



Directions: Resources for Your Child's Care

Connecticut Edition, 2008

For information and to obtain this book,
visit www.ct.gov/dph.

For *Directions: Resources for Your Child's Care*,
look under Publications.

This book is also available on the Danbury Children First
website at www.danburychildrenfirst.org.

CONNECTICUT DEPARTMENT OF
PUBLIC HEALTH

Keeping Connecticut Healthy

How to Use Directions

Directions was created for you, a parent of a child with special health needs. It can help you plan and coordinate care for your child. In *Directions* you will find:

- Ways to organize your child's health information
- Information about caring for your child's special needs
- Resources
- Tips from other parents of children with special health care needs

Directions has many forms to fill out and a lot of information to read through. Take your time to fill out the forms that are useful to you, gather your child's records, and read through the chapters. You may want to use different forms and sections at different points in your child's life. This notebook can be very helpful to you and your child's health care providers.

Organizing Tips:

- Keep your child's ***Immunization Record*** with this book. Take it with you every time you go to a health care visit, whether it is a check-up or an emergency visit.
- Use the calendar to write down important dates and appointments.
- Write down information about your child's health and health care in *Chapter 1*.
- Keep your child's health records in *Chapter 2*. Include copies of letters, bills, receipts, prescriptions, and other documents. If you run out of space, it is time to buy another 3-ring binder!
- Keep copies of your child's school records and care plans in *Chapter 3*.
- The ***Glossary*** at the end of this book has the meaning of some words and terms.
- Ask for help. There are many people who can help you organize this notebook, such as your child's primary care provider, nurse, care coordinator, case manager, teacher, other parents, or other family members.

Bring this notebook to your child's appointments and meetings with health care providers.



Internet Tips

The Internet is a good way to communicate and find information about your child's special needs. If you have access to the Internet, you can use a computer to:

- Find information about health and health care on the World Wide Web. Many excellent websites are listed in this notebook.
- Download (transfer) information from the Internet onto your own computer (like *Directions*, for example).
- Send email (electronic mail) with text and other types of files, including documents, images, and sounds.

How to Access the Internet

The Internet can be accessed from a home computer, or from:

- **Public Libraries** – Most public libraries have computers that are connected to the Internet and free to use.
- **Your Child's School** – Most schools have computers that are connected to the Internet. Ask your child's teacher or principal whether you may use a school computer to access health information for your child.
- **Family Resource Centers** – Many sites (such as your child's school, hospital, or primary care provider's office) have family resource centers or libraries that have access to the Internet. Check with one of these sites to find out if you can use a computer to access health information for your child.

Learning to Use the Internet?

There are many books and classes. If you are new to the Internet and the World Wide Web, contact your local library or school system for help.

Table of Contents

How to use <i>Directions</i>	iii
Calendar	
Chapter 1: Information about Your Child	
• Parent/Guardian and Emergency Contact Information.....	Form A
• Health Insurance Plan.....	Form B
• Diagnoses	Form C
• Allergies	Form D
• Emergency Information Form for Children with Special Needs	Form E
• All about Me	Form F
• Birth and Development: About Mother’s Pregnancy	Form G
• Birth and Development: About Your Baby	Form H
• Family Health History	Form I
• Health Care Providers	Form J
• Hospitals.....	Form K
• Other Health Care Providers	Form L
• Home Health Agency	Form M
• School/Day Care Center	Form N
• Pharmacies	Form O
• Medications	Form P
• Event Diary	Form Q
• Supplies/Equipment	Form R
• Hospital Stays	Form S
• Important Tests	Form T
• Meeting/Appointment Log	Form U
• Phone Log	Form V
• Important Information for a Sitter	Form W
Chapter 2: Health Records	
Chapter 3: School Records	
Chapter 4: Being Prepared for an Emergency	
• Preparing for a Medical Emergency	3
• Emergency Information Form for Children with Special Needs	4
• Emergency Response Plan	7
• Preparing for an Emergency at Home	8
• Preparing for a Disaster Emergency	11

Chapter 5: Your Child’s Medical Team

• What is Primary Care?	15
• What is a “Medical Home?”	16
• Talking with Your Child’s Health Care Providers	17
• Questions to Ask Your Child’s Primary Care Provider	18
• Tips on Making the Most of a Health Visit	20
• Seeing a Specialist	21
• Seeing a Mental Health Provider	22
• Finding a Mental Health Provider	23
• Seeing a Dentist	24
• Seeing an Ear, Nose & Throat Doctor.....	24A
• Working with a Care Coordinator	25
• Health Care Providers by Specialty (What They Do)	26
• Changing Health Care Providers	28
• Your Child’s Hospital Care	29
• Tips on Supporting Your Child During a Hospital Stay	30
• Preparing for the Hospital Discharge	31
• Hospital Discharge Checklist	32
• Resources to Help During a Hospital Stay	33
• Medical Privacy and Communication	34

Chapter 6: Your Child’s Everyday Care

• Medication	38
• Keeping Medications Organized	39
• Nutrition	40
• Oral Health Care.....	40A
• Durable Medical Equipment	41
• Assistive Technology (AT)	42
• Transportation	43
• Car Seat Safety	43
• Using Home Health Services	44
• Important Information about Home Health Services	45
• Questions to Ask a Home Health Agency	47
• Using a Personal Care Attendant (PCA)	48
• Childcare	50
• Choosing a Sitter	51
• Respite Care	52
• Hospice Care	53
• Moving to a New Community	54
• Moving Checklist	56
• Planning a Vacation	57

Chapter 7: Your Child’s Health Plan

• Calling a Member Service Representative	62
• Case Management	63
• Mental Health Services	64

• The Prior Authorization Process	65
• The Appeal Process	66
• What if I Have a Grievance or a Complaint?	67
• Changing Health Insurance Plans	68

Chapter 8: Making Education Work for Your Child

• Your Child’s Legal Rights	71
• Early Intervention: Services for Your Child from Birth to Age 3	73
• Your Child’s Early Intervention “Team”	74
• The Individualized Family Service Plan (IFSP)	75
• Preschool Age 3-5	76
• Services for Your School-Aged Child	77
• The Individualized Education Program (IEP)	79
• Your Child’s IEP “Team”	80
• 504 Plan	81
• The Individualized Health Care Plan (IHCP)	82
• Key People to Help with Your Child’s Educational Needs	84
• Tips on Building a Relationship with Your Child’s School or Child Care Center	85
• Education Resources	86

Chapter 9: As Your Child Grows Up

• Transition	89
• When Your Child is Younger	90
• When Your Child Becomes a Teenager	91
• For Teens: Keeping Track of My Own Health Care	93
• As Your Teen Becomes an Adult	94
• Teen Tips: Communicating with Health Care Providers	95

Chapter 10: Connecting Parents and Families

• Parenting a Child with Special Healthcare Needs	99
• Taking Care of Yourself	100
• Getting Connected with Other Parents	101
• Resources for Parents and Families	102
• Recreation and Support for Your Child	105
• Connecting Brothers and Sisters – Sibling Supports	106
• Speaking Up for Your Child	107
• Communication	108

Glossary

• List of Terms	109
• Abbreviations Related to Medications	118
• Commonly Used Abbreviations	119
• Quick Links to Resources	121

Acknowledgments