Address: _____
Street *City* *Zip*

Phone: _____

Contact Person's Name: _____

Will this clinic take care of your child if your child is sick? _____

CHILD'S ILLNESS / INFECTION / INJURY RECORD

Child's Name: _____

Illnesses/Infections/Injuries *	Date	How Long it Lasted	Drugs Taken/Treatment	Physician	Location

* Write down serious injuries only, those that require a doctor's attention.

IMMUNIZATION AND ALLERGY RECORD

Child's Name: _____

	Date	Physician	Reaction	Date	Physician	Reaction	Date	Physician	Reaction	Date	Physician	Reaction	Date	Physician	Reaction
Hepatitis B															
Diphtheria-Tetanus (Combined: DT)															
Diphtheria-Pertussis-Tetanus (Combined: DPT)															
Tetanus															
Polio															
Influenza Type B															
MMR (Measles, Mumps and Rubella)															
Measles (Rubeola)															
Mumps															
Rubella (3 day measles)															
Varicella Zoster															

	Date	Result	Date	Result	Date	Result
Tuberculin Test						
Lead Screening						
Other						

Communicable Diseases:

	Date	Duration	Drugs Taken
7 day regular measles			
German Measles (rubella)			
Chickenpox			
Mumps			
Pertussis (whooping cough)			
Scarlet Fever			
Strep Throat			
Roseola			
Other (rashes, etc.)			

ALLERGY RECORD

Allergy	Type of Reaction	Date

Dental Record

Child's Name: _____

Dentist's Name: _____

Address: _____

Telephone: _____

9 Dentist has been informed of child's medical condition and medical specialists' recommendations.

All children should have routine dental care. Such care may be even more important when your child has a special health care need. He or she may need to be followed by a dentist with special skills. Consult with your family dentist or your child's medical specialist to determine if he or she requires specialized dental services.

Before your child is examined, the dentist should have information regarding your child's medical condition and current care. Any precautions recommended by your child's medical specialist should be discussed with the dentist. It is also essential that you provide the dentist with a list of current medications received by your child.

You may wish to use the space below to keep track of your child's dental appointments.

Date	Time	Appointment Information

Specialized Health Care

Medical Specialties and Specialists

Allergist - Specialist in the diagnosis, treatment and prevention of allergic diseases

Anesthesiology - Science in the loss of the sensation of pain as it is induced to permit performance of surgery or other painful procedures

Audiology - Diagnosis and rehabilitation of person with impaired hearing that cannot be improved by medication or surgical therapy

Cardiovascular - Pertaining to the heart and blood vessels

Colon and Rectal Surgery - Surgical management of diseases of the intestinal tract, rectum, anal canal and perianal area

Counseling - Professional guidance by utilizing psychological methods especially in collecting case history data using various techniques of the personal interview, and testing interests and aptitudes

Critical Care - Management of all aspects of the critically ill patient (primary base of operation is the Intensive Care Unit)

Dermatology - Science of the skin and its disorders

Emergency Medicine - Treatment of acutely ill or injured patients who require immediate medical treatment

Endocrinology - Science of the endocrines, or ductless glands, and their functions

ENT (Ear, Nose and Throat) - See otolaryngology

Family Practice - Comprehensive medical care with particular emphasis on the family unit

Gastroenterology - Science of the stomach, intestines and related structures

Hematology - Science of the form and structure of the blood and blood forming tissues

Immunology - Study of immunity to disease

Infectious Disease Specialist - Specialist in the diagnosis and treatment of diseases caused by infection (usually from bacteria, viruses, rickets, fungi and animal parasites)

Inhalation Therapy - Administration of medicines, water vapors, gases (such as oxygen, carbon dioxide, or helium), or anesthetics by breathing

Internal Medicine - Diagnosis of diseases of organs in the chest, abdomen or head, does not include surgery

Neonatology - Study of the care and treatment of newborn infants

Nephrology - Diagnosis and treatment of kidney disorders

Neurosurgery - Surgery of the nervous system

Neurology - Diagnosis and treatment of nervous system

Obstetrics - Management of pregnancy, labor and the puerperium (the period of 42 days following childbirth)

Occupational Therapy - Treatment based on the use of the work related or daily living activities to restore the physically or mentally disabled person to independence or to prevent further disability

Oncology - Diagnosis and treatment of tumors

Ophthalmology - Diagnosis, medical and surgical treatment of diseases and defects of the eye and related structures

Optometry - Determination of the presence of vision problems and prescription and adaptation of lenses to preserve or restore maximum efficiency of vision

Orthodontics - Branch of dentistry which deals with the prevention and correction of irregularities of the teeth

Orthopaedic Surgery - Surgical prevention and correction of deformities of the musculoskeletal system (muscles and bones)

Orthotics - Science pertaining to mechanical appliances for orthopedic use (such as braces)

Otolaryngology - Medical and surgical treatment of the head and neck, including the ears, nose and throat

Pediatrics - Science of the development and care of children and treatment of childhood diseases

Pedodontics - Branch of dentistry dealing with care of children's teeth

Perinatal - Management of the fetus and infant before, during and immediately after birth

Periodontics - Field of dentistry dealing with treatment of diseases of the tissues around the teeth

Physical Medicine and Rehabilitation - Treatment of disease by physical agents such as heat, cold, light, electricity, manipulation, or use of mechanical devices to restore a person who has been ill or who is handicapped to a useful life

Physical Therapy - Treatment using exercise, heat, cold, electricity, ultraviolet and massage to restore function and prevent disability

Physician Desk Reference (PDR) - Book of information about drugs

Plastic Surgery - Restoration, reconstruction, correction or improvement in the shape and appearance of body structures by surgery

Preventive Medicine - Prevention of disease and the promotion of health

Prosthetist - Maker of artificial limbs

Prosthodontics - Branch of dentistry dealing with construction of artificial appliances for the mouth

Psychiatry - Diagnosis, treatment and prevention of mental disorders

Psychology - Science dealing with mental processes, both normal and abnormal, and their effects upon behavior

Pulmonary Disease - Diagnosis and treatment of lung disorders

Radiology - Diagnosis and treatment of disease by means of radiant energy (e.g., x-rays and radium).

Respiratory Therapy - Treatment to preserve or improve lung function

Rheumatology - Diagnosis and treatment of rheumatic disease (characterized by inflammation and pain in muscles or joints)

Speech Therapy - Treatment using special techniques for correction of speech, language, swallowing/feeding, voice and fluency disorders.

Thoracic Surgery - Surgical treatment of disorders of the chest or thorax

Urology - Treatment of the urinary tract in both male and female, and the genital tract in the male

Funding

Introduction

Medical care costs money, so do medications, special equipment, supplies and other services your child may require. Insurance may cover some or all of these costs, but choosing insurance that will best suit the needs of you and your child may not be an easy task. There are public insurance options that may be available, but you need to know what is offered and how to apply for these benefits. This section includes information that can help you in obtaining financial support for the expenses that you encounter in pursuing services for your child.

You may wish to personalize the section by including pages of information about your own private insurance, with such details as the policy number and the extent of coverage. If you are involved with any other public funding resources (such as the Illinois Department of Public Aid, Division of Specialized Care for Children or the Office of Rehabilitation Services) you may record information in this section, such as the name and phone number of your contact person at the agency, the agency address, and any information about the services they provide. Pamphlets from these agencies can be placed in the pocket of the section divider.

Like the other sections of the resource book, this section can be removed if you find it useful to take just this section with you to an appointment. It can then be readily replaced.

Tips

- Learn what funding resources may be available to help meet your child's particular needs and how to contact those resources. Some private or

benevolent organizations offer services for children with specific health care needs. Check the Resource Section (pages V-14/V-19) near the back of this workbook.

- Consider applying for Supplemental Security Income (SSI) for your child. If your child is found ineligible at the time of the first application, learn the reason (perhaps appropriate medical reports were not available to make your child's medical diagnosis clear). Be willing to appeal a denial or reapply.
- Community fund raising events on your child's behalf may affect financial eligibility for some public services for which your child would otherwise be eligible. You may wish to consult an attorney regarding how to manage funds raised in such a manner to be sure that the fund raising benefit is most useful to your child. You may also check with your child's case manager at the Division of Specialized Care for Children to obtain advice.
- Working with government programs can be very frustrating. Hang in there. All public agencies have formal appeal processes that can be initiated whenever services are denied to an applicant. Learn about these appeal processes and your rights. (See the information on appeals in the Rights Section of the Coordinated Care Record, pages IV-8/IV-9.)

Ask other parents about helpful tips they may have.

- **Income Tax** (These tips came from Internal Revenue Service Booklets)

Check with the Internal Revenue Service (IRS) for booklets that may help you identify your deductions. Tax laws change frequently so it is important to stay currently informed.

If you are claiming a large amount of deductions because of the disability, send a letter along with your income tax return to explain your child's disability.

Ask your child's physician(s) to also write a letter explaining the nature of your child's disability and identifying treatment services and therapies that are part of your child's medical care plan. Enclose this with your tax return.

Record every expense related to your child's disability. Include both prescription and nonprescription medication costs. Keep all receipts.

Keep track of transportation expenses related to your child's medical care.

Save receipts and deduction-related records for seven years in case you need them for a tax audit.

A deduction is allowed for the expense of child care that is necessary to permit employment.

Expenses related to removal of architectural barriers or other modifications to your house necessitated by your child's disability may be deductible.

Expenses for medical care that exceed 7.5% of family adjusted gross income may be deductible if you are itemizing deductions and these expenses were not reimbursed by insurance or a government program. Included among these deductions are: health insurance premiums, doctor and hospital fees, x-ray and laboratory charges, the costs of long-distance phone calls related to medical care, equipment costs, lodging and meal expenses necessitated

when taking a child for medical care, costs of eyeglasses and hearing aids and the expenses related to attending special workshops or subscribing to publications that relate to your child's disability.

Financial Planning

Financial planning is important for the future of all your children. It is especially important for a child with special health care needs.

It is wise to write a will in order to protect your child. Consider how and where he or she will be cared for and how this would be paid for. Involve an estate planner, financial advisor or attorney to help determine the effects of inheritance on your child's eligibility for government programs and benefits.

Suggest that your attorney review an article on estate planning for the disabled in the July 1987 issue of the Illinois Bar Journal.

Consider designating a portion of your estate as a gift to another relative to be used for the disabled child. However, discuss with your lawyer possible problems that can develop with this approach to estate planning.

Money received from insurance and direct gifts from others can jeopardize a child's eligibility for government benefits.

Designating a child as a beneficiary of pension funds or an individual retirement account can also cause similar problems.

Support trusts can protect the assets of minor children, but you should be aware that payments made from a trust to a child may be considered income and may jeopardize eligibility for government benefits. A trust set up for medical care expenses may have to be used before government benefits can be used.

Ask your attorney about a "discretionary spendthrift trust." If it is constructed properly, it can supplement available

government benefits without having to be utilized prior to use of government benefits.

NOTE: Be sure to discuss options with your attorney. You may wish to contact such organizations as the Illinois Bar Association, Association for Retarded Citizens, Equip for Equality (1-800-537-2632), or other advocacy organizations to ask for help in locating an attorney skilled in estate planning.

Private Insurance

Private insurance is purchased from a private insurance company as a group plan or an individual plan. Most of the insurance people receive through their jobs is group insurance. Very few insurance plans pay for all medical care. Be sure to learn what your policy covers.

The Illinois Insurance Code states that every medical policy must cover the care of a baby born with a congenital defect for as long as the policy is in effect.

If you have any problems with payment of your insurance claim, you may write to:

Assistant Deputy Director
Illinois Department of Insurance
Life, Accident and Health Compliance
Section
320 West Washington
Springfield, IL 62767
Telephone Number: (217) 782-4254
Chicago Tele. Number: (217) 917-2427

If you have problems with "self-insured" or "self-funded" plans, you may contact the Pension Welfare Benefits Administration of the U.S. Department of Labor at 1-800-998-7542 and/or express your concerns to your legislator.

Remember, most insurance companies have a mechanism in place by which you can appeal unfavorable decisions. Find out

how this works in your insurance company and use it when necessary.

Types of Insurance Organizations

A. Health Maintenance Organization

A Health Maintenance Organization (HMO) is an organized health care system that is responsible for both the financing and the delivery of health services. It provides comprehensive health care to an enrolled population at a predetermined price. Members pay fixed, periodic fees and in return receive health care services as the HMO primary care physician deems necessary and appropriate. HMO enrollment requires the individual to choose a primary care physician from a list of the HMO's contracted physicians. The individual must seek health care service or preapproved physician referrals through the primary care physician.

HMOs operate under a payment structure in which services are paid in advance for an enrolled person prior to knowing the services the person may require. This is different than the traditional fee-for-service payment structure in which a service is provided, the fee is billed and the provider is paid for the service. Under the traditional fee-for-service structure, the member will usually be responsible for a portion of the cost of each service. Members may pay deductibles or might be responsible for charges over the usual and customary rate allowable. With an HMO the member will usually only have a small cost responsibility through co-payments, e.g., the physician might charge \$5.00 per office visit in addition to what he receives from the HMO. HMO providers CANNOT bill members for charges or costs over the prearranged fee reimbursement for covered services.

B. Preferred Provider Organization

A Preferred Provider Organization (PPO) is an organization that arranges contracts between a select group of health care providers (hospitals, physicians) and purchasers of health care (employers, unions), but in itself is neither a provider nor a purchaser. Provider fees are negotiated in advance and providers offer discounts in return for rapid reimbursement and potential increase in patient load. Payment is on a fee-for-service rather than a capitated basis as with an HMO. Strict utilization controls are combined with flexible benefits and freedom of choice with respect to health care providers.

PPOs exist within the traditional plan structure unlike an HMO which is an alternative to a traditional health plan. PPOs typically reimburse services by non-preferred providers at a lower rate than participating providers, but cover, to some extent, all medically necessary services. An HMO requires services be rendered by participating providers in order to be covered. PPOs are usually not regulated, and HMOs are strictly regulated by federal and state law. A PPO facilitates the delivery of cost effective health care and is more of a manager or broker while an HMO delivers health care.

C. Point of Service Organization

A point of Service (POS) is a hybrid of the traditional HMO and PPO plan. The POS offers a member the choice of using network or out-of-network providers for health care. Under the network option, a member chooses a primary care physician (PCP) and seeks all care or referrals for care through the PCP. The out-of-network option allows the member to seek care from any provider. To encourage members to use the network option, services are

reimbursed at a higher payment level (e.g., 100% compared to 60%).

POS plans operate under a payment structure similar to HMOs in which the PCP is paid a fixed payment per member per month. In addition, network providers have negotiated fees in advance and offer discounted fees in return for rapid reimbursement and potential increase in patient load. A POS facilitates the delivery of cost-effective health care as a manager which is similar to a PPO.

Public Insurance

“Public” insurance means programs that are funded by state and/or federal tax money to provide support for medical care of eligible persons. These programs are: Medicaid, the University of Illinois Division of Specialized Care for Children (DSCC), Comprehensive Health Insurance Plan (CHIP), Supplemental Security Income (SSI), and the Office of Rehabilitation Services (ORS). These programs will be discussed in the following pages.

Medicaid

The Illinois Department of Public Aid administers the federal Medicaid program, which is designed to assure low-income family's adequate medical care. Application for Medicaid is made at the local Public Aid office.

Medicaid covers the following medical services: inpatient and outpatient hospital care, clinic visits, physical rehabilitation, physician's services, eye care, dental care, chiropractic services, laboratory studies, prescription medications, prosthetic and orthotic devices, and some transportation related to medical care. Other services may also be available depending on the specific situation. Medicaid does not pay for care provided by other available insurance or for items or services that are not considered medically necessary.

Often a family applying to Public Aid for assistance will be eligible for more than one service. Public Aid may be able to provide a monthly check, medical assistance, food stamps, assistance with utility expenses, or even job training. In some cases, individuals in the family may be eligible for only the medical card. When this is the case, the Public Aid client is said to be receiving "MANG," which stands for "Medical Assistance-No Grant." A child who receives Supplemental Security Income (SSI) may be eligible for MANG and, if eligible, would receive his or her own medical card in addition to the monthly SSI check.

Sometimes a person who applies for MANG has income that is above the eligibility level for the medical card. In such a case, the person may be assigned a "spend-down." This means that the person is responsible for payment of an assigned dollar amount of medical bills before Public Aid will agree to pay the rest, somewhat like a deductible of an insurance policy. Once the person has incurred the spend-down amount of medical bills (even if the bills are not yet paid), he or she is given a medical card from Public Aid. When the person applies for the medical card and is assigned a spend-down, that assigned spend-down is in effect for twelve months, at which time the person would need to make a new application. The spend-down is assigned on a month-by-month basis. For any month in which the spend-down amount is incurred, a medical card can be issued for the remainder of that month.

Every public agency has an appeal process. If you think you have been denied eligibility from Public Aid without justification, ask the caseworker or his or her supervisor to advise you regarding the steps you need to take to appeal the decision that has been made. If you win the appeal and receive Medicaid, the coverage will be backdated to the day you applied.

Medicare

Medicare is another form of "public insurance" that is available to individuals who meet specific requirements. Both Medicare and Medicaid are federal government programs, using federal dollars to pay for medical care. The names of the two programs are similar, but they are administered separately by different agencies. Medicaid is administered by the state, Medicare by the federal government. Determination of eligibility for these programs is also handled in different ways.

Medicare, in its most commonly known form, is a hospital care program for people receiving Social Security benefits, who are usually over 65 years of age. This hospital insurance coverage is called Medicare Part A and is automatically available to anyone receiving Social Security. It is paid for by Social Security taxes. Medicare Part B covers doctor bills and other expenses not covered by Part A; there is a monthly premium for Part B.

A disabled child, who has a parent already receiving some form of Social Security benefits, would be eligible to receive his or her own Social Security Disability payments upon reaching age 18. After receiving disability payments for two years, this person would then be able to obtain coverage from Medicare Part A and Medicare Part B.

Division of Specialized Care for Children (DSCC)

The Division of Specialized Care for Children (known as "DSCC" or "the Division") is an official agency of the State of Illinois. It is supported by both state and federal funds. The purpose of the Division is to help children with certain chronic medical problems obtain specialized medical care and other services they may require.

In order to receive services from DSCC, children must be determined medically eligible for the program. In order to receive

assistance with medical expenses, families must also submit a financial application. If a child is medically eligible and the family is found to be financially eligible, DSCC will pay for **SPECIALIZED** medical care, equipment and other needs which are preapproved and meet DSCC guidelines. Routine medical and dental care and care not related to the eligible condition are not provided.

Financial eligibility is usually determined for two years; however, an eligibility period may be less than two year's duration in certain instances.

A brochure about DSCC is in the front pocket of this section. Specific information about your current financial assistance can be kept at the back of this section.

For additional information about the Division of Specialized Care for Children, call the toll-free number, 1-800-322-3722.

Comprehensive Health Insurance Plan (CHIP)

CHIP is a program that creates a comprehensive health insurance plan for people unable to obtain traditional insurance because they are considered "high-risk" due to a current or past medical condition.

To inquire about CHIP coverage and request an application, you may contact Mutual of Omaha (Illinois CHIP Administrator) at 1-800-456-0224.

If you would like to be placed on the CHIP Informational Mailing List, contact the Illinois Attorney General's Office or write to the Illinois Department of Insurance, 320 West Washington, 4th Floor, Springfield, IL 62767, Attention: Mr. Rick Carlson.

Supplemental Security Income (SSI)

SSI is not a health insurance program, but it does provide additional or supplemental funds for parents to use in the care of their disabled child.

Children who have a severe physical or mental disability may be eligible for Supplemental Security Income (SSI). SSI is a federal program administered by the Social Security Administration. If your child is found to be both medically and financially eligible for the SSI program, you will receive monthly SSI checks for your child.

Contact your nearest Social Security Administration office in order to begin the application process. If you do not know the location of an office, you may find out by calling 1-800-234-5772.

If your child is approved for SSI, he or she may also be eligible for medical coverage from Public Aid (see "Medicaid" earlier in this section). You may wish to inquire about Medicaid eligibility at your nearest Public Aid office. You should also be aware that receipt of an SSI check could affect your eligibility for other programs.

Office of Rehabilitation Services (ORS)

The Office of Rehabilitation Services provides services to persons with disabilities and is supported by state and federal funding. Its primary function relates to educational and vocational training, but it may also be of some assistance with medical services. For older children (over age 16) this could possibly be medical care that is not eligible for coverage by the Division of Specialized Care for Children and is necessary to further the child's vocational potential. For younger children, the ORS Home Services Program may provide services designed to keep the child from being unnecessarily or prematurely institutionalized; a personal care attendant, home health services and assistive equipment are some of the services that may be provided. Some home remodeling (including construction of ramps) may also be provided by ORS.

You may wish to contact your local ORS office to discuss available services. If you

are not aware of the location of the ORS office serving your area, contact your DSCC case manager for assistance or phone 1-800-275-3677.

See the Education/Vocation Section for additional information on ORS services.

Other Possible Funding Resources

Clinic and Hospital Care

Shriners Hospitals and Clinics - Inpatient and outpatient treatment of orthopedic problems and orthopedic related problems resulting from birth defects, injury or disease. Immediate or long-term care following a burn, and/or reconstructive plastic surgery related to burns and selected birth defects. Treatment to support the development of independence and self-care of children who otherwise qualify for the services provided by the particular Shriners Hospital.

A cooperative venture between Shriners and state programs servicing children with special health care needs is called the CHOICES Program. This program compliments the aforementioned by:

- A. Providing more options for quality health care.
- B. Improving access and referral to services for both Shriners Hospitals and the child's state program serving children with special health care needs.
- C. Creating a partnership with the patient/parent being a key member of the care team.

To be eligible for services from Shriners Hospitals, the child must be less than 18 years of age at time of application and require treatment that, if provided elsewhere, would pose a financial burden to the family. The child must be sponsored by a Shriner, or can telephone the following number to

obtain information regarding sponsorship: 800-237-5055 or 312-622-5400.

Equipment/Orthotics/Prosthetics

Elk's Club - Illinois Chapter has special interest in disabled children. May be a resource for obtaining wheelchairs or specialized equipment.

Contact them at:

Elk's Commission
R.R. 1, Box 2A
P.O. Box 222
Chatham, IL 62629-0222

Or you may contact your local Elk's Club.

Lion's Club - Has special interest in eye care and conditions as well as hearing loss. May assist with eye care, purchase of glasses or special eye services under certain conditions, may purchase hearing aids and other assistive devices.

Contact them at:

Lions of Illinois Foundation
1701 South First Avenue, Suite 406
Maywood, Illinois 60153
(708) 681-8800

Or you may contact your local Lion's Club.

Specialty Medical Resource or Parent Groups

Muscular Dystrophy Foundation, Illinois Spina Bifida Association, etc. (see Resource Section) may offer funding for specific needs related to a certain medical condition. Contact the specific agency for details.

Township Government

Some townships may have funding for special health care and/or related habilitative needs. Contact your local township officer.

Religious Organizations, Churches

May be willing to help with cost of items. Contact your church to discuss this.

Some communities have information and referral services that provide information to area residents about services that are available in the community. Check the yellow pages of your phone book, under "Social Services Organizations," to find the phone number of the local information and referral service.

Insurance Terms Glossary

The following terms are commonly used by insurance companies:

Applicant: Person applying for insurance coverage.

Assignment of Benefits: Written authorization by the insured giving the insurance carrier permission to pay benefits directly to the medical care provider.

Benefit Period: A specific period of time (generally 12 months) during which benefits are payable.

Birthday Rule: When a child is covered by both parents under two plans and both plans follow the birthday rule, the primary plan will be the plan of the parent whose birthdate falls earlier in the year.

Capitative Payment: A method of payment for health care services in which the health care provider is paid a fixed fee in advance for each person to be served. The payment is on a per capita basis and has no relationship to the type of services provided or the number of services each patient receives.

Case Management: A method of managing the provision of health care to members with catastrophic or high cost medical conditions. The goal is to

coordinate the care to both improve continuity and quality of care as well as lower costs. Usually performed by the utilization review department.

Champus: Civilian Health and Medical Program of the Uniformed Services. The federal program providing health care coverage to families of military personnel, military retirees, certain spouses and dependents of such personnel, and certain others.

Claim: A request for reimbursement from the insurance carrier by the insured (or provider).

COB: Coordination of benefits. An agreement that uses language developed by the National Association of Insurance commissioners and prevents double payment for services when a subscriber has coverage from two or more sources.

COBRA: Consolidated Omnibus Reconciliation Act. Cobra requires an employer to offer the opportunity for terminated employees to purchase continuation of health care coverage under the employer's group plan.

Comprehensive Health Insurance Plan (CHIP): The Illinois General Assembly created the Comprehensive Health Insurance Plan to offer a program of health insurance to certain eligible Illinois residents who have been denied major medical coverage by private insurers due to a pre-existing health condition or disability.

Conversion: The right of an individual to convert from group coverage to an individual policy. This is offered to individuals who lose their group coverage (e.g., through job loss, death of a working spouse) and are ineligible for coverage under another group contract coverage.

Co-insurance or Co-payment: A set amount of money an insured must pay

toward covered medical expenses during any one benefit period. It may be a percent of the total covered cost or a dollar amount. For example: Under a major medical plan, the co-insurance determined amount may be 20% of the covered medical expenses or may be \$10 for each office visit (applies to HMOs etc). This is known as a copayment in the HMO plans.

Coordinated Home Care Program: An organized skilled patient care program initiated by a hospital to facilitate early discharge of a patient with home care. Care may be rendered by a hospital's home health department or other licensed home health agency. Patient must be homebound (e.g., unable to leave home without assistance and requiring supportive devices or special transportation) and must require skilled nursing services on an intermittent basis under physician direction.

Coverage: The benefits provided under a health plan.

Covered Expense: An expense for which a health plan will provide reimbursement.

CPT-4: Current Procedural Terminology. Current Procedural terminology is a listing of descriptive terms and identifying codes for medical services and procedures performed by physicians to provide uniform billing nationwide.

CSS: Central Support Services

Custodial Care Service: Services which do not require the technical skills or professional training of medical and/or nursing personnel in order to be safely and effectively performed. Examples are: assistance with activities of daily living, administration of oral medications, assistance in walking, turning and positioning in bed and acting as a sitter or companion.

Deductible: An amount the insured must pay before the health plan benefits (reimbursement for expenses) begin.

Down Coding: An insurance carrier's process of assigning the lowest priced code number when a bill is received without a procedure code and/or without using the standard description of the procedure rendered.

DME: Durable medical equipment. Medical equipment which is not disposable (i.e., is used repeatedly) and is only related to care for a medical condition. Examples would include wheelchairs, home hospital beds, and so forth.

DRG: Diagnosis-related groups. A statistical system of classifying any inpatient stay into groups for purposes of payment. This is the form of reimbursement that the HCFA uses to pay hospitals for Medicare recipients. Also used by some private health plans for contracting purposes.

ERISA: Employment Retirement Income Security Act. ERISA was developed as protection for employee's overall benefits program. The primary focus of protection is through federal requirement that written summary documents describing the benefit program in detail be maintained by the employer and made available to the employees. ERISA does not mandate employers to provide benefits and does not prohibit discrimination.

Exclusion: Specific medical diagnoses, services, supplies and/or equipment not covered by a health plan. These exclusions are listed in the health plan contract.

Explanation of Benefits: A report provided by the health insurance company summarizing how a claim reimbursement or denial was determined.

EPO: Exclusive Provider Organization. An EPO is similar to an HMO in that it often uses primary physicians as gatekeepers, often capitates providers, has a limited provider panel, and uses an authorization system, etc.

Fee for Service: A method of payment where providers are paid for each service provided.

Gatekeeper: An informal, though widely used term that refers to a primary care case management model health plan. All care from providers other than the primary care physician, except for true emergencies, must be authorized by the primary care physician before care is rendered.

Gender Rule: When a child is covered by both parents under two plans and both plans go by the gender rule, the plan of the father is considered primary.

Group Insurance: An insurance program protecting a group of associated individuals against financial loss resulting from illness, injury, or death.

Group Master Contract: A binding contract between the insurer (insurance company) and purchaser of a health insurance plan (e.g., employer or union) which specifically details the legal name of the policyholder and location of employees to be insured, classes (job classifications) of employees eligible for coverage, the effective date of the plan, the coverage purchased (both benefits and exclusions), the amount of employee contributions, the policyholder premium payment, and the claims payment method.

Group Number: A number that identifies to the insurance carrier which particular group an insured is enrolled in.

HCFA - Health Care Financing Administration: The federal agency that

oversees all aspects of health financing for Medicare and also oversees the office of Prepaid Health Care Operating and Oversight (OPHCOO).

HCFA - 1500: A claims form used by professionals to bill for services. Required by Medicare and generally used by private insurance companies and managed care plans.

HCPCS - HCFA Common Procedural Coding System: An alpha-numeric coding system which supplements CPT coding, but also has codes not included in CPT coding. Example: durable medical equipment, medical and surgical supplies, orthotic and prosthetic procedures.

Health Maintenance Organization: An organization providing comprehensive health care to an enrolled population at a predetermined price.

HIPAA - Health Insurance Portability and Accountability Act: Federal law guaranteeing access to health insurance to most workers who change or lose jobs. Limits exclusion due to pre-existing conditions. Prohibits dropping individuals from insurance plan due to illness.

ICD-9 - International Classification of Diseases, 9th Edition: This coding system is used to transfer verbal and written description of diseases and injuries and medical procedures into a numerical code.

Insurance: Protection against risk, loss, or ruin by a contract in which an insurance company guarantees to pay a sum of money for such an event in return for a premium payment. Examples are: medical, life, auto, property, disability, etc. Insurance may be purchased by a group or an individual.

Insured: An individual who is eligible to receive benefits under an insurance policy.

Also known as policyholder, subscriber. Insured may also be used to describe the employer or organization who purchased the policy.

Lifetime Limit: A specific dollar amount an insurance company will pay toward medical expenses over an individual's lifetime.

Maintenance Occupational Therapy/Maintenance Physical Therapy/Maintenance Speech Therapy: Therapy administered to maintain a level of function at which no demonstrable and measurable improvement of a condition will occur.

Major Medical Insurance: Health insurance to finance the expense of major illnesses and injuries. Major medical insurance policies usually include a substantial deductible clause, but generally have large benefit maximums.

Managed Health Care: This is a form of health care delivery that tries to manage the cost of health care, the quality of that health care and access to that care.

Mandated Benefits: Benefits that a health plan are required to provide by law. Self-funded plans are exempt from mandated benefits under ERISA.

Medically Necessary: Services and/or supplies rendered by a medical provider to identify or treat an illness or injury and are consistent with the symptoms or diagnosis of the illness or injury; are commonly accepted standards of medical practice; are not solely for convenience and are the most appropriate supply or level of service which can be safely provided as determined by the health plan.

Medical Services Advisory: A special unit of health care professionals, usually registered nurses, that help manage health benefits when inpatient treatment and outpatient surgeries are recommended.

MSA staff have experience in a full range of medical specialties, can answer questions and work with the providers to ensure getting the best and most appropriate coverage available.

Open Enrollment Period: The specified period of time (commonly 30 days) an employee has to enroll, add or drop dependents, and/or change insurance plans prior to the policy effective date.

OPHCOO - Office of Prepaid Health Care Operations and Oversight: The federal agency that oversees federal qualifications and compliance from HMOs. Once part of the Public Health Service, now part of HCFA.

Out of Pocket Maximum: The maximum amount the insured will have to pay for covered expenses under a health plan.

Participating Provider: A physician or other medical care provider who has entered into a contract with an organization, the government, or an insurance company to provide medical care to enrolled persons (insured). The provider is to accept the insurance company's approved fee and only bill the insured for deductibles, copayments/coinsurance or uncovered services/supplies.

Participating Provider Option: A program of health care benefits designed to provide economic incentives for using designated providers of health care services.

POS: Point of service. A plan where members do not have to choose how to receive services until they need them. The most common use of the term applies to a plan that enrolls each member in both an HMO (or HMO-like) system and an indemnity plan. Occasionally referred to as an HMO swing-out plan, an out-of-plan benefits (e.g., 100% coverage rather than 70%) depending on whether the member

chooses to use the plan (including its providers and in compliance with the authorization system) or go outside the plan for services. Dual choice refers to an HMO-like plan with an indemnity plan, and triple choice refers to the addition of a PPO to the dual choice. An archaic, but still valid definition applies to a simple PPO, where members receive coverage at a greater level if they use preferred providers (albeit without a gatekeeper system) than if they choose not to do so.

Precertification: The process of obtaining authorization from a health plan (HMO, PPO, POS) before services are rendered as specified by the plan. Failure to obtain precertification often results in a financial penalty to either the provider or the policyholder.

Pre-existing Condition: A condition that existed, or for which a participant was being treated, before the health plan coverage began. Benefits are usually limited or not available and are restricted to a specified time period.

Preferred Provider Organization: An organization which arranges contracts between a select group of health care providers (hospitals, physicians) and purchasers of health care (employers, unions), but is itself is neither a provider nor a purchaser.

Primary Care Physician: The physician (commonly a family practitioner or pediatrician) who is responsible for providing, arranging and coordinating all aspects of the insured or covered dependent's health care when the insurance plan is an HMO.

Private Duty Nursing: Skilled nursing service provided on a one to one basis by a practicing, licensed practical nurse or registered nurse who is not employed by a hospital or home health agency.

RRVS - Resource Based Relative Value Scale: A system developed by HCFA for determining the level of provider payments based upon the amount of work involved in the treatment, the skill level of the physician, and the medical malpractice risk.

Self-Funded or Self-Insured: A health plan where the risk for medical costs are assumed by the employer (association) rather than the insurance company.

Third Party Administrator: A person or organization providing certain administrative services to group benefits plans, including record keeping, claims review and payment, claims utilization review and maintenance of employee eligibility records.

Tri-Care: The managed care program for the Army, Navy and Air Force.

UB-92: The common claim form used by hospitals to bill for services. Some managed care plans demand greater detail than is available on the UB-92, requiring the hospitals to send additional itemized bills.

Underwriter: The insurance carrier or governmental agency that sets all policy benefits and establishes all procedural rules for determination of the payment of benefits.

Upcoding: The practice of a provider billing for a procedure that pays better than the service actually performed.

Usual and Customary Charge: The maximum amount an insurance carrier will consider eligible for reimbursement under the group health plan. Used to control claims costs.

Utilization Review: A cost-control mechanism used by some insurance carriers and employers that evaluates health care on the basis of appropriateness, necessity, and quality. For hospital review, it can include pre-admission certification, concurrent review with discharge planning, and retrospective review.

Write-off: A reduction in the amount charged for medical services after the provider receives the insurance carrier's payment. The reduction is the difference between the fee charged and the fee allowed by insurance.

Funding

General Insurance Information

The worksheets in this section are for you to identify your child's specific insurance or financial assistance coverage to help pay your medical bills. It is important for you to learn the rules the insurance company will follow in paying bills **BEFORE** you send them a bill. This is especially true if you are a member of a Health Maintenance Organization (HMO) which places restrictions on which physicians can provide services for your child and on how those services may be provided.

It may be helpful for you to put a copy of your insurance handbook in the pocket at the front of this section.

Answering the following questions should help you receive the maximum benefits available from your insurance company, regardless of the type of insurance plan. The insurance company or your employer will be able to assist you in providing the answers to these questions.

- When do benefits begin?
- What benefits are covered by the plan?
- What limits are placed on these benefits? For example, are there limits on the number of visits which your insurance will cover or on the dollar amount of the coverage? Do you need to check with the insurance company before hospitalization for an elective procedure (that is, one that's not an emergency) in order to obtain the best insurance payment? If so, record the telephone number.
- Does the policy have a pre-existing condition clause or a waiting period? (A "pre-existing condition" clause may place a limit on the coverage of an

insurance policy, such as not paying for care related to a medical condition that is present at the time the policy is obtained until a set time period (not to exceed 12 months) has elapsed, or placing a dollar limit on coverage for a medical condition that is already present at the time the policy is obtained. Be sure you understand exactly what such a clause means for you and your child's coverage.)

- What is the policy deductible(s), co-insurance or co-payment amount?
- Is there a lifetime maximum benefit amount per family member or per family? If so, what is that amount?
- Are there specific limits that apply only to your child's special health care needs?
- What are the policy's requirements for filing a claim? For example, does the policy holder need to file the claim or can the service provider do so? Is there a time limit on filing claims?
- What should you do to coordinate benefits from this policy with other insurance coverages or other financial assistance programs you may have?

If your policy is with a **Health Maintenance Organization (HMO)**:

- Obtain and keep on file a list of the HMO's providers (physicians and hospitals) and an outline of the HMO's service area.
- Who is your child's primary physician?
- Does your child's primary physician participate in the HMO?

- How can your primary physician refer your child for specialty care:

Within the HMO _____

Outside the HMO _____

- Will the HMO allow benefits for services received from a physician or at a hospital that does not participate in the HMO plan?
- If your child is already being treated by a physician who is not in the HMO, will the HMO require that you choose a physician from its list of providers in order to receive HMO benefits or will the HMO continue to pay that doctor to care for your child?
- Are referrals required for specialty care, emergency care or medical care received outside of the HMO service area?
- What does the HMO require from you before it will pay a bill?
- What do you need to do to coordinate HMO care with other insurance policies or financial assistance you may have?
- If your child should require emergency care outside the HMO (if you are out of town, for instance), what must you do before the HMO will pay the bill?
- What is the appeal procedure for your HMO?
- For your family, considering all members, is there an overall value to enrolling in an HMO?

Does your policy include benefits for using “preferred providers” who are members of a **Preferred Provider Organization (PPO) or Point of Service (POS) plan**? If so:

- Obtain and keep on file a list of the PPO’s or POS’s providers.
- What additional benefits are available when you receive services from one of the preferred providers of the PPO/POS plan?
- How will the PPO/POS provide the specialty care your child will require?
- Are there pre-existing conditions that are excluded?
- What should you do to coordinate benefits from this company with other insurance or financial assistance you may have?
- Do you need to have pre-admission approval before hospitalization?
- What kind of notice does the PPO/POS require for it to pay a bill?

Funding Worksheets

YOUR CHILD'S INSURANCE INFORMATION

Child's Name _____

Insurance Company _____

Address _____

Telephone (____) _____

Name of contact person _____

Insurance contact person at place of employment _____

Telephone (____) _____

Name of Employer _____

Address of Employer _____

Name of Insured _____ Policy Number _____ Group Number _____

Policy Effective Dates _____

Is this policy the _____ primary or _____ secondary policy for payment of your child's medical bills?

How much is your deductible? _____

How much is covered for the following services:

Doctor's Office Visits? _____

Doctor's Hospital Visits? _____

Emergency Room Care? _____

Hospitalizations? _____

Surgeries? _____

Outpatient Hospital Care? _____

Outpatient Hospital Care? _____

Durable Medical Equipment? _____

Orthotic/Prosthetic Devices? _____

Medical Supplies? _____

Prescribed Medications? _____

Home Care? _____

Skilled Nursing Care? _____

Therapy?

Speech _____

Occupational _____

Physical _____

Respiratory _____

Cardiac Rehabilitation _____

Other _____

Diagnostic Tests?

Laboratory _____

X-Ray _____

Other _____

Ambulance Services? _____

Dental Care? _____

Mental Health Services?

Inpatient _____

Outpatient _____

What services are excluded from coverage? _____

PRIVATE INSURANCE WORKSHEET

Child's Name: _____

SERVICE: _____ **DATE OF SERVICE:** _____

PAYOR #1:	BILL SUBMITTED:	AMOUNT PAID:	DATE PAID:	BALANCE:
PAYOR #2:	BILL SUBMITTED:	AMOUNT PAID:	DATE PAID:	BALANCE:
PAYOR #3:	BILL SUBMITTED:	AMOUNT PAID:	DATE PAID:	BALANCE:

SERVICE: _____ **DATE OF SERVICE:** _____

PAYOR #1:	BILL SUBMITTED:	AMOUNT PAID:	DATE PAID:	BALANCE:
PAYOR #2:	BILL SUBMITTED:	AMOUNT PAID:	DATE PAID:	BALANCE:
PAYOR #3:	BILL SUBMITTED:	AMOUNT PAID:	DATE PAID:	BALANCE:

SERVICE: _____ **DATE OF SERVICE:** _____

PAYOR #1:	BILL SUBMITTED:	AMOUNT PAID:	DATE PAID:	BALANCE:
PAYOR #2:	BILL SUBMITTED:	AMOUNT PAID:	DATE PAID:	BALANCE:
PAYOR #3:	BILL SUBMITTED:	AMOUNT PAID:	DATE PAID:	BALANCE:

Funding Assistance Forms and Eligibility Letters

Early Intervention/Education/Vocation

Introduction

Many children with special health care needs also need special education services. All states are required to provide a free and appropriate education for children with disabilities. In Illinois, services are available from public schools for children with disabilities from ages three through twenty-one. Since a child's future depends on his or her education, these can be very important services to obtain.

In the front pocket of this section is a booklet titled A Parent's Guide: The Educational Rights of Students with Disabilities. This resource has been prepared by the Illinois State Board of Education and contains much useful information about special educational services in Illinois. Your DSCC consultant can help you learn to use this booklet. Written information is also available on early intervention. Ask your consultant to help you obtain these materials.

In Illinois, if a parent requests, early intervention services must be provided for all children, 0-3, with serious developmental delays or a diagnosed medical or physical condition that is likely to result in developmental delays. Early intervention services are provided by child development specialists, social workers, therapists and other professionals.

Vocational training becomes an important service for many children with disabilities when they reach adolescence. It can often help them prepare for a life of independence and self-support.

Not all children with special health care needs require special education services or vocational services. Parents do have the right and responsibility, however, to request an evaluation to determine the need for such services. Information is included in this

section to help parents learn where to go to obtain such evaluations and services. There are tips from other parents of children with special health care needs and from professionals who work with those children. There are also worksheets to help you personalize the information you learn to your child's needs. You can insert additional pages of your own at the back of this section, such as a copy of your child's Individualized Family Service Plan (IFSP), Individualized Education Plan (IEP), or other school reports.

Children who are not eligible for special education services, may be eligible for special accommodations at school under Section 504 because of their special health care needs. If your child is not eligible for special education, it is important to ask for a Section 504 plan. Each school has a Section 504 coordinator. The Section 504 plan can identify any special accommodations your student needs, including an individual health plan, and a transition plan.

Personalize this section to make it fit your needs.

Early Intervention

Children who have chronic illnesses or developmental disabilities may benefit from services in addition to medical care.

Sometimes parents have concerns about how their infant or toddler (a child under 36 months of age) is developing. When parents have a concern about their child's development, free screenings and assessments are available through Child & Family Connections to determine if the child may have a delay in his or her developmental delay, or those infants and toddlers with a medical condition that often results in a developmental delay, and their families, may be eligible to receive services to enhance the child's development. In

Illinois, 30 Child & Family Connections, the early intervention system of point of entry, will determine your child's eligibility, assist you in understanding your early intervention rights and work with you to develop an Individualized Family Service Plan (IFSP). The IFSP identifies services to help you with your child's development. If you would like more information on infant and toddler development or the early intervention services available in your area, contact your local DSCC consultant.

Tips

- There are many misunderstandings about special education and the services required by law. When you meet with people from the school district to discuss your child's education, ask them to explain your rights to you. Don't hesitate to ask any questions you may have.
- Take an active part in your child's education. It is as important for you to be an active member of the educational team as it is for you to be an active member of the medical team.
- It is usually in your child's best interest to share information about your child's medical condition with the school staff. You may need to help them learn about your child's special health care needs. This record may be very helpful to school personnel.
- Schools are not required to hire school nurses. Ask if your child's school has a nurse.
- If your child is on medication, try to develop a schedule that will not require your child to take the medication at school. If your child must take medication during the school day, ask the school staff how they will insure the safe administration of that medication. Be sure they know what the medication

is for and its side effects. Check with the school staff to see if your child is having any problems with the medication.

- If your child requires the services of a nurse to stay in school, request a Case Study Evaluation to determine the impact of the medical problem on your child's learning.
- If your child is referred for special education services, there will be evaluations performed and reports written. You can ask for a copy of those reports and keep them in this record. There will also be meetings about your child. You can ask for a copy of the reports from the meetings as well.
- Not all children with special health care needs require special education services, but it is still important for the parents and the school to work together to help the child receive the best education possible.
- If your child is going to be out of school for medical reasons, be sure to let the school know. Plans will need to be made for your child to make up school work and/or for a teacher to provide instruction in the hospital or in your home until the child can return.
- School systems often do not understand the health care system and vice versa. Your child will be receiving services from both systems and you can help bridge the gap by asking questions and sharing information.
- Ask your child's special education team leader or teacher to explain terms and abbreviations used in describing your child's school program. The words and terms used may mean different things in different school districts. Keep asking until you completely understand your child's school program.

Vocational Information

Vocational training may be a part of your child's special education program. It may also be provided by the Illinois Office of Rehabilitation Services (ORS). You can request more specific information from your DSCC consultant.

The following tips are from "Vocational Training and Employment: Guidelines for Parents" by M. Sherril Moon and Andrew V. Beale in the December 1984 issue of The Exceptional Parent. If you would like to read the entire article, please ask your DSCC consultant for a copy.

The steps outlined here are to help you insure that your child receives proper vocational training and job placement during his or her school years.

Elementary School Level

Vocational training should focus on helping children to develop self-care and daily living skills, positive human relationships and good social skills, and an awareness of vocational opportunities at the upper grade levels and as an adult.

For your child:

1. Familiarize yourself with your state's regulations dealing with the education of children with disabilities.
2. Assign specific jobs/duties to your child around the home.
3. Find out about successful school and adult training programs and the variety of employment options that are now opening up for citizens with profound disabilities.

With your child:

1. Create opportunities for your child to learn about workers and what they do.
2. Emphasize personal appearance, physical fitness and good social and communication skills.

Middle School Level

For your child:

1. Actively support the teacher's efforts to provide job training in community-based sites.
2. See that your child's IEP addresses specific vocational training in a variety of potential jobs.
3. Make sure that you know what job training is available for your child in the high school program.
4. Get in touch with your local rehabilitation agency to find out about the training services and job possibilities available for your child.
5. Find work outside the home for your child to do during summer, weekends and after school.

With your child:

1. Continue to work with your child on improving his or her appearance and physical fitness.
2. Require your child to complete household chores on a regular basis and provide an allowance only on the basis of correctly completing allotted chores.
3. Get your child into the community for leisure activities.

High School Level

For your child:

1. See that vocational training in specific jobs is built into your child's IEP.
2. See that a transition team composed of yourself, the teacher and a rehabilitation agency representative is formed to plan for your child's employment after graduating.
3. Encourage school personnel to find, place and train your child in a job, full or part-time, that pays a wage while he or she is still in school.

4. Find out about all adult programs in your community and make plans before graduation to have your child enter one where some sort of employment is offered if earlier employment cannot be secured.

With your child:

Continue to do all the things you began while your child was in middle school.

Worksheets

Education Information

Child's Name: _____

If your child is under the age of three, and you are interested in early intervention services, ask your doctor or your DSCC consultant for information about EI services in your local area. Tell the contact person about your child and what you think his or her needs are. Request an evaluation to identify your child's need for service.

Early Intervention System Point of Entry: _____

Address: _____

Telephone: (____) _____

Contact Person: _____

If your child is over the age of three, and you are interested in learning about special education services for your child, call your local grade school. Talk to the principal about your child and what you think his or her problems are. Request a special education screening or a case study evaluation to identify your child's special education needs. Please read pages 3-6 of the booklet *A Parent's Guide: The Educational Rights of Students with Disabilities* (in the front of this section) to learn more about the screening and diagnostic services available from the public schools.

Local Grade School: _____

Address: _____

Telephone: (____) _____

Principal's Name: _____

Date Called: _____ Date of Screening Appointment _____

If you have any problems getting your child screened, please call your DSCC consultant at _____
It is your right to have the screening done.

Child's Educational Plan and School Reports

Rights

Introduction

This section includes information that you need to know about legal and procedural matters that you may encounter. Included is a description of steps to take in obtaining your child's medical reports. Most public and private service agencies have appeal processes and those rights are described.

Obtaining Medical Records

You may wish to obtain copies of your child's medical records to assist you in the management of your child's health care. In recent years legislation has been enacted at both the state and federal levels to define when and how you can obtain this information.

Hospital Records

Although your child's hospital record is the property of the hospital, the information contained in that record is considered to be your property (or your child's, if he or she is over eighteen years of age).

You (or your child's physician or your attorney) have the right upon written request to review or obtain copies of hospital records following your child's discharge from the hospital. You can review and copy your child's medical history, bedside notes, charts, pictures and x-rays, and other information included in the hospital chart. Send your request to review and/or copy portions of the record in writing to the hospital administrator.

Physician's Records

Your access to the records of a physician who sees your child in his office is less clearly defined by law. One Illinois law does identify the rights of your child's physician or attorney to examine and copy your child's

records, in response to your written request (or that of your child, if he or she is over eighteen years or age). The law does not specify that you or your child have the right to examine and copy the record contents. However, the Illinois Mental Health and Developmental Disabilities Confidentiality Act does give you such a right, if your child is legally classified as developmentally disabled.

The federal definition of developmental disability includes the requirements that the disabled person must have incurred the disability prior to his or her twenty-second birthday and it must be likely that it will affect the person for a long time into the future, perhaps forever. Therefore, to be classified as developmentally disabled, your child's disability must be severe and chronic and must have been caused by a mental or physical impairment, or a combination of the two. The disability must affect your child's functioning in at least three of the following areas: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living and capacity for self-sufficiency. Thus, while some medical conditions will clearly qualify your child as developmentally disabled, not all special health care needs will lead to your child being classified as developmentally disabled.

However, with the Mental Health and Developmental Disabilities Confidentiality Act and the federal Family Privacy Act serving as precedents, a trend toward easier family access to medical records seems to be developing.

A physician must comply with your properly written request to share your child's record with another physician or with your attorney (see next paragraph). A physician does have the right to payment for any "reasonable expenses incurred in arranging

for the examination or copying of these records.

Time Frames and Penalties

Whether records originate in a hospital or in the office of a physician, Illinois law states that records must be made available for your examination or copying within 60 days of receipt of your written request. If this time limit is met, the law provides for the payment of expenses and reasonable attorneys' fees incurred in connection with any court action that you may be required to initiate to enforce the provisions of these Illinois laws.

Written Requests for Medical Records

In order for you to obtain copies of medical records, your request must be put in writing. Often a hospital or physician will have a preprinted release form that you can complete and sign to request the reports. A handwritten note will usually be sufficient; however, if you include the following information:

1. Identifying information regarding your child, such as his or her name, birth date and address.
2. The name of the hospital, physician, or facility from whom records are being requested.
3. A specific description of the record material being requested, including the dates when your child received services, when possible. The more specifically the record material is described, the easier it is for the physician or facility to promptly honor your request.
4. Your signature, if your child is less than eighteen years of age, or your child's signature, if he or she is eighteen or older. If your child is older than eighteen and has been designated in court as legally incapable of making such decisions and a guardian has been

appointed by the court, it is that guardian who must sign requests for medical records. (Note that your requests for reports related to any mental health evaluation or treatment that your child has received must also have your child's signature, if he or she is over twelve years of age, according to the Mental Health and Developmental Disabilities Confidentiality Act.)

5. The date you signed the request.

Because there are many laws (state and federal) which address release of medical and non-medical records and because some of these may not fit specific situations exactly, different physicians, hospitals and agencies may have variations in what additional information they require on a release form. However, the above items will usually be the minimum required.

Much the same information will be required when you ask a hospital or physician to send medical records to another hospital, physician or agency. Laws concerning confidentiality of medical information have been designed primarily to protect the rights of patients. Therefore, preprinted, formal release forms may be provided to you by either the physician or facility from which material will be requested or by the physician/facility/agency which is to receive the records. These release forms are often constructed in a manner designed to inform you of your rights related to the transfer of sensitive personal information and they are often more readily accepted by the facility or physician you are asking to release the records.

Confidentiality of Records

Medical information is considered to be confidential and cannot be released by a physician or hospital without your written consent (or your child's consent, if he or she is eighteen years of age or older). Certain information may, however, be considered "nonprivileged." This means that it can be

shared without consent. This information includes the name, age, sex and address of your child and whether he or she is known to the facility or physician. Information can also be released in "statistical" form, if it does not reveal the identify of your child.

Your Right to Request Amendment of Records

Upon reviewing your child's medical records, you may not agree with the content of the records. If this happens, you have the right to request in writing that the content be altered. Upon review, this request may be granted by the physician or hospital. However, if it is not, the Mental Health and Developmental Disabilities Confidentiality Act (if your child is classified as developmentally disabled) does require that the record henceforth contain a statement of your disagreement and any time that the disputed material is shared with another hospital, physician or other facility or person, the statement of disagreement must also be shared.

Appeals

Your child is potentially eligible for financial assistance and special educational, social and vocational services from public agencies. You and your child have certain rights which are safeguarded by federal and state statutes.

Among these are rights which permit you to request another evaluation of any decision or action related to the benefits and services for your child.

All public agencies are required to have written appeal procedures and are required to inform you of the opportunity to appeal any decisions that are made about your eligibility for services.

Appeal procedures may differ from agency to agency. However, all appeal procedures have characteristics in common which are

important for you to understand if you are considering an appeal.

1. There is a specified period of time from the date of the contested decision or action, within which you are allowed to request appeal. Failure to make the request for appeal within the specified time may result in forfeiture of your right to appeal a specific decision or action.
2. You must usually make any request to appeal a decision in writing, stating the reasons for the appeal.
3. The agency must respond to you in writing within a specified time in order to schedule a meeting date, time and place. This first meeting often is with agency supervisory staff. The agency administrator should be uninvolved at that initial meeting.
4. You have the right to review your child's record, to copy it, and to review any other agency information related to the contested action.
5. You have the right to be accompanied or represented by a relative, friend, advocate or attorney.
6. You have the right to present oral and written information and evidence, and to question or challenge agency staff at the meeting.
7. You are to be sent written notification of the results of the meeting within a specified time.
8. You may appeal the decision of the meeting, often to the agency administration or administrative hearing.
9. Appeal procedures of some agencies require that your child's benefits that are in question continue during the appeal period.

Appeal procedures and time limits vary from agency to agency. It is important for you to acquire specific information about these procedures and to adhere to them in order to receive your full rights to appeal. It is critical for you to be fully prepared for the initial meeting, and any subsequent hearings. You should seriously consider being accompanied and represented by another individual or advocate fully acquainted with appeals procedures.

Refer to the Resource Section of this manual for a list of legal and advocacy agencies and groups in Illinois who may assist you with appeals (V-9).

Release of Information Form

Date _____

Dear _____:

I, _____, the parent/legal guardian of,

whose birth date is _____,

am requesting copies of medical records/lab reports/discharge summaries from _____

(name of physician, hospital, clinic)

for the following dates: _____

Please mail this information to the following address:

Signed:

Parent/Legal Guardian

Date

Other

Introduction

This section contains additional useful information that does not fit within any of the other sections. There is a bibliography which lists books and other reading material that other parents in similar circumstances have found to be valuable. A glossary of common medical terms is included, along with a list of resource agencies that can be contacted for further information, services or just for support.

As with the other sections, portions of this section can be removed if you wish to take them with you for reference during an appointment. Also, you can add pages with additional information that you have found useful. The pocket on the section divider at the beginning of this section can be used to hold booklets, pamphlets or other material.

Tips

How to leave instructions for caretakers:

Parents need to occasionally leave their children in the care of a babysitter or other adult caretaker. This can be a stressful experience, particularly if the child requires specialized care. The following are some tips that may make leaving your child with another caretaker easier for everyone involved.

1. Meet with the caretaker ahead of time to teach him or her about the care of your child.
2. Prepare a list of instructions for the caretaker, including a phone number at which you can be reached, your destination, route to the destination, emergency phone numbers, name and phone number of physician(s), and the hospital to which you would prefer your child to be taken if an emergency necessitates such action. Also indicate your expected time of return and other people you would like to have contacted, in case of an emergency, if you cannot be reached. Leave this by the phone.
3. Leave with the caretaker a written description of your child's current medical condition, medical history, treatment plan, medications currently being received, etc. (You may find it useful to leave all or portions of your child's Coordinated Care Record.
4. Discuss with the caretaker, beforehand, your wishes regarding feeding, naps, discipline, play activities, snacks, television viewing, and so forth. Special precautions related to your child's medical condition should be put in writing and discussed person-to-person to be sure that they are clearly understood by the caretaker.
5. If your child is not able to communicate his or her needs and wishes verbally, discuss with the caretaker the nonverbal cues that you have learned to recognize (such as how your child shows that he or she is hungry or tired). The approach to comforting which works best for your child is useful information for the caretaker. If possible, also put this information in writing.
6. Put together an easily transported bag of supplies and medications required by your child. This can be left with the caretaker, who will then be able to quickly locate it and take it along in case an emergency requires a hasty departure.
7. If your child requires a car seat, leave the car seat with the caretaker during your absence in case the child must be transported by car. Discuss with the caretaker any plans for recreational or other outings that may be planned during your absence.

Responding to Questions

Most parents of children having special health care needs must at times deal with questions from friends, relatives, neighbors, and even to total strangers regarding their children and their medical conditions. Sometimes the questions are asked directly; at other times the questions are inferred from a remark or a stare, even by teasing initiated by neighborhood children.

Your response may depend on how you feel at the time or how you interpret the intent of the questioner. You may wonder if you responded appropriately or you may feel that you said too much or too little. You may feel anger or frustration.

A question (or a comment or a stare) may represent genuine curiosity about your child and his or her condition. If so, a factual, straight forward response can do much to promote understanding, compassion and tolerance.

Questions, whispers, and stares can be upsetting at times, even if they are not meant to be negative. You may have become quite accustomed to your child's appearance, but a question from a stranger can remind you anew that your child is different, thus reviving the feelings of hurt, anger and grief that you may have been able to suppress or adjust to over the course of time. Your reaction to the question may then be one of anger based on your own inner feelings, regardless of the intentions of the questioner.

Your response to a question may need to vary according to the situation. A brief explanation to a stranger on the street may be all that's needed. More detailed information might be appropriate, however, for people who see your child on a regular basis, such as school classmates or neighborhood children. Supplying information can resolve curiosity. Not supplying it can lead to continued questioning, staring, and misunderstanding.

But, you should also keep in mind that you don't owe an answer to anyone, especially if the questioner is clearly rude or does not intend to use the information in a positive manner. To a certain extent, you must also respect your own feelings; if you don't feel like answering, you have a right not to respond.

In general, however, an honest explanation, whether brief or detailed, will promote understanding. The questioner may even have personal experiences similar to yours that he or she wishes to share with you.

Vacation Planning

The following are things to consider before you go on vacation with your child with special health care needs:

1. Plan ahead. The safety of your child is very important.
2. Your child with special health care needs may require unexpected medical care while you are on vacation.
3. Be sure that care is readily available before you go.
4. Ask your medical specialist to refer you to a physician located nearest to your vacation site.
5. Talk to your insurance company, DSCC consultant, Public Aid caseworker, etc., before you go. Be sure arrangements are made to pay for medical care you may need while away. Do not assume you will be covered.
6. Ask your doctor for a letter about your child and what he would like done should an emergency occur. Note: DSCC requires that the child's specialist in Illinois be contacted about emergencies related to the care of a medically eligible condition.

7. Be sure your travel plans are safe for your child. Discuss this with your doctor. Is it safe for your child to fly or to go on a long train, bus, or automobile trips?
8. Think of things that could go possibly wrong and plan for a way to handle them.

Most parents are able to adjust and cope and, although the feelings of grief will come back from time to time, they are able to live normally. Some parents have needed professional counseling to be able to work through their feelings. If you are worried about how you are feeling, talk to your doctor or your DSCC Consultant.

Grief

SHOCK is what parents say they first feel when they realize their child has a special health care need, a handicap, or a disability. The doctor may be the first to tell them, but many times parents say "I knew something was wrong even before I saw the doctor." No matter how you learn about your child's problem, IT HURTS. The initial shock and pain - maybe a sense of numbness - soon changes into other feelings that have been described in a process called "grief" or "coping."

There have been many articles written about the grief process and several stages have been described. If you like, your DSCC Consultant can share more information with you. It is important for you to realize that feelings like anger, guilt, depression, or isolation may occur and are normal. Many parents have said "I thought I was crazy, I felt so upset all the time." It helped when they learned this was a normal part of adjusting to and coping with the changes in their life as a result of their child's special health care needs.

Many parents find help and support from their families and the professionals working with their child. But most find talking to other parents of children with similar health care needs especially helpful; other parents understand what you are going through and feeling. There are many parent support groups in Illinois. Some of them are listed in this section. Your DSCC Consultant can help you identify groups in your area if you would like to meet other parents of children with special health care needs.

Local Parent Support Groups

These are a wide variety of small local support groups who meet to share information, provide practical help and emotional support to you and your family.

The following suggestions should help you find a group in your area which is best suited to your needs.

1. Hospital where your child receives treatment (the Social Service Department often keeps listings of local self-help groups).
2. Doctor - (your child's doctor or his nurse or receptionist can often direct you to local groups).
3. Service Providers, such as DSCC, ARC, UCP and/or national organizations which have local chapters, mental health clinics, etc.
4. Pediatric Medical Centers, Social Service Departments and Public Service Departments.
5. Special Education Centers, and special education teachers in your school district.
6. Newspaper, community calendar/events section will often list notices for upcoming meetings held by parent support groups.
7. The Self-Help Center (1600 Dodge Ave., Evanston, IL 60201, 708-328-0471) keeps an extensive listing of local, county and regional groups who provide parent support.

A Handbook of Heart Terms, prepared by the National Heart, Lung, and Blood Institute

Telephone Directory

One of your greatest assets for finding help in your area is your telephone directory. Below are some examples of headings to look under to aid you in finding the help you need in your area:

1. Yellow Pages

Social Services - Local social service providers, specific disability organizations, mental health clinics

Fraternal Organizations - Local civic groups who help with funding or equipment needs specific services (such as Home Health Care, Medical Supplies and Equipment, In-home Nursing Services)

2. White Pages

Illinois State of, then specific department such as Public Health, Rehabilitation Services, Mental Health, Public Aid, etc.

United States, then specific office, such as Social Security Administration.

Schools - Public, then Special Education Department or Centers

Recommended Reading

A Child Goes to The Hospital, available from the Association for the Care of Children's Health

A Difference in the Family - Living with a Disabled Child, Helen Featherstone

A Doctor's Tools, Kenny DeSantis

A Glossary of Heart Terms, Upbeat

A Guide for Teachers; Children and Hospitals, available from the Association for the Care of Children's Health

A Handicapped Child in the Family, Verda Heisler

A Hospital Story: An Open Family Book for Parents and Children Together, Sara B. Stein

A Parent's Guide to Learning Disabilities, Alice C. D'Antoni

A Practical Dictionary of Medical Terms for Parents of Children with Heart Disease, Mid-Michigan Parent Group

A Visit to the Hospital on Sesame Street, Deborah Houtzig

About Dying, published, New York Walker & Company

After the Tears, Robin Simons

Alternatives: A Family Guide to Legal and Financial Planning for the Disabled, L. Mark Russell

Anna Joins In, Katrin Arnold

Becky's Story, Donna Bazik

Betsy and the Chicken Pox, Gunilla Wolde

Betsy and the Doctor, Gunilla Wolde

Bibliotherapy With Children Experiencing Loss, Evelyn and Duff Berg

Books for Children about Death, Carolyn R. Haridean

Cancer: The Whispered Word, Judy Swenson and Roxane Kunz

Children Die Too, Joy Johnson and Dr. S.M. Johnson

Dare to Discipline, James Alabson

Directory of Self Help Mutual Aids Groups, published, The Self Help Center
Disabled? Yes, Defeated? No, Kathleen Cruzic

Emergency Room, Bob and Diane Wolfe

Eric Needs Stitches, Barbara Marino

Explaining Death to Children, Earl A. Grollman

Feeling Down: The Way Back Up, Roxane B. Kunz and Judy H. Swenson

For Those Who Live, Kathy LaTour

Going to the Doctor, Fred Rogers

Good Grief, G. E. Westberg

Growing Pains: Helping Children Deal with Everyday Problems through Reading, Maureen Cuddigan and Mary Beth Hanson

Handbook for Parents of Children with Learning Disabilities, R. J. Schoonover

Harry's Dog, Barbara Porte

Help for Your Child: A Parent's Guide to Mental Health Services, S. Brehm

Helping Children with Learning Disabilities: In the Home, Church and Community, Ruth Dinkins Rowan

Helping Your Exceptional Baby: A Practical and Honest Approach to Raising a Mentally Handicapped Child, C. Cunningham and P. Sloper

Home Care for the Chronically Ill or Disabled Child, Monica Jones

Hospital Roadmap: A Book to Help Explain the Hospital Experience to Young Children, Ingrid Elliot

How to Build Special Furniture and Equipment for Handicapped Children, Ruth Hofmann

How to Discipline Without Feeling Guilty, Melvin Silberman and Susan Wheelan
I Am, I Will, I Can, F. Rogers

I Wish I Was Sick Too!, Franz Brandenburg

Is Human Life Precious?, A. E. Dudale

It's Easy to Make Aides for Your Handicapped Child, Al Gaston

I'll Never Love Anything Ever Again, Judy Delton

Jeff's Hospital Book, Harriet Sobol

Jeff's New Pacemaker, Medtronics, Inc. (Available through Medtronics salesman)

Living When a Loved One Has Died, E. A. Goldman

Living with the Handicapped Child, Evelyn Ayauet

Meeting the Challenge of Disability or Chronic Illness, L. A. Goldfarb, M. J. Brotherson, J. A. Sanmenrs and A. Turnbull

Mentally Retarded Children: What Parents and Others Should Know, H. E. Blodgett

Michael and the Dentist, Bernard Wolf

Miffy in the Hospital, Dick Bruna

Mr. Rogers Talking with Young Children about Death, available through Family Communications, Inc.

My Book for Kids with Cansur, Jason Gaes

My Dentist, Harlow Rockwell

My Doctor, Harlow Rockwell

My Hospital Book, William L. Coleman

No Easy Answers - The Learning Disabled Child, S. Smith

No Measles, No Mumps for Me,
Paul Showers

No One to Play With: The Social Side of Learning Disabilities, Betty B. Osman with Henriette Blinder

Nobody Cares About Me, Sarah Roberts

On Becoming a Special Parent; A Mini Support Group in a Book, Marcia Routberg

On Death and Dying, Elizabeth Kubler-Ross

One Miracle At A Time: How to Get Help For Your Disabled Child - From the Experiences of Other Parents, Irving R. Dickman and Sal Gordon

Our Special Child, Bette M. Ress

Parent Effectiveness Training, Thomas Gordon

Patty Gets Well, Patricia Frevert

Pop-Up Going to the Hospital, Bettina Clark and Lester L. Coleman

Preparing Your Child for Repeated and Extended Hospitalizations, available from the Association for the Care of Children's Health

Promises to Keep: A Handbook for Parents of Learning Disabled, Handicapped and Brain-Injured Children, David Melton

Raising A Handicapped Child, Charlotte Thompson, M.D.

Retarded Isn't Stupid Mom!, Sandra Z. Kaufman

Sesame Street Hospital Kit, Available from local parents' groups in the Chicago area

Sick in Bed, Anne and Harlow Rockwell

Something's Wrong With My Child, M. Brutton

Sorrow into Joy, Hugh Salisbury

Spots are Special!, Kathryn O. Galbraith

Support Groups for Parents Whose Children Die, Compassionate Friends

Talking About Death, A Dialogue Between Parents and Child, published, Boston Beacon Press

Taryn Goes to the Dentist, Jill Kremetz

Teaching Individuals with Physical and Multiple Disabilities, June Bigge

Teddy Bears Cure a Cold, Susanna Gretz and Alison Sage

Tell Me Papa, Joy and Marve Johnson

Telling a Child About Death, published, New York Hawthorne Books, Inc.

The American Heart Association Cookbook, published, the American Heart Association

The Bereaved Parent, Harriet Sarnoff Schiff

The Checkup, Harold Roth

The Child with the Disabling Illness, John Downey and Neils Law

The Chronically Ill Child and Family in the Community, available from the Association for the Care of Children's Health

The Chronically Ill Child: A Guide Book for Parents and Professionals, Audrey F. McCollin

The Dentist and Me, Joy Schaleben-Lewis

The Emergency Room, Anne and Harlow Rockwell

The Exceptional Parent Magazine, published, Exceptional Parent

The Grief of Parents When a Child Dies, Mary Shandial Miles

The Heart of a Child, William J. Potts

The Hospital Book, James Howe

The Hospital Scares Me, Paula and Kirk Hogan

The Inner World of Childhood, Francis Wickes

The New American Pocket Medical Dictionary, published, C. Scriber Publishers

The New Diary, Tristine Rainer

The Single Parent Experience, Carole Klein

The Special Child Handbook, John McNamara and B. McNamara

The Special Child: A Source Book for Parents of Children with Developmental Disabilities, Siegfried Pueshel, James Bernier and Leslie Weidenman

The Tenth Good Thing About Barney, J. Viorst

The Ultimate Loss: Coping with the Death of a Child, Joan Bordow

The Wheelchair Child, Philippa Russell

Understanding Your Cardiac Catheterization, Gayle Lacita and Suzanne Burae

Ways for the Disabled Magazine, published, First Publications, Inc.

We Remember Phillip, Norma Simon

Wendy Well and Billy Better Ask a "Mill-Yun" Hospital Questions, John Welzenbach

Wendy Well and Billy Better Meet the Hospital Sandman, John F. Welzenbach

Wendy Well and Billy Better Say "Hello Hospital", John F. Welzenbach and Nancy Cline

Wendy Well and Billy Better Visit the Hospital See-Through Machine, John F. Welzenbach

When Bad Things Happen to Good People, Harold S. Kushner

When You Visit the ICU, the Association for the Care of Children's Health

Where's Jess, Joy and Marve Johnson

Whoever Said Life is Fair?, Sara Kay Cohen

You and Your Grief, E. Jackson

Your Child's Heart Catheterization, Variety Club

Your Heart Test, Candice Superira

Your Hospital: Meeting the Special Needs of Children, available from the Association for the Care of Children's Health

Your Turn Doctor, Carla Perez and Deborah Robison

Resources

Academy of Dentistry for Persons with Disabilities
211 E. Chicago Avenue
Suite 948
Chicago, IL 60611
312-440-2660

Professional Organization

American Foundation for the Blind-Illinois Chapter
401 N. Michigan Avenue
Chicago, IL 60601
312-245-9961

Provides information on conditions that lead to vision loss and blindness, as well as information on services available to the blind.

American Heart Association - Illinois Chapter

P. O. Box 2666
1181 North Dirksen Parkway
Springfield, IL 62708
800-252-8511 or 217-525-1350

Mission is to reduce premature disability and death due to heart and vascular diseases through research, education and community programs.

Arthritis Foundation - Illinois Chapter
111 E. Wacker Drive
Chicago, IL 60603
312-616-3470

Provides educational programs and peer support to patients and families with arthritis. Group meets monthly. Membership is open to persons with arthritis and family members.

Association for Retarded Citizens of the U.S. - Illinois Chapter
925 W. 175th Street
Homewood, IL 60430
708-206-1930

Goal: to advance through all resources, the total well being, dignity and rights of all citizens who are mentally retarded and to foster the prevention of mental retardation. Program includes: early infant intervention, adult vocational program, adult residential services, family support, respite care, foster care and recreational assistance.

Association for the Care of Children's Health
3615 Wisconsin Avenue N. W.
Washington, DC 20016
202-244-1801

Professional Organization

Children's Defense Fund
122 C. Street, N.W.
Suite 400
Washington, DC 20001
202-628-8787

Provides information and/or advocacy for individuals with disabilities and their families. Families of Spinal Muscular Atrophy
P.O. Box 1 465

Compassionate Friends, Inc.
P.O. Box 3696
Oak Brook, IL 60522
708-990-0010

National organization offering support for families of children who have died.

Coordinating Council for Handicapped Children
20 East Jackson, Room 900
Chicago, IL 60604
312-939-3513 (Voice) 312-939-3519 (TDD)

Provides parent information, advocacy and training with regard to special education, including information and written material related to Public Law 94-142 and Public Law 99-457. Provides information on parent/child rights and responsibilities.

Cystic Fibrosis Foundation - Illinois Chapter
150 North Michigan Ave., Suite 400
Chicago, IL 60601
800-824-5064 312-236-4491

Provides information on support groups for parents of children with cystic fibrosis. Also, may coordinate telephone network in some groups. Meetings are for patients, parents and siblings.

Epilepsy Foundation - Illinois Chapter
20 E. Jackson Blvd., Suite 1300
Chicago, IL 60604
312-939-8622

Informs and shares experiences in coping with the various aspects of epilepsy. Topics of discussion include family and psychological problems, the treatment of epilepsy, vocational problems, insurance and social security problems. Meetings are twice monthly for families and friends.

Highland Park, IL 60035
312-432-5551

Offers families support and up-to-date information; sets up library of protocol for different stages of management; raises money for research to reach goals of treatment, prevention and cure; forms national registry and clearinghouse.

Family Resource Coalition
200 S. Michigan Avenue, 16th Floor
Chicago, IL 60604
312-341-0900

Information and resources, including updated research regarding "family centered care" of children with disabilities. Newsletter.

Illinois Association of Community Mental Health Agencies
110 W. Lawrence Avenue
Springfield, IL 62704
217-789-1380

Provides referrals to local mental health offices for child, family and individual counseling on a sliding fee scale based on ability to pay.

Illinois Early Childhood Intervention Clearinghouse
830 S. Spring Street
Springfield, IL 62706
800-852-4302

Operates resource library of books and videotapes, printed material, bibliographies and copies of medical/social/educational articles. All information services and publications are provided free of charge, with the exception of some film rentals. A rich source of information regarding all aspects of caring for a "special needs" child. Newsletter.

Illinois Department of Mental Health and Developmental Disabilities

401 S. Spring Street
Springfield, IL 62765
217-782-2753

Assists with referrals to local offices for family and/or child counseling and developmental testing. Information regarding current programs which serve individuals with developmental disabilities in Illinois. Coordinates information regarding respite services. Operates regional institutions for mentally ill/developmentally disabled persons. Operates Home Individual Program (HIP) Homes, "foster" placements for developmentally disabled individuals who cannot live in their own homes and who require extensive rehabilitation services, but who do not require institutional placement.

Illinois Department of Rehabilitation Services
625 East Adams
P.O. Box 19429
Springfield, IL 62794-9429
217-782-2093 or 1-800-275-3677

Responsible for vocational training services for older teenagers and adults. Offers limited home health care and respite services to families who are income eligible. Provides human rights and disability rights advocacy services. Administers Illinois School for the Deaf, Illinois School for the Visually Impaired and Illinois Children's School and Rehabilitation Center. Provides information and assistance.

Illinois State Board of Education
100 N. First Street
Springfield, IL 62777
217-782-6601

Administers and oversees implementation of Illinois Special Education Rules and Regulations. Supports parent advocacy efforts.

Lekotek
National Center
2100 Ridge Avenue
Evanston, IL 60201-2796
708-328-0001

Provides resources for parents of children (0-8 years old) who have special needs, whether permanent or temporary: 1) toy lending library; 2) parent support group (monthly); 3) preschool project; 4) computer project. Provides parents with a resource center.

National Down Syndrome Congress
1605 Chantilly Drive, Suite 250
Atlanta, GA 30324
800-232-6372

National Easter Seal Society
230 W. Monroe
Chicago, IL 60606-4802
312-726-6200 (Voice) 312-726-4258 (TDD)

Has a wide range of services and therapies for people with congenital or acquired disabilities. Operates information and referral services, parent education classes and self-help groups and equipment lending "libraries." Not all services are available at every center.

National Hydrocephalus Foundation
Route 1 River Road
Box 210A
Joliet, IL 60436

Not-for-profit organization for parents of children or adults with hydrocephalus, mainly offering educational and referral services. People with similar concerns are linked; symposiums held and new groups formed. Parents and adults with hydrocephalus have formed their own subgroup and support system.

Neurofibromatosis Incorporated
407 Indianapolis Avenue
Downers Grove, IL 60515
800-322-6363 or 708-963-6040

Provides information to people with neurofibromatosis (NF), the medical community and the public. Offers support to people and families affected by NF and seeks to end the isolation felt by those with rare disorders.

Parents of Chronically Ill Children
1527 Maryland Avenue
Springfield, IL 62702
217-522-6810

Parent Coalition Group

Equip for Equality
11 East Adam, Suite 1200
Chicago, IL 60603
800-537-2632 or 312-341-0022

Advocates legal and human rights of persons with disabilities. Specific services includes information and referral, legal advice and representation in negotiations, assistance with administrative hearings in court, if necessary. P&A also provides training and education sessions on legal rights and self advocacy techniques and information regarding guardianship.

United Cerebral Palsy
1-800-872-5827

Provides a variety of supportive services, including assessment, equipment loan and early intervention. Services vary somewhat among the seven affiliate offices.