Collaborative Care Notebook

For more information call
(801)272-1068
Or toll free in Utah
1-800-468-1160

For Children & Youth with Special Health Care Needs

Utah FAMILY VOICES

A Family to Family Health Information Center

About your Care Notebook

What is a Care Notebook?

A Care Notebook is an organizing tool for families who have children with special health care needs. Use a Care Notebook to keep track of important information about your child's health care. This Care Notebook has been designed for families of Children and Youth with Special Health Care Needs.

How can a Care Notebook help me?

In caring for your child with special health needs, you may get information and paperwork from many sources. A Care Notebook helps you organize the most important information in a central place. A Care Notebook makes it easier for you to find and share key information with others who are part of your child's care team.

About this Care Notebook

This version of a Care Notebook was "built" by a parent of a child with multiple special health care needs from the Utah Family Voices Family to Family Health Information center. This book can be used "as is" or you can remove or add pages according to your child's needs. Below, you can learn how to "build your own care notebook" from twenty different versions from different states. You may notice that the pages in this book all look different, and each page will indicate from which state or program it was created. The Utah Family Voices F2F Health Information Center found the process of building your own care notebook from the National Center for Medical Home Initiatives to be an innovative, creative, and easy way to put together a file for any child or youth with special health care needs. It can be built to suit any variety of needs.

Why build my own care notebook?

The Care Notebook is an organizing tool for families and will help you keep track of important information. Care Notebooks are very personal to your child and ideally should be customized to reflect your child's medical history and current information. For this reason, the American Academy of Pediatrics-National Center for Medical Home Initiatives for Children with Special Health Care Needs has developed a section of their website to allow you to build a Care Notebook that best meets the needs of your child. Utah Family Voices recommends use of this website to create your individualized Care Notebook.

How do I build my own Care Notebook?

Go to http://www.medicalhomeinfo.org/tools/care_notebook.html Twenty Care Notebooks have been divided into sections with similar content and made available in both Microsoft Word and PDF formats. Your computer must have Microsoft Word software to open and use the Word documents or to delete, modify, or add your own text to reflect the information you want to include in that particular section of your Child's Care Notebook. You will need the free Adobe Reader on your computer to open and view the PDF documents. You can fill-in and print completed PDF forms from the web site or print blank forms and complete them manually. You cannot save completed PDF forms unless you purchase and have Adobe Acrobat software on your computer. Most people will want to fill-in and save the Care Notebook documents and this is most easily done with the word documents. However, those who do not have Word software on their computer are able to use the PDF format version with the understanding that the forms cannot be altered (or changed). It is recommended to view the online examples before building your own care notebook.

Fill and update your Care Notebook:

-Track changes in your child's medicines or treatments

-Add new information to the Care Notebook whenever your child's treatment changes.

-List telephone numbers for providers and contacts

-Prepare for appointments

-File information about your child's health history

Use your Care Notebook:

-Store the Care Notebook where it is easy to find. This helps you and anyone who needs information when you are not there.

-Share new information with your child's primary care physician, school nurse, daycare staff, and others caring for your child

-Take the Care Notebook with you to appointments and hospital visits so that information you need will be easy to find.

Setting up Your Care Notebook

-Include your child when working on the Care Notebook. Let them know that the Care Notebook contains information about them and their care.

Follow these steps to set up your Care Notebook:

Step 1: Gather information you already have.

- ♥ Gather up any health information about your child you already have. This may include reports from recent doctor's visits, recent summary of a hospital stay, this year's school plan, test results, or informational pamphlets.

Step 2: Check out the pages of the Care Notebook

- ♥ Which of these pages could help you keep track of information about your child's health or care?
- ♥ Use the Care Notebook as it is, remove pages or get or more pages that will help you personalize your book to your child's needs are available at: http://www.medicalhomeinfo.org/tools/care_notebook.html
- ♥ For a printed copy, call Utah Family Voices at 801-272-1068 or 1-800-468-1160.

Step 3: Decide which information is most important to keep in your child's Care Notebook

- ♥ What information do you look up often?
- ♥ What information do caregivers for your child need?
- ♥ Consider storing other information in a file drawer or box where you can find it if needed.

Step 4: Assemble your Care Notebook

- ♥ Everyone has a different way of organizing information. The KEY is to make it easy for **you** to find again. Here are some suggestions for supplies used to create a Care Notebook:
- ♥ **3-ring notebook** . Hold papers securely.
- ♥ **Tabbed dividers**. Create your own information sections.
- ♥ **Pocket dividers.** Store reports.
- ♥ **Plastic pages.** Store business cards and photographs.

Care Notebook Contents

Myself

- Child Information Page - UT
- Child's Health Page - ND
- Family Information Page- UT
- Make a Calendar - ME
- Notes - UT

My Health Care

- Emergency Information Sheet-UT
- Doctor's Appointments - TN
- Diagnoses - MA
- Nutrition - UT
- Diet Tracking Form - UT
- Growth Tracking Form - UT
- Immunizations and Allergy - IL
- Medications - TN
- Nebulizer & Vest Treatments - IL
- Catheterization Schedule - IL
- Respiratory – ND
- Dental – IL
- Surgeries / Procedures – TN
- Event Diary – MA
- Seizure / Behavior Log – CA
- Medical Supplies – IL
- Notes - UT

My Contacts

- Health Care Providers - IN
- Family Support Resources - IN
- School Contacts - UT
- Emergency Contacts - ME
- Personal Contacts - ME
- Contact Log - VA
- Notes – UT

My Plan

- Care Schedule - MO
- Mealtime Routine - TN
- Therapy - IL
- Activities of Daily Living - UT
- Social Experiences - OH
- Recreation – UT
- Communication – UT
- Communication Info. – UT
- Coping/Stress Tolerance – UT
- Mobility – UT
- Social/Play – UT
- Rest/ Sleep – UT
- Transition – UT
- Notes – UT

My Coverage

- Insurance – UT
- Medical Bill Communication - UT
- Tracking of Medical Bills – TN
- Medical Travel Expense Log – IL
- Out of Pocket Expense Log – CA
- Notes - UT

Note: You may use all or just a part of these pages. Not all of the pages may apply to your family situation. Look on the website to add different pages.

Organize your pages any way that works for you. (See "**Setting up Your Care Notebook**.")

Use dividers or tabs to help you organize your note book. Sheet protectors, plastic sleeves and folders will also be helpful.

Use the "Myself" section of your Care Notebook to create an identity profile for your child. This section includes a personal profile, family, friends and a calendar to schedule your child's appointments and activities.

Myself

Child's Page

Photo of Me!

My name is: _____

My nickname is: _____

My birthday is: _____

I like to: _____

I don't like to: _____

I have a pet yes ☐ no ☐ My pet is a _____ Named _____

My friends are _____

My caregivers are _____

When I am happy I _____

When I am sad I _____

When I feel pain I _____

I need help with _____

I can do these things for myself _____

If you need to know something else, call _____

My Favorite Things

Toys _____

TV shows _____

Games _____

Hobbies _____

Songs _____

Animals _____

Favorite foods _____

Least Favorite foods _____

(Adapted from the Care Notebook with permission, Children's Hospital and Regional Medical Center, Seattle, WA, 2003.)
Utah Department of Health, c. 2005.

Child's Page

Use this page for your child's words and thoughts about his or her life now as well as later.

Date:_____

Family Information

Child's Name: _____ Nickname: _____

Date of Birth: _____ Social Security Number: _____

Diagnosis: _____ Blood Type: _____

Legal Guardian: _____

Address: _____ Phone: _____
_____

Mother's Name: _____
Address: _____

Daytime Phone:_____ Evening Phone: _____

Father's Name:_____

Address: _____

Daytime Phone: _____Evening Phone: _____

Name: _____Age: _____ Name: _____ Age: _____
Name: _____Age: _____ Name: _____ Age: _____

Other household members:

_____

Important Family Information:

_____
_____
_____

Language(s) spoken at home: _____
Interpreter Needed? Yes: _____ No: _____
Preferred interpreter? Name: _____Phone: _____

Emergency Contact

Name: _____
Address: _____
Daytime Phone: _____ Evening Phone: _____

"Make-A-Calendar"

Month _____ *Year* _____

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday

Name:_____ **DOB:**_____

My Health Care

The "My Health Care" section of your Care Notebook is to keep all information about your child's health care and health care needs. This section will be very helpful at appointments with doctors and specialists.

CSHCN Emergency Health Information Sheet
(Información De Emergencia)

Name: *(Nombre)*

1. Nonverbal ☐ 2. Hearing Impaired ☐
3. Visually Impaired ☐ *1. No puede hablar* ☐
2. No puede oir ☐ 3. *No puede ver* ☐

Birthdate: *(fecha de nacimiento)*

Primary Language: *idioma preferido*

Usual reason for calling EMS: *(Razon usual para llamar EMS)*

Which hospital should your child be transported to?
(Cual hospital preferia Ud. Para transportar el nino/a)

Diagnoses: *(Diagnosticos)*	Past Procedures/Surgery: *(procedimientos y cirugias pasadas)*
1.	1.
2.	2.
3.	3.

Procedures to Avoid: *(procedimientos que deben evitar)* Why? *(¿por qué?)*

1.
2.
3.
4.

Allergies: (alergias) Reaction Symptoms: (*Reacción)*

1.
2.
3.

Baseline PE and Vitals: *(condicion normal)* _____ Weight*(peso)* _____lbs Height*(altura)*_____

Pulse *(pulso por minuto)* _____ beats per minute Blood Pressure *(presión sanguínea)*_____/_____

Respiratory Rate *(frecuencia respiratoria)* _____per minute Oxygen Saturation _____ **%**

Feeding Pump (bomba de aleimentación)☐ Suction Machine (maquina de succión) ☐ Gastrostomy ☐
Pulse Oximeter *(oximetro)*☐ Apnea Monitor (monitor de apnea) ☐ Oxygen *(oxygen)* ☐
Tracheostomy *(traquiostomia)* ☐ Ventilator *(ventilator)* ☐ NG Tube *(tubo nasogatrico)* ☐
Wheelchair *(silla de ruedas)* ☐ NG/NJ Tube *(tubo nasogastrico)* ☐ Other *(otro)*: _____

Trach Size & Type: *traqueostomia medida/marca*	Ventilator Type & Mode: *ventilador marca/moda*
Best Location for IV: *(lugar mejor para localizacion del suero)*	Location to draw blood: *(lmajor sitio para sacar sangre)*

Medications *(List Indication)*:*(medicinas)* Dose/Administration:*(dosis/ruta de administración)*

1.
2.
3.
4.
5.
6.

Form # _____ DATE SHEET LAST UPDATED EMSC NOTIFIED OF DISTRIBUTION
Source: _____ FOR THIS CHILD: _____ Date: _____ Signed:_____

MANAGEMENT INFORMATION: *(información médica)*

Baseline Labs xrays, ECG, etc: *(Rangos normales de las pruebas de laboratorio, rayos-x, ECG del paciente)*	Baseline Neuro Status: *(condición neurologica del paciente)*
	Developmental age: *(edad de desarrollo)*

Immunizations Current? (Vacunas al día ?) *Yes (si)* ☐ *No* ☐ As of Date *(Fecha)*

Common Presenting Problems and Suggested Managements: *(Problemas communes y sugerencia de su manejo)*

Problem *(problema* Suggested Diagnostic Studies *(estudios diagnosticos sugeridos)* Treatment Considerations *(tratamiento)*

1.

2.

3.

Special Needs as Identified by Physician and Family: *(necesidades médicas especiales)* & Physician Comments on Family Needs (*Financial, Social, etc.)* (comentarios del medico sobre otras necesidades de la familia, como aspectos financieros, socials, etc)

Physician Order For DNR
Completed: Yes ☐ **No** ☐ **Attached: Yes** ☐ **No** ☐

Physician Signature (Serves as orders if hospitalized)

_____

Physician Name (Print)_____

Date_____

CONTACT INFORMATION

Name: *(Nombre)*	Parent/Guardian: *(Nombre de Padre/Tútor)*
Address: *(dirección)*	Home Phone: *(Número de teléfono- casa)*
	Work Phone: *(Número de teléfono-trabajo)*
Emergency Contact Name/Relationship/Phone: *(Persona de contacto en caso de emergencia-Nombre/relación/teléfono)*	Signed Permission for Emergency Care: *(Permiso firmado para dar tratamiento de emergencia)* Print Name (Imprimir nombre) Sign Name (Firmar nombre)
	Out of State Emergency Contact: *Persona de contacto fuera del Estado en caso de emergencia* Name Relationship Phone:
Insurance Info: *(Seguro medico/Aseguranza)*	Insurance Phone/Address: (teléfono/dirrecion del seguro)

Spiritual Orientation: *(Religión)*

Form # _____ DATE SHEET LAST UPDATED EMSC NOTIFIED OF DISTRIBUTION
Source:_____ FOR THIS CHILD: _____ Date: _____ Signed:_____

Medical Home/ PC Physician: *(Médicos/Especialistas)*	Phone *(teléfono de emergencia)*:
Address: *(dirección)*	Fax: Care Coordinator *(coordinatador de cuidado)*
Specialist Name: *(Especialistas)*	Office Phone *(Número de la oficina)*:
Title/Specialty *(titulo/especialidad)*:	Emergency Phone *(teléfono de emergencia)*:
Specialist Name *(especialistas)*:	Office Phone *(Número de la oficina)*:
Title/Specialty *(titulo/especialidad):*	Emergency Phone *(teléfono de emergencia)*:
Specialist Name *(especialistas)*:	Office Phone *(Número de la oficina)*:
Title/Specialty *(titulo/especialidad):*	Emergency Phone *(teléfono de emergencia)*:
Specialist Name *(especialistas)*:	Office Phone *(Número de la oficina)*:
Title/Specialty *(titulo/especialidad):*	Emergency Phone *(teléfono de emergencia)*:
Pharmacy Name/Phone: *(fNombre de farmacia/teléfono)*	

Form # _____ DATE SHEET LAST UPDATED EMSC NOTIFIED OF DISTRIBUTION
Source: _____ FOR THIS CHILD: _____ Date: _____ Signed:_____

Instructions for utilizing the CSHCN Emergency Information Sheet

- **Register – go to https://health.utah.gov/ems/emsc/cshcn/?user_type=parent_guardian**
  Fill out the form, and your child will be registered. You will receive the storage tube in the mail.

- **Update when there are changes in your child's health, medications, contacts, etc.**

- **Complete this form and keep one copy in the following places. This will give your child the best possible outcome in an emergency situation.**

a. **Doctor's office**
b. **ER – local**
c. **Home – inside the refrigerator in a tube provided once you register at the website**
d. **Vehicles – in each parents vehicle**
e. **Work – at each parent's workplace**
f. **Purse/wallet – of each parent**
g. **School – on file**
h. **Child's backpack/travel bags**
i. **Emergency contact – at the house of that person**

DOCTOR'S APPOINTMENTS

Doctor's Name	Appointment Date	Appointment Time	Questions to Ask at Appointment

Child's Name_____ Date of Birth_____

Diagnoses

Diagnosis Given	Provider who Gave Diagnosis	Date Noted	Notes

Developed by the Massachusetts Department of Health, 2004
(www.mass.gov/dph/fch/directions)

Nutrition

Use this page to talk about your child's nutritional needs. Describe foods and any nutritional formulas your child takes, any food allergies or restrictions, and any special feeding techniques, precautions or equipment used for feedings. Describe any special mealtime routines your family and child have.

Date:_____

Diet Tracking Form

	SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY
Tube Feeding							
Breakfast							
Lunch							
Dinner							
Snacks							
Notes							

(Adapted from the Care Notebook with permission, Children's Hospital and Regional Medical Center, Seattle, WA, 2003.)
Utah Department of Health, c. 2005.

Growth Tracking Form

DATE	HEIGHT	WEIGHT	HEAD CIRCUMFERENCE	CHECKED BY

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						

Immunization and Allergies

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

MEDICATIONS

Name of Medication	Prescription Number	Pharmacy	Strength (see label)	Reason for Medication	Dosage / Frequency (amount)	Route (how taken)	Start Date			End Date			Reason for Ending Medication
							Mo	Day	Yr	Mo	Day	Yr	

Pharmacy	Pharmacist	Address	Phone #

Nebulizer Treatments and Vest Treatments

Name:____

Date	Time	Neb given	O2sat pre	O2 sat post	Vest given	O2 sat pre	O2 sat post	Comments	Initials

Nebulizer Treatments and Vest Treatments

Signature:______________________________Initials______________
Signature:______________________________Initials______________
Signature:______________________________Initials______________
Signature:______________________________Initials______________

Catheterization Schedule

Catheterization Information for:___________Month:________________

Date	Time	Amount of urine obtained	Additional comments (See chart)	Date	*Time*	Amount of urine obtained	Additional Comments (see chart)

Catheterization Schedule

Respiratory

Use this page to talk about your child's respiratory care needs. Describe the care or treatments your child needs and any special techniques or precautions you use when giving care. Include any special routines your child has for respiratory care.

Date:_____

DENTAL RECORD

Child's Name: _____

Dentist's Name: _____

Address: _____

_____

Telephone: _____

☐ 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

Child's Name:_____

SURGERIES OR PROCEDURES

Type of surgery/procedure	Surgeon/Physician/Hospital	Date(s)

HOSPITAL ADMISSIONS (FOR REASONS OTHER THAN SURGERY)

Reason for admission	Hospital	Date(s)

Lab Work / Tests / Procedures

DATE	TEST	RESULT	COMMENTS

(Adapted from the Care Notebook with permission, Children's Hospital and Regional Medical Center, Seattle, WA, 2003)
Utah Department of Health, c. 2005.

Child's Name_____Date of Birth_____

Event Diary

Use this sheet to keep track of important events related to your child's health that may happen from time to time. Some examples include behaviors, seizures, oxygen requirements,frequency of suctioning, vomiting.

Date	Activity/Information

Developed by the Massachusetts Department of Health, 2004 (www.mass.gov/dph/fch/directions)

Child's Name:____________________________________DOB:________________

Seizure / Behavior Log

Seizure or Behavior	☐ Not Applicable to my child

Date/Time	Duration of Seizure [or] Behavior	Description of Seizure (extremities involved, intensity, etc.) [or] Behavior you are concerned about
______	______	______
______	______	______
______	______	______
______	______	______
______	______	______
______	______	______
______	______	______
______	______	______
______	______	______
______	______	______
______	______	______
______	______	______
______	______	______
______	______	______
______	______	______
______	______	______
______	______	______
______	______	______
______	______	______
______	______	______
______	______	______
______	______	______
______	______	______
______	______	______
______	______	______
______	______	______
______	______	______
______	______	______

Seizure or Behavior ☐ **Not Applicable to my child**

Only use this log if it applies to your child.

Date/Time	**Duration of Seizure [or] Behavior**	**Description of Seizure** (extremities involved, intensity, etc.) **[or] Behavior you are concerned about**
_______	_______	_______
_______	_______	_______
_______	_______	_______
_______	_______	_______
_______	_______	_______
_______	_______	_______
_______	_______	_______
_______	_______	_______
_______	_______	_______
_______	_______	_______
_______	_______	_______
_______	_______	_______
_______	_______	_______
_______	_______	_______
_______	_______	_______
_______	_______	_______
_______	_______	_______
_______	_______	_______
_______	_______	_______
_______	_______	_______
_______	_______	_______
_______	_______	_______
_______	_______	_______
_______	_______	_______
_______	_______	_______
_______	_______	_______
_______	_______	_______
_______	_______	_______
_______	_______	_______
_______	_______	_______

Seizure / Behavior Log

Monthly Medical Supplies

MONTHLY MEDICAL SUPPLIES FOR:_____

Vendor Name:_____

Phone:_____

Fax:_____

E-Mail:_____

PRODUCT DESCRIPTION	PRODUCT CODE	QUANTITY	RECEIVED	BACK ORDER	COMMENTS

Note: This form can be used to order supply needs

Notes

Notes

My Contacts

Use the "My Contacts" section for your Care Notebook for the people who provide services and give care to your child, and are just a part of their life. Include school, emergency, and personal contacts.

Health Care Providers

Primary Medical Provider _____

Address _____

City _____ **State** _____ **Zip** _____

Phone ( ) _____

Email _____

Preferred Hospital _____

Address _____

City _____ **State** _____ **Zip** _____

Phone ( ) _____

Email _____

Specialty Hospital _____

Address _____

City _____ **State** _____ **Zip** _____

Phone ( ) _____

Email _____

Specialist Name _____ **Type** _____

Clinic/Hospital _____

Address _____

City _____ **State** _____ **Zip** _____

Phone ( ) _____

Email _____

Specialist Name _____ **Type** _____

Clinic/Hospital _____

Address _____

City _____ **State** _____ **Zip** _____

Phone ( ) _____

Email _____

Name_____**DOB**_____

Adapted from *Medical Passport* (unpaged) by the Indiana State Department of Health Children's Special Health Care Services, 1-800-475-1355, printed (n.d.), Project MCJ-18IS23-02

Specialist Name _____ **Type** _____
Clinic/Hospital _____
Address _____
City _____ **State** _____ **Zip** _____
Phone ( ) _____
Email _____

Specialist Name _____ **Type** _____
Clinic/Hospital _____
Address _____
City _____ **State** _____ **City** _____
Phone ( ) _____
Email _____

Specialist Name _____ **Type** _____
Clinic/Hospital _____
Address _____
City _____ **State** _____ **City** _____
Phone ( ) _____
Email _____

Dentist Name _____
Address _____
City _____ **State** _____ **Zip** _____
Phone ( ) _____
Email _____

Orthodontist Name _____
Address _____
City _____ **State** _____ **Zip** _____
Phone ( ) _____
Email _____

Health Care Providers

Adapted from *Medical Passport* (unpaged) by the Indiana State Department of Health Children's Special Health Care Services, 1-800-475-1355, printed (n.d.), Project MCJ-18IS23-02

Public Health Nurse

Address

City **State** **Zip**

Phone ( )

Email

Nutritionist

Address

City **State** **Zip**

Phone ( )

Email

Social Worker

Address

City **State** **Zip**

Phone ( )

Email

Healthy Families Contact

Address

City **State** **Zip**

Phone ( )

Email

Home Health Agency

Start Date **End Date**

Contact Person

Address

City **State** **Zip**

Phone ( )

Email

Adapted from *Medical Passport* (unpaged) by the Indiana State Department of Health Children's Special Health Care Services, 1-800-475-1355, printed (n.d.), Project MCJ-18IS23-02

Home Health Agency

Start Date _____ End Date _____

Contact Person _____

Address _____

City _____ State _____ Zip _____

Phone ( )

Email _____

Home Health Agency

Start Date _____ End Date _____

Contact Person _____

Address _____

City _____ State _____ Zip _____

Phone ( )

Email _____

Pharmacy

Contact Person _____

Address _____

City _____ State _____ Zip _____

Phone ( )

Email _____

Pharmacy

Contact Person _____

Address _____

City _____ State _____ Zip _____

Phone ( )

Email _____

Adapted from *Medical Passport* (unpaged) by the Indiana State Department of Health Children's Special Health Care Services, 1-800-475-1355, printed (n.d.), Project MCJ-18IS23-02

Occupational Therapist (OT) _____

Start Date _____ End Date _____
Agency _____
Address _____
City _____ State _____ Zip _____
Phone ( )
Email _____

Physical Therapist (PT) _____

Start Date _____ End Date _____
Agency _____
Address _____
City _____ State _____ Zip _____
Phone ( )
Email _____

Speech-Language Pathologist _____

Start Date _____ End Date _____
Agency _____
Address _____
City _____ State _____ Zip _____
Phone ( )
Email _____

Other Therapist _____

Start Date _____ End Date _____
Agency _____
Address _____
City _____ State _____ Zip _____
Phone ( )
Email _____

Other Therapist _____

Start Date _____ End Date _____
Agency _____
Address _____
City _____ State _____ Zip _____
Phone ( )
Email _____

Respite Care Provider _____

Start Date _____ End Date _____
Agency _____
Address _____
City _____ State _____ Zip _____
Phone ( )
Email _____

Adapted from *Medical Passport* (unpaged) by the Indiana State Department of Health Children's Special Health Care Services, 1-800-475-1355, printed (n.d.), Project MCJ-18IS23-02

Family Support Resources

Parent-to-Parent _____

Address _____

City _____ State _____ Zip _____

Phone ( ) _____

Email _____

Parent Group _____

Address _____

City _____ City _____ City _____

Phone ( ) _____

Email _____

Religious Organization _____

Address _____

City _____ City _____ City _____

Phone ( ) _____

Email _____

Service Organization _____

Address _____

City _____ City _____ City _____

Phone ( ) _____

Email _____

Counseling Services _____

Address _____

City _____ State _____ Zip _____

Phone ( ) _____

Email _____

Other _____

Address _____

City _____ State _____ Zip _____

Phone ( ) _____

Email _____

Child's Name_____DOB_____

Adapted from *Medical Passport* (unpaged) by the Indiana State Department of Health Children's Special Health Care Services, 1-800-475-1355, printed (n.d.), Project MCJ-18IS23-02

School/Preschool _____

Principal _____

School Contact _____

Start Date _____ **End Date** _____

Address _____

City _____ **State** _____ **Zip** _____

Phone ( ) _____

Email _____

School Nurse _____

Address _____

City _____ **State** _____ **Zip** _____

Phone ( ) _____

Email _____

Teacher _____

Address _____

City _____ **State** _____ **Zip** _____

Phone ( ) _____

Email _____

Special Education Teacher _____

Address _____

City _____ **City** _____ **City** _____

Phone ( ) _____

Email _____

Other _____

Address _____

City _____ **City** _____ **City** _____

Phone ( ) _____

Email _____

Other _____

Address _____

City _____ **City** _____ **City** _____

Phone ( ) _____

Email _____

Adapted from *Medical Passport* (unpaged) by the Indiana State Department of Health Children's Special Health Care Services, 1-800-475-1355, printed (n.d.), Project MCJ-18IS23-02

Transportation Agency _____
Contact Person _____
Address _____
City _____ State _____ Zip _____
Phone ( ) _____
Email _____

Transportation Agency _____
Contact Person _____
Address _____
City _____ City _____ City _____
Phone ( ) _____
Email _____

Respite Care Provider _____
Start Date _____ End Date _____
Agency _____
Address _____
City _____ State _____ Zip _____
Phone) _____
Email _____

Respite Care Provider _____
Start Date _____ End Date _____
Agency _____
Address _____
City _____ State _____ Zip _____
Phone ( ) _____
Email _____

Respite Care Provider _____
Start Date _____ End Date _____
Agency _____
Address _____
City _____ State _____ Zip _____
Phone ( ) _____
Email _____

_____
_____
_____
_____
_____
_____

Adapted from *Medical Passport* (unpaged) by the Indiana State Department of Health Children's Special Health Care Services, 1-800-475-1355, printed (n.d.), Project MCJ-18IS23-02

School Contacts

(Some parents store IEP and 504 plan information in sheet protectors following this section.)

- **School District:**_____

  Address:_____

  _____

  Phone:_____ **Fax:**_____ **Web Site:**_____

  Special Education Coordinator:_____

  Address:_____

  Phone:_____ **Fax:**_____ **Web Site:**_____

  504 Accommodation Plan Coordinator:_____

  Address:_____

  Phone:_____ **Fax:**_____ **Web Site:**_____

  District Nurse assigned to your child's school:_____

  Address:_____

  Phone:_____ **Fax:**_____ **Web Site:**_____

- **School / Preschool:**_____

  Address:_____

  Phone:_____ **Fax:**_____ **Web Site:**_____

  Principal / Administrator:_____

  Phone:_____ **Fax:**_____ **Web Site:**_____

  Classroom Teacher:_____

  Phone:_____ **Fax:**_____ **Web Site:**_____

  Resource Instructor:_____

  Phone:_____ **Fax:**_____ **Web Site:**_____

  Aide / Assistant / Intervener:_____

  Phone:_____ **Fax:**_____ **Web Site:**_____

  Special Education Director / Teacher(s):_____

  Phone:_____ **Fax:**_____ **Web Site:**_____

  Therapist(s):_____

  Phone:_____ **Fax:**_____ **Web Site:**_____

  Other Contacts:_____

  _____

Emergency Contact Person(s)

Name_____

Address_____

City_____ State_____ Zip_____

Phone_(____)_____ Relationship_____

Name_____

Address_____

City_____ State_____ Zip_____

Phone_(____)_____ Relationship_____

Name_____

Address_____

City_____ State_____ Zip_____

Phone_(____)_____ Relationship_____

Name_____

Address_____

City_____ State_____ Zip_____

Phone_(____)_____ Relationship_____

Name_____

Address_____

City_____ State_____ Zip_____

Phone_(____)_____ Relationship_____

Name_____

Address_____

City_____ State_____ Zip_____

Phone_(____)_____ Relationship_____

Name_____ DOB_____

Designed by members of the Family Advisory Council to Maine's Children with Special Health Needs program.

Personal Contacts

Name/Address	Phone Office Fax Cell Email

Name/Address	Phone Office Fax Cell Email

Name/Address	Phone Office Fax Cell Email

Name/Address	Phone Office Fax Cell Email

Name/Address	Phone Office Fax Cell Email

Name:_____DOB:_____

Designed by members of the Family Advisory Council to Maine's Children with Special Health Needs program.

Contact Log

Date	Name of Person Contacted	What was Discussed

Notes

The "My Plan" section of your Care Notebook is where you can lay out what is happening in your child's life and what you would like to see happen in the future, This includes daily care, mealtime routine, therapies recreation, communication, play, and more.

My Plan

Care Schedule

TIME	CARE
Morning	
Afternoon	

TIME	CARE
Evening	
Night	

MEALTIME ROUTINE

Usual eating times:_____

Usual length of time to eat:_____

Food allergies	**Foods to avoid**

Favorite foods / food dislikes:_____

Feeding equipment / utensils used / positioning:_____

Feeding tips:_____

THERAPY

TYPE: PHYSICAL ☐ OCCUPATIONAL ☐ SPEECH ☐ DEVELOPMENTAL ☐

CHILD'S NAME:_____MONTH/YEAR_____

			WEEKLY: *A: Achieved / C: Continue*				
#	GOALS	COMMENTS	1	2	3	4	5

Activities of Daily Living

Use this page to talk about your child's abilities to fee him or herself, bathe, get dressed,
use the bathroom, comb hair, brush teeth, etc. Describe what your child can do by herself and any help or equipment your child uses for these activities.
Describe any special routines your child has for bath time, getting dressed, etc.

Date _____

Social Experiences

What activities make life meaningful for your son or daughter? What leisure activities does your child enjoy? List all hobbies, interests recreational and social activities and vacation preferences. Make a list of place and situation that your child is uncomfortable with or dislikes.

Favorite TV shows/movies

_____

_____

_____

Hobbies/Activites in the home

_____

_____

_____

Leisure Activities/Clubs outside the home

Name of Club_____

Contact Person_____

Phone Number_____

How Often_____

Name of Club_____

Contact Person_____

Phone Number_____

How Often_____

Special Interests
(Example: loves Cincinnati Reds Games in person but not on TV)

_____

_____

_____

Favorite Vacations/Travels

_____

_____

_____

Recreation

A number of organizations have programs designed to give children and adults with special needs Recreation opportunities. These include local park and recreation programs. Check with your providers to find out more about recreation opportunities close to your home. Some parents include brochures and activity calendars in this section of their Care Notebook.

☼ Recreation Opportunity: _____
Contact Person:_____
Address: _____
Phone: _____ Fax: _____ E-Mail: _____
Schedule:_____ _____

☼ Recreation Opportunity: _____
Contact Person:_____
Address: _____
Phone: _____ Fax:_____ E-Mail:_____
Schedule: _____

☼ Recreation Opportunity: _____
Contact Person: _____
Address: _____
Phone: _____ Fax: _____ E-Mail: _____
Schedule: _____

☼ Recreation Opportunity: _____
Contact Person: _____
Address: _____
Phone: _____ Fax: _____ E-Mail: _____
Schedule: _____

☼ Recreation Opportunity: _____
Contact Person: _____
Address: _____
Phone: _____ Fax: _____ E-Mail: _____
Schedule: _____

Notes:

_____
_____
_____
_____
_____

(Adapted from the Care Notebook with permission, Children's Hospital and Regional Medical Center, Seattle, WA, 2003.)
Utah Department of Health, c. 2005.

Communication

Use this page to talk about your child's ability to communicate and to understand others. Describe how your child communicates. Include sign language words, gestures, or any equipment or help your child uses to communicate or understand others. Include any special words your family and child use to describe things.

Date: _____

Communication Information

Use this page to record your child's ability to communicate and to understand others. Describe how your child communicates; including sign language words, gestures, or any assistive technology or help your child uses to communicate. Include any special words your family and child use to describe things.

Date	Place Of Interaction	Child's means of communication	Types of Assistive Technology	Special Words

Developed by the Parent Network Specialist Program of the Center for Excellence in Disabilities, West Virginia Department of Health and Human Resources

Coping/Stress Tolerance

Use this page to talk about how your child copes with stress. Stressful events might include new people or situations, a hospital stay, or procedures such as having blood drawn. Describe what things upset your child and what your child does when upset or when he or she has "had enough." Describe your child's way of asking for help and things to do or say to comfort your child.

Date: _____

Mobility

Use this page to talk about your child's ability to get around. Describe how your child gets around. Include what your child can do by him or herself and any help or equipment your child uses to get around. Describe any activity limits and any special routines your child has for transfers, pressure releases, positioning, etc.

Date: _____

Social / Play

Use this page to talk about your child's ability to get along with others. Describe how your child shows affection, shares feelings, or plays with other children. Describe what works best to help your child get along or cooperate with others. Describe your child's favorite things to do. Include any special family activities or customs that are important.

Date: _____

(Adapted from the Care Notebook with permission, Children's Hospital and Regional Medical Center, Seattle, WA, 2003.)
Utah Department of Health, c. 2005.

Rest / Sleep

Use this page to talk about your child's ability to get to sleep and sleep through the night. Describe your child's bedtime routine and any security or comfort objects your child uses.

Date: _____

Transitions-Looking Ahead

Your child and family will experience many transitions, small and large, over time. Three predictable transitions occur for most children: reaching school age, approaching adolescence, and moving from adolescence into adulthood. Many children do not experience these transitions in the way most children experience them. Other transitions may involve moving into new programs, working with new agencies and care providers, or making new friends. Transitions involve changes: adding new expectations, responsibilities, or resources, and letting go.

Looking at transitions may be hard, depending on your circumstances. You may have limited time just to do what needs to get done today. You may find it helpful, though, to jot down a few ideas about your child's and family's future. You might start by thinking about your child's and family's strengths. How can these strengths help you plan for "what's next" and for reaching long-term goals? What are your dreams and your fears about your child's and family's future?

Date: _____

Notes

Notes

My Coverage

The "My Coverage" section is where you can record all information on Health Care Coverage, Medical Bills, correspondence, and out of pocket expenses.

Insurance, Etc.

- Insurance Name:_____
  Policy Number:_____
  Contact Person/Title:_____
  Address:_____
  _____
  Phone:_____ Fax:_____

- Medicaid (HMO Name if applicable – this is the company name that appears above your child's name and ID Number on the Medicaid Identification Card):_____
  Policy Number:_____
  Contact Person/Title:_____
  Address:_____
  _____
  Phone:_____ Fax:_____

- Insurance Name:_____
  Policy Number:_____
  Contact Person/Title:_____
  Address:_____
  Phone:_____ Fax:_____ Website/Email:_____

- Supplemental Security Income (SSI):_____
  Contact Person/Title:_____
  Address:_____
  Phone:_____ Fax:_____ Website/Email:_____

- Other:_____
  Contact Person/Title:_____
  Address:_____
  Phone:_____ Fax:_____ Website/Email:_____

- Other:_____
  Contact Person/Title:_____
  Address:_____
  Phone:_____ Fax:_____ Website/Email:_____

Medical Bill Communication Log

Information About the Bill				Information About Who You Talk To					NOTES
Account #	Provider	Date of Service	What bill is for:	Date of Contact	Time	Name	Title (like Account Representative)	Credentials (RN, Dr., none)	

(Adapted from the Care Notebook with permission, Children's Hospital and Regional Medical Center, Seattle, WA, 2003.)
Utah Department of Health, c. 2005.

Tracking of Medical Bills

Tracking of Medical Bills

Date of Service	Provider (hospital, doctor's office, etc.)	Service (tests, surgery, etc.)	Cost	Insurance Company	Insurance Paid	Date Paid	Family Owes	Date Paid
			$		$		$	
			$		$		$	
			$		$		$	
			$		$		$	
			$		$		$	
			$		$		$	
			$		$		$	
			$		$		$	
			$		$		$	
			$		$		$	
			$		$		$	
			$		$		$	
			$		$		$	
			$		$		$	
			$		$		$	
			$		$		$	
			$		$		$	
			$		$		$	
			$		$		$	
			$		$		$	
			$		$		$	
			$		$		$	
			$		$		$	
			$		$		$	
			$		$		$	

MEDICAL TRAVEL EXPENSE

Child's Name _____

DATE	TRAVEL FROM	TRAVEL TO	MILES	ADDITIONAL EXPENSES (MEALS, LODGING, ETC.)	REASON FOR TRAVEL

Note: This sheet may be used for income tax filing purposes

Out of Pocket Expense Log

Use this log to track expenses incurred that are not covered by insurance.
Make sure to save all receipts for tax purposes.

Date	Item Description / #	Cost	Date	Item Description / #	Cost

Out of Pocket Expense Log

Notes

Notes

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Utah Department of Health, c. 2005.

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