Care Organizing tools on CSHCN.org

- Equipment and Supplies
- Equipos y suministros
- 设备和用品
- Оборудование и принадлежности
- Qalabka iyo Saadka
- Thiết bị và Vật dụng y tế

- Medications
- Medicamentos
- 服藥
- Лекарства
- Daawada
- Dùng Thuốc

- Insurance and Finance
- Finanzas
- 財務
- Финансы
- Xisaabaha
- Tài Chánh
-

- Tracking tools
- Herramientas para seguimiento
- 追踪工具
- Методика отслеживания
- Aaladaha Raadraaca
- Các công cụ theo dõi thông tin

- Contacts
- Contactos
- 联系人
- Контактная информация
- Xiriiryada
- Người liên lạc
-

- Family Support
- Recursos – Apoy
- 資源 - 支援
- Источники помощи – Поддержка
- Ilaha kaalmada
- Các Nguồn Trợ Giúp
-

- Emergency
- Emergencias
- 紧急情况
- Экстренные ситуации
- Xaaladaha degdegga ah
- Trường hợp khẩn cấp

- School
- Escuela
- 學校
- Школа
- Dugsi
- Trường Học

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www.cshcn.org

Washington State Department of Health

Care Organizing tools on CSHCN.org

Care Organizing Content on cshcn.org:

Contact Information

- Health care provider contact list
- Hospital & clinic information
- Pharmacy contacts
- Childcare, respite and babysitter

Tracking Tools

- Portable medical summary
- Appointment log
- Hospital stays tracking form
- Immunization record
- Care schedule
- Allergy log
- Lab work, tests and procedures
- Event and behavior log
- Growth tracking form
- Diet tracking form
- My child's development history
- Call log

Medication

- Medications list
- Daily medication tracking sheet

Support Resources

- Family support resources

School

- School, preschool and developmental center contacts

Equipment and Supplies

- Equipment and supplies list

Financial

- Insurance funding sources
- Out-of-pocket expense log

Emergency

- In case of emergency form

To download and print these pages for your care organizer, please visit www.cshcn.org/planning-record-keeping/care-notebook

Washington State Fathers Network (WSFN)

A powerful voice for fathers and families of children with special needs

WSFN accomplishes its mission through:

- Clarifying the needs of fathers raising children with special needs and responding to those needs whenever possible.
- Developing father support programs throughout the state of Washington.
- Sponsoring evening and weekend programs specifically designed for men involved in the lives of their children with special needs, with fathers serving as facilitators, organizers, speakers, and panelists.
- Presenting at regional, state and national parent and professional conferences.
- Assisting organizations in reviewing their current services and making their programs increasingly father friendly.
- Networking through the WSFN *Connections* newsletter twice a year.
- Sponsoring programs that bring men and families together from existing programs, i.e. social events, campout, BBQ, etc.
- Sponsoring state and regional conferences to provide places for men to meet and exchange ideas with other men facing similar challenges.
- Developing written and video materials in both English and Spanish.
- Building our current several thousand member database of fathers and providers interested in promoting and participating in activities for men & fathers.
- Developing & maintaining our state wide Steering Committee committed to making WSFN a vital organization.
- Strengthening and maintaining the WSFN website with resources for dads, families, and professionals at: www.fathersnetwork.org
- Partnering with a wide range of organizations across the state & nation so all fathers and families of children with special needs are provided useful connections to needed resources.

We Are:

Founded on the belief that fathers are crucially important in the lives of their children & families. Washington State Fathers Network (WSFN) is a powerful voice for father & male involvement in all aspects of family life.

WSFN is a proud non-profit program of Kindering funded by the Washington State Department of Health, Children with Special Health Care Needs Program, grants, and private donations. WSFN provides support and resources for all fathers, men and families involved in the life of a child with special health care needs or developmental disability.

KINDERING
Helping infants and children with special needs

Washington State Department of Health

WASHINGTON STATE FATHERS NETWORK

WSFN
16120 NE 8th Street
Bellevue, WA 98008
425.653.4286
greg.schell@kindering.org

Finding Resources for Your Child with Special Needs

Having a child with special needs can be a challenge. You may feel confused and overwhelmed. Here you will find descriptions of some of the people that may be of help to you and your family.

Public Health Nurses

Public health nurses work in local health departments. They can answer questions about your child's health, growth and development and help you find local resources.

Children with Special Health Care Needs Coordinators (CSHCN)

CSHCN Coordinators, generally public health nurses, can provide screening and assessment of your child, refer you to services and resources, provide health information and help you coordinate services.

Family Resource Coordinator (FRC)

FRCs provide information about child growth and development, coordinate resources and services for your family, and find screening for your child if you have concerns about his or her development.

Health Care Providers

Your child's doctors, nurses or social workers can also help you find services and resources.

People at Your Child's School

Teachers, school nurses, counselors, or therapists can help your child with medications, equipment, therapies and homework. If your child goes to a private school, you can still get help from the public school system.

Other Parents

Other parents can tell you about their experiences, give you tips, tell you about helpful providers, and give you hope. Parent to Parent www.arcwa.org/parent_to_parent.htm and The Fathers Network www.fathersnetwork.org are two parent-run organizations that provide emotional and informational support to parents.

To find these resources and others in your community:

1. Call the toll-free ASK Resource Line (Answers for Special Kids) at 1-800-322-2588, or visit http://www.withinreachwa.org/ourservices/special_needs.htm. They can connect you to Family Resource Coordinators, Children with Special Health Care Needs Coordinators, health insurance coverage, parenting support, recreational opportunities, local and national disability-related organizations and adolescent transition care.
2. Call the Children's Hospital Resource Line and ask for a copy of Starting Point, a free resource guide for Washington families who have a child with special needs: (206) 987-2500, or toll-free 1-866-987-2500. Starting Point is also online at www.cshcn.org.

Create a Contact List for Your Child

Health Care Providers

Name: _____

Phone/Email: _____

Name: _____

Phone/Email: _____

School Contacts

Name: _____

Phone/Email: _____

Name: _____

Phone/Email: _____

Other Important Numbers

Name: _____

Phone/Email: _____

Name: _____

Phone/Email: _____

Name: _____

Phone/Email: _____

Name: _____

Phone/Email: _____

Parents

Name: _____

Phone/Email: _____

Name: _____

Phone/Email: _____

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Emergency Preparedness for Children with Special Needs

"I used to get overwhelmed about emergency preparedness, but once I broke it down into small steps it got easier. Each week I put a few items on my shopping list. Then I got other supplies at second hand stores and the Red Cross. I feel better knowing I'm ready instead of worrying about getting ready". –Parent

In an emergency, we all have to plan to be self sufficient and possibly spend several days without utilities, medical aid or communications.

Three Ways to Get Ready

1. *Think* about your child's special needs in an emergency.
2. *Plan* now for emergencies that can happen in your area.
3. *Pack* an emergency supplies kit.

1. Think about your child's special needs in an emergency.

- Consider your child's needs if there was:
- No water, electricity, telephone, heat, air conditioning, computer
- No local access to prescription refills or health products
- No refrigeration
- Separation from your family
- Evacuation to a shelter or elsewhere
- Lack of transportation
- Limited emergency rescue services

2. Planning for your child's needs

- Plan for and get supplies for natural disasters. Pack an emergency supply kit for your child to have at school.
- Talk with your child's doctor about how to care for your child during different types of emergencies.
- Contact an emergency shelter near your home. Your family can use an emergency shelter for storing medicine, charging equipment, help with medical needs, getting a meal and more.
- If your child depends on dialysis or other life sustaining treatment, know the location of more than one facility and find out *their* plans for emergencies and how your child will get treatment, medications etc. Get their emergency contact numbers.
- Create and practice an escape plan for your home. Are there clear exit paths for a child who uses a wheel chair or has vision loss?
- Keep a pair of shoes stored under the bed of each family member for them to use in an emergency.
- Talk to your local police and fire departments to see if they have emergency services or plans for children with special needs.
- Ask your doctor about a medical alert bracelet for your child.

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Emergency Preparedness for Children with Special Needs

3. Pack emergency supplies and copy medical information

- Current medical information and records stored on a CD, flash drive, or phone app (keep one paper copy in a waterproof bag).
- Extra contact lenses, glasses, and lens supplies.
- Batteries for hearing aids and communication devices.
- Special dietary foods and supplies.
- Items that calm or entertain your child.
- Identification to be carried by each child in case your family gets separated.

Create a support network

A support network includes family, neighbors or friends that can help you and your child. They may be your first source of help in an emergency.

- Tell your support network about your child's special needs and where your emergency supplies are stored.
- Give a trusted member of your network a key to your house or apartment.
- Agree upon a system with your neighbors to signal for help if phones and electricity are not working.
- Show others how to handle your child's wheelchair or other equipment.

Power supplies:

- A generator for back up power support (never use a generator indoors).
- An AC adaptor for your car for small equipment such as a nebulizer.
- Adaptor for a car to charge your cell phone.
- Batteries for medical equipment your child uses.
- Manual wheelchair or other non-electric equipment,

Medical supplies and medications:

Talk with your child's doctor about how to obtain an extra supply of medicines for emergencies. Ask your pharmacist about storage of medicines.

- Two-week supply of medical items including syringes, dressings, nasal cannulas, suction catheters, etc.
- At least a three day supply of medications (fourteen days is ideal).
- Chemical ice packs for storing medications that must be kept cold.
- Prescription information for your wallet, survival kit and cell phone. Include name, location and phone number of an out of town pharmacy.

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Emergency Preparedness for Children with Special Needs

Other helpful tips:

- Pack a smaller "to go" kit for use in an evacuation and store in multiple places (car, work, school, etc.)
- Store your supplies in a waterproof and pest-proof container.
- Update supplies yearly, replace water every six months, and update emergency contact and medical forms as needed.

Emergency preparedness resources:

- *Thirty Ways to Plan for an Emergency* from Washington State PAVE. www.cshcn.org/sites/default/files/webfm/file/PAVEEmergencyPrepDoc.pdf
- *Disaster Preparedness Checklist*: for children with special nutritional needs from the University of Washington www.depts.washington.edu/cshcnnut/download/resources/disasterchecklist.pdf
- *Keeping Children and Youth with Special Health Care Needs Safe During Emergencies and Disasters*: from Family Voices www.familyvoices.org/work/caring?id=0004

Tips for people with:

Mobility challenges
www.seattle.gov/emergency/docs/Prepare%20if%20I%20have%20mobility%20challenges.pdf

Hearing loss
www.seattle.gov/emergency/docs/Prepare%20for%20Hearing%20Impaired.pdf

Vision loss
www.seattle.gov/emergency/docs/prepare%20if%20I'm%20visually%20impaired.pdf

Special medical needs
http://www.seattle.gov/emergency/docs/Prepare%20with%20Medical%20Needs.pdf

For more information on general emergency preparedness and other resources on caring for a child with special health care needs, visit www.cshsn.org

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What's the Plan?

Name:	**Date of Birth:**	**Provider:**
Parent's Name:		**Today's Date:**
Questions/Concerns: What do I want to talk about today?		
What do I hope to have happen?		
Next steps? What needs to be done?		
Who will do this?		
By when? (time frame)		
How will we follow-up?		

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In Case of Emergency

Today's Date: _____

Your Name:	**Nickname:**	
Birth Date:	**Primary Language/Communication:**	
Home Address:		
Parents/Guardians:	**Relationship:**	**Home #:** **Other #'s:**
Diagnosis:		

Medications	Dose	Time

Allergies:		
Emergency Contact:	**Relationship:**	**Phone #'s:**

PHYSICIAN INFORMATION

Primary Doctor:	**Phone:**	**Fax:**
Specialist:	**Phone:**	**Fax:**
Specialist:	**Phone:**	**Fax:**
Insurance:		

HOSPITAL INFORMATION

Name: **Address:**	**Phone:** **ER Phone:**

PHARMACY INFORMATION

Name: **Address:**	**Phone:**

OTHER

Most Important Things to Know About Me in an Emergency:

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Center
2008

Getting to Know Me

My Name:	**Nickname:**
Date of Birth:	**Today's Date:**
My Current Medicines/Doses:	
My Allergies:	
Things to Avoid: (food, activities, and procedures)	
My Equipment/Assistive Technology: (braces/orthotics, walker, wheelchair, communication device, home O_2, insulin pump, nebulizer, suction)	
Ways You Can be Helpful to Me:	

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Center 2010

Getting to Know Me

My Name:	**Nickname:**
Date of Birth:	**Today's Date:**
A Little About Me:	
My Strengths: (things that are easy for me)	
My Challenges: (communication, feeding, learning, mobility, social, energy, behavior)	
My Life in the Community: (school, childcare, place of worship, my favorite places)	
My Home and Family Information:	
My Diagnosis (Diagnoses):	
My Overall Health:	
My Prior Surgeries, Procedures, Lab/Diagnostic Studies:	

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Children's
Hospital & Regional Medical Center
Center for Children with Special Needs

Dear Parents,

This Care Notebook has been developed just for you—parents with children with special health care needs. We offer this Notebook to you with deep appreciation for the central role you play in the life and care of your child. We hope it will serve as a guide in organizing and keeping track of your child's records, appointments, and other important information. The Care Notebook is produced by the Center for Children with Special Needs and the Washington State Department of Health, Children with Special Health Care Needs Program, with invaluable input from parents and community professionals.

Families tell us they value having a central place to keep information they can easily take to appointments.

> *"I used a paper bag for my file! It took forever to find what I needed! Now I can just turn to the right section."*

> *"This way I don't have to keep it all in my head."*

> *"I'd use the notebook to organize my thoughts and concerns before a doctor's appointment. It gave me confidence and credibility."*

Families also use the Notebook to improve communication with doctors and other health care providers.

> *"Didn't have to repeat information...I've taken it to all the doctors and when they ask what happened, I just pull out the notebook and show them."*

> *"I use the notes as a diary. I write down what the doctor has said, word for word. This really helps when I go to the next doctor and he wants to know what that doctor said."*

We encourage you to make this Notebook work for you! Create your own sections; remove and rearrange pages to fit your needs; and personalize it with drawings, stickers, photographs, and special articles and resources you've found helpful. The Care Notebook pages may be downloaded and printed from **http://www.cshcn.org**. You can find other resources and information for you and your family at this website.

If you have suggestions or comments about the Care Notebook, please feel free to contact Megan Sety at (206) 987-5310 or megan.sety@seattlechildrens.org.

Most sincerely,

Kathy Fennell
Manager

Megan Sety
Program Assistant

6901 Sand Point Way NE P.O. Box 50020/S-219 Seattle, WA 98145-5020 Office: (206) 987-5735 Fax: (206) 987-5705 www.cshcn.org

Care Notebook: A Quick Guide

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 and care.

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.

Use your Care Notebook to:

- ❑ Track changes in your child's medicines or treatments
- ❑ List telephone numbers for health care providers and community organizations
- ❑ Prepare for appointments
- ❑ File information about your child's health history
- ❑ Share new information with your child's primary doctor, public health or school nurse, daycare staff, and others caring for your child

What are some helpful hints for using my child's Care Notebook?

- ❑ Store the Care Notebook where it is easy to find. This helps you and anyone who needs information in your absence.
- ❑ Add new information to the Care Notebook whenever there is a change in your child's treatment.
- ❑ Consider taking the Care Notebook with you to appointments and hospital visits so that information you need will be close at hand.

How do I set up my child's Care Notebook?

Follow these steps to set up your child's notebook:

Step 1: Gather information you already have.

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

Step 2: Look through the pages of the Care Notebook.

- ❑ Which of these pages could help you keep track of information about your child's health or care?
- ❑ Choose the pages you like. Print copies of any that you think you will use. The Care Notebook pages are available from the Internet at http://www.cshcn.org. Go to "Resources" and then choose "Care Organizing Tools."

Step 3: Decide which information about your child is most important to keep in the Care Notebook.

- ❑ What information do you look up often?
- ❑ What information is needed by others caring for your child?
- ❑ Consider storing other information in a file drawer or box where you can find it if needed.

Step 4: Put the Care Notebook together.

- ❑ Everyone has a different way of organizing information. The only important thing 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 or large accordion envelope. Hold papers securely.
- ❑ tabbed dividers. Create your own information sections.
- ❑ pocket dividers. Store reports.
- ❑ plastic pages. Store business cards and photographs.

CHILDREN'S HOSPITAL AND REGIONAL MEDICAL CENTER, SEATTLE, WASHINGTON
WASHINGTON STATE DEPARTMENT OF HEALTH,
CHILDREN WITH SPECIAL HEALTH CARE NEEDS PROGRAM

Care Notebook
List of Pages

Pages to Keep Track of Appointments and Care

- ❑ Appointment Log
- ❑ Diet Tracking Form
- ❑ Emergency Information Form
- ❑ Equipment/Supplies
- ❑ Growth Tracking Form
- ❑ Hospital Stay Tracking Form
- ❑ Lab Work/Tests/Procedures
- ❑ Make-a-Calendar
- ❑ Medical Bill Tracking Form
- ❑ Medical/Surgical Highlights
- ❑ Medications
- ❑ Notes

Pages to Create a Care Summary: Abilities and Special Care Needs

- ❑ Activities of Daily Living
- ❑ Care Schedule
- ❑ Child's Page—Now and Later
- ❑ Communication
- ❑ Coping/Stress Tolerance
- ❑ Mobility
- ❑ Nutrition
- ❑ Respiratory
- ❑ Rest/Sleep
- ❑ Social/Play
- ❑ Transitions—Looking Ahead

Pages to Create a Care Team and Resources List

- ❑ Children's Hospital and Regional Medical Center

Community Health Care/Service Providers:

- ❑ Medical/Dental
- ❑ Public Health
- ❑ Home Care
- ❑ Therapists
- ❑ Early Intervention Services
- ❑ School
- ❑ Child Care
- ❑ Respite Care
- ❑ Pharmacy
- ❑ Special Transportation

- ❑ Family Information
- ❑ Family Support Resources
- ❑ Funding Sources
- ❑ Alphabet Soup Acronym Index

Children's Hospital and Regional Medical Center

4800 Sand Point Way NE
Seattle, WA 98105

Hospital Operator (206) 987-2000 or 1-866-987-2000
Resource Line (206) 987-2500 or 1-866-987-2500
Emergency Room (206) 987-2222

Medical Record Number:_____

- CHRMC Clinic:_____

  Date of First Visit:_____

  Physician:_____

  Contact Person / Title:_____

  Phone:_____ Fax:_____

- CHRMC Clinic:_____

  Date of First Visit:_____

  Physician:_____

  Contact Person / Title:_____

  Phone:_____ Fax:_____

- CHRMC Clinic:_____

  Date of First Visit:_____

  Physician:_____

  Contact Person / Title:_____

  Phone:_____ Fax:_____

Appointment Log

DATE	PROVIDER	REASON SEEN / CARE PROVIDED	NEXT APPOINTMENT

Diet Tracking Form

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

Emergency Information Form for Children With Special Needs

American College of Emergency Physicians*

American Academy of Pediatrics

Date form completed	Revised	Initials
By Whom	Revised	Initials

Last name:

Name:	**Birth date:**	**Nickname:**
Home Address:	**Home/Work Phone:**	
Parent/Guardian:	**Emergency Contact Names & Relationship:**	
Signature/Consent*:		
Primary Language:	**Phone Number(s):**	

Physicians:

Primary care physician:	**Emergency Phone:**
	Fax:
Current Specialty physician:	**Emergency Phone:**
Specialty:	**Fax:**
Current Specialty physician:	**Emergency Phone:**
Specialty:	**Fax:**
Anticipated Primary ED:	**Pharmacy:**
Anticipated Tertiary Care Center:	

Diagnoses/Past Procedures/Physical Exam:

1.	**Baseline physical findings:**
2.	
3.	**Baseline vital signs:**
4.	
Synopsis:	
	Baseline neurological status:

*Consent for release of this form to health care providers

Diagnoses/Past Procedures/Physical Exam continued:

Medications:	Significant baseline ancillary findings (lab, x-ray, ECG):
1.	
2.	
3.	
4.	Prostheses/Appliances/Advanced Technology Devices:
5.	
6.	

Management Data:

Allergies: Medications/Foods to be avoided	and why:
1.	
2.	
3.	
Procedures to be avoided	**and why:**
1.	
2.	
3.	

Immunizations (mm/yy)

Dates					
DPT					
OPV					
MMR					
HIB					

Dates					
Hep B					
Varicella					
TB status					
Other					

Antibiotic prophylaxis: Indication: Medication and dose:

Common Presenting Problems/Findings With Specific Suggested Managements

Problem	Suggested Diagnostic Studies	Treatment Considerations

Comments on child, family, or other specific medical issues:

Physician/Provider Signature: **Print Name:**

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Equipment / Supplies

- Name of Equipment:_____

  Description (brand name, size, etc.):_____

  _____

  Date obtained:_____ Supplier:_____

  Contact Person:_____ Phone:_____

- Name of Equipment:_____

  Description (brand name, size, etc.):_____

  _____

  Date obtained:_____ Supplier:_____

  Contact Person:_____ Phone:_____

- Name of Equipment:_____

  Description (brand name, size, etc.):_____

  _____

  Date obtained:_____ Supplier:_____

  Contact Person:_____ Phone:_____

- Name of Equipment:_____

  Description (brand name, size, etc.):_____

  _____

  Date obtained:_____ Supplier:_____

  Contact Person:_____ Phone:_____

Growth Tracking Form

DATE	HEIGHT	WEIGHT	HEAD CIRCUMFERENCE	CHECKED BY

Hospital Stay Tracking Form

DATE	HOSPITAL	REASON	NOTES

Lab Work / Tests / Procedures

DATE	TEST	RESULT	COMMENTS

"MAKE-A-CALENDAR"

Month_____ Year _____

SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY

Medical Bill Tracking Form

DATE	PROVIDER	COST	INSURANCE PAID	DATE PAID	FAMILY OWES	DATE PAID

Medical / Surgical Highlights

DATE	PROCEDURE	RESULT	COMMENTS

Medications

Allergies: _____

Pharmacy: _____ Phone: _____

DATE STARTED	DATE STOPPED	MEDICATION	DOSE / ROUTE	TIME GIVEN	PRESCRIBED BY

Notes

Care Summary:
Activities of Daily Living

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

Date: _____

Care Schedule

TIME	CARE
Morning	
Afternoon	

Care Schedule

TIME	CARE
Evening	
Night	

Care Summary:
Child's Page—Now and Later

Use this page for your child's words and thoughts about his or her life now as well as later. What are your child's dreams? What does he or she do well now that might give direction for life later? What does your child want to be when he or she grows up?

Date: _____

Developed in partnership with staff from the Adolescent Health and Transition Project

Care Summary:
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: _____

Care Summary:
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: _____

Care Summary: 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: _____

Care Summary: 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: _____

Care Summary: 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: _____

Care Summary:
Rest / Sleep

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

Date: _____

Care Summary:
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: _____

Care Summary:
Transitions—Looking Ahead

Your child and family will experience many transitions, small and large, over the years. Three predictable transitions occur: when your child reaches school age, when he or she approaches adolescence, and when your child moves from adolescence into adulthood. 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 of others.

It's not always easy to think about the future. There may be many things, including what has to be done today, that keep you from looking ahead. It may be helpful to take some time 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: _____

Developed in partnership with staff from the Adolescent Health and Transition Project

Medical / Dental
Community Health Care Providers

- Primary / Community Care Provider:_____

  Date of First Visit:_____

  Office Nurse:_____

  Address:_____

  _____

  Phone:_____ Fax:_____

- Community Hospital:_____

  Medical Record Number:_____

  Address:_____

  _____

  Phone:_____ Fax:_____

- Community Specialty Care Provider:_____

  Date of First Visit:_____

  Address:_____

  _____

  Phone:_____ Fax:_____

- Community Specialty Care Provider:_____

  Date of First Visit:_____

  Address:_____

  _____

  Phone:_____ Fax:_____

- Dentist / Orthodontist:_____

  Date of First Visit:_____

  Address:_____

  _____

  Phone:_____ Fax:_____

Home Care
Community Health Care / Service Providers

- Home Nursing Agency:_____

  Start Date:_____

  Contact Person:_____

  Address:_____

  _____

  Phone:_____ Fax:_____

- Home Nursing Agency:_____

  Start Date:_____

  Contact Person:_____

  Address:_____

  _____

  Phone:_____ Fax:_____

- Home Nursing Agency:_____

  Start Date:_____

  Contact Person:_____

  Address:_____

  _____

  Phone:_____ Fax:_____

Therapists
Community Health Care / Service Providers

Therapists:

- Occupational Therapist (OT):_____

  Start Date:_____

  Agency:_____

  Address:_____

  _____

  Phone:_____ Fax:_____

- Physical Therapist (PT):_____

  Start Date:_____

  Agency:_____

  Address:_____

  _____

  Phone:_____ Fax:_____

- Speech-Language Pathologist:_____

  Start Date:_____

  Agency:_____

  Address:_____

  _____

  Phone:_____ Fax:_____

Early Intervention Services
Community Health Care / Service Providers

- Developmental Center:_____

  Start Date:_____

  Contact Person:_____

  Address:_____

  _____

  Phone:_____ Fax:_____

- Family Resources Coordinator:_____

  Start Date:_____

  Agency:_____

  Address:_____

  _____

  Phone:_____ Fax:_____

School
Community Health Care / Service Providers

- School / Preschool:_____

  Start Date:_____

  Address:_____

  _____

  Phone:_____ Fax:_____

- School Nurse:_____

  Phone:_____ Fax:_____

- Contact Person / Title:_____

  Phone:_____ Fax:_____

- Contact Person / Title:_____

  Phone:_____ Fax:_____

Child Care
Community Health Care / Service Providers

- Child Care Provider:_____

  Start Date:_____

  Contact Person:_____

  Address:_____

  _____

  Phone:_____ Fax:_____

- Child Care Provider:_____

  Start Date:_____

  Contact Person:_____

  Address:_____

  _____

  Phone:_____ Fax:_____

- Child Care Provider:_____

  Start Date:_____

  Contact Person:_____

  Address:_____

  _____

  Phone:_____ Fax:_____

Public Health
Community Health Care / Service Providers

- Public Health Department:_____

  Address:_____

  _____

  Phone:_____ Fax:_____

- Public Health Nurse:_____

  Phone:_____ Date of First Visit:_____

- Nutritionist:_____

  Phone:_____ Date of First Visit:_____

- Social Worker:_____

  Phone:_____ Date of First Visit:_____

- Other:_____

  Phone:_____ Date of First Visit:_____

Respite Care
Community Health Care / Service Providers

- Respite Care Provider:_____

  Start Date:_____

  Contact Person:_____

  Agency:_____

  Address:_____

  _____

  Phone:_____ Fax:_____

- Respite Care Provider:_____

  Start Date:_____

  Contact Person:_____

  Agency:_____

  Address:_____

  _____

  Phone:_____ Fax:_____

- Respite Care Provider:_____

  Start Date:_____

  Contact Person:_____

  Agency:_____

  Address:_____

  _____

  Phone:_____ Fax:_____

Pharmacy
Community Health Care / Service Providers

- Pharmacy:_____

  Contact Person:_____

  Address:_____

  _____

  Phone:_____ Fax:_____

- Pharmacy:_____

  Contact Person:_____

  Address:_____

  _____

  Phone:_____ Fax:_____

- Pharmacy:_____

  Contact Person:_____

  Address:_____

  _____

  Phone:_____ Fax:_____

Special Transportation
Community Health Care / Service Providers

- Transportation (to and from medical / therapy appointments)

Contact Person:_____

Agency:_____

Address:_____

_____

Phone:_____ Fax:_____

- Transportation (to and from medical / therapy appointments)

Contact Person:_____

Agency:_____

Address:_____

_____

Phone:_____ Fax:_____

Family Information

- Child's Name:_____ Nickname:_____
  Date of Birth:_____ Social Security Number:_____
  Diagnosis:_____
  Blood Type:_____

  Legal Guardian:_____
  Address: _____ Phone:_____
  _____

Family Members

- Mother's Name:_____
  Social Security Number:_____
  Address:_____
  Daytime Phone:_____ Evening Phone:_____

- Father's Name:_____
  Social Security Number:_____
  Address:_____
  Daytime Phone:_____ Evening Phone:_____

- Sibling's Name:_____ Age:_____ Name:_____ Age:_____
- Sibling's Name:_____ Age:_____ Name:_____ Age:_____

- Other household members:_____

- Important Family Information:_____
  _____
  _____

- Language spoken at home:_____
  Other language(s):_____
  Interpreter Needed? Yes:_____ No:_____
  Interpreter:_____ Phone:_____

Emergency Contact

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

Family Support Resources

- Parent to Parent:_____

  Contact Person:_____

  Address:_____

  _____

  Phone:_____ Fax:_____

- Parent Group:_____

  Contact Person:_____

  Address:_____

  _____

  Phone:_____ Fax:_____

- Religious Organization:_____

  Contact Person:_____

  Address:_____

  _____

  Phone:_____ Fax:_____

- Service Organization:_____

  Contact Person:_____

  Address:_____

  _____

  Phone:_____ Fax:_____

- Counseling Services:_____

  Contact Person:_____

  Address:_____

  _____

  Phone:_____ Fax:_____

(continued)

Family Support Resources

- Division of Developmental Disabilities:_____

  Contact Person:_____

  Address:_____

  _____

  Phone:_____ Fax:_____

- Other:_____

  Contact Person:_____

  Address:_____

  _____

  Phone:_____ Fax:_____

Funding Sources

- Insurance Name:_____

  Policy Number:_____

  Contact Person / Title:_____

  Address:_____

  _____

  Phone:_____ Fax:_____

- Insurance Name:_____

  Policy Number:_____

  Contact Person / Title:_____

  Address:_____

  _____

  Phone:_____ Fax:_____

- Insurance Name:_____

  Number:_____

  Contact Person / Title:_____

  Address:_____

  _____

  Phone:_____ Fax:_____

- Supplemental Security Income (SSI):_____

  Contact Person / Title:_____

  Address:_____

  _____

  Phone:_____ Fax:_____

(continued)

Funding Sources

- Other:_____

  Contact Person / Title:_____

  Address:_____

  _____

  Phone:_____ Fax:_____

- Other:_____

  Contact Person / Title:_____

  Address:_____

  _____

  Phone:_____ Fax:_____

Alphabet Soup
Acronym Index

The following index lists a wide variety of acronyms used by professionals who work with families.

ACCH	Association for the Care of Children's Health
ADA	Americans with Disabilities Act
ADD	Attention Deficit Disorder
ADHD	Attention Deficit Hyperactivity Disorder
AFDC	Aid to Families with Dependent Children
AIDS	Acquired Immune Deficiency Syndrome
ARC	The Arc: Advocates for the Rights of Citizens with Developmental Disabilities and their families
ARNP	Advanced Registered Nurse Practitioner
BIA	Bureau of Indian Affairs
BD	Behaviorally Disabled
CAP	Community Alternative Program (Medicaid), Community Action Program (Dept. of Community Development), Client Assistance Program (Division of Vocational Rehabilitation)
CD	Communication Disorders
CDS	Communication Disorders Specialist
CEC	Council for Exceptional Children
CFR	Code of Federal Regulations
CHAP	Children Have a Potential (Air Force assistance program)
CHDD	Center on Human Development and Disability at the University of Washington
CHRMC	Children's Hospital and Regional Medical Center
CP	Cerebral Palsy
CPS	Child Protective Services
CSHCN	Children with Special Health Care Needs
CSO	Community Service Office, DSHS
DCD	Department of Community Development
DCFS	Division of Children and Family Services
DD	Developmentally Disabled
DDD	Division of Developmental Disabilities, DSHS
DDPC	Developmental Disabilities Planning Council
DH	Developmentally Handicapped
DMH	Division of Mental Health
DOH	Department of Health
DSB	Department of Services for the Blind
DSHS	Department of Social and Health Services
DVR	Division of Vocational Rehabilitation
ECDAW	Early Childhood Development Association of Washington
ECEAP	Early Childhood Education and Assistance Program
ED	Emotionally Disturbed
EEG	Electroencephalogram
EEU	Experimental Education Unit, CHDD
EFMP	Exceptional Family Member Program (helps military families locate to areas with services)
EKG	Electrocardiogram
EPSDT	Early Periodic Screening, Diagnosis, and Treatment
ESD	Educational Service District
FAPE	Free Appropriate Public Education
FRC	Family Resources Coordinator
HHS	Health and Human Services
HI	Health Impaired or Hearing Impaired
HMO	Health Maintenance Organization
HO	Healthy Options, DSHS, Medicaid Managed Care Program
HOH	Hard of Hearing
ICC	Interagency Coordinating Council; county ICC and state ICC.
IDEA	Individuals with Disabilities Education Act
IEP	Individual Education Plan
IFSP	Individual Family Service Plan

(continued)

Alphabet Soup
Acronym Index

I & R	Information and Referral
ISP	Individual Service Plan
LD	Learning Disabled
LDA	Learning Disabilities Association
LEA	Local Education Agency
LICWAC	Local Indian Child Welfare Advocacy Board
LRE	Least Restrictive Environment
MAA	Medical Assistance Administration
MCH	Maternal and Child Health
MD	Medical Doctor
MDT	Multi-Disciplinary Team
MH	Multiply Handicapped
MR	Mentally Retarded
MS	Multiple Sclerosis
NICU	Neonatal Intensive Care Unit
OCR	Office of Civil Rights
OFM	Office of Financial Management
OI	Orthopedically Impaired
OSEP	Office of Special Education Programs
OSERS	Office of Special Education and Rehabilitation Services
OSPI	Office of Superintendent of Public Instruction
OT	Occupational Therapy/Therapist
OTR	Licensed and Registered Occupational Therapist
PAVE	Parents Are Vital in Education
P & A	Protection and Advocacy
PFTH	Program for the Handicapped (military program)
PHN	Public Health Nurse
PL	Public Law
PT	Physical Therapy/Therapist
PTA	Parent Teacher Association
RCW	Revised Code of Washington (state law)
RN	Registered Nurse
RPT	Registered Physical Therapist
SBD	Seriously Behaviorally Disabled
SEA	State Education Agency
SEAC	Special Education Advisory Council
SEPAC	Special Education Parent/Professional Advisory Council
SLD	Specific Learning Disability
SSA	Social Security Administration
SSI	Social Security Income
STOMP	Specialized Training of Military Parents
SW	Social Work/Worker
TAPP	Technical Assistance for Parents and Professionals
TASH	The Association for Persons with Severe Handicaps
TBI	Traumatic Brain Injury
TDD	Telecommunication Device for the Deaf
TTY	Telecommunication Device for Deaf, Hearing Impaired, and Speech Impaired Persons
VI	Visually Impaired
WAC	Washington Administrative Code
WACD	Washington Association for Citizens with Disabilities
WIC	Women, Infants and Children Supplemental Food Program
WSMC	Washington State Migrant Council
WSSB	Washington State School for the Blind

This list was adapted from and used with permission of PAVE.

Care Notebook: A Quick Guide

+ 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 and care.

+ How can a Care Notebook help me?

In caring for your child with special health needs, you may get information and papers 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.

+ Use your Care Notebook to:

- ❑ Track changes in your child's medicines or treatments
- ❑ List phone numbers for health care providers and community organizations
- ❑ Prepare for appointments
- ❑ File information about your child's health history
- ❑ Share new information with your child's primary doctor, public health or school nurse, daycare staff, and others caring for your child

+ What are some helpful hints for using my child's Care Notebook?

- ❑ Keep the Care Notebook where it is easy to find. This helps you and anyone who needs information in your absence.
- ❑ Add new information to the Care Notebook when there is a change in your child's treatment.
- ❑ Take the Care Notebook with you to appointments and hospital visits so that information you need will be close at hand.

+ How do I set up my child's Care Notebook?

Follow these steps:

+ Step 1: Gather information

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

+ Step 2: Review the Care Notebook.

- ❑ Which of these pages could help you keep track of information about your child's health or care?
- ❑ Choose the pages you like. Print copies of any that you think you will use. You can get additional Care Notebook pages at http://cshcn.org/planning-record-keeping/care-notebook.

+ Step 3: Choose what to keep in the Care Notebook.

- ❑ What information do you look up most often?
- ❑ What information is needed by others caring for your child?
- ❑ Store other information in a file drawer or box where you can find it if needed.

+ Step 4: Put the Care Notebook together.

- ❑ Each of us has our own way of organizing information. The only key is to make it easy for you to find again. Here are some ideas for supplies used to create a Care Notebook:
- ❑ 3-ring notebook or large accordion envelope.
- ❑ Tabbed dividers. Create your own sections.
- ❑ Pocket dividers. Store reports.
- ❑ Plastic pages. Store business cards and photographs.

Center for Children with Special Needs, Seattle Children's
Washington State Department of Health, Children with Special Health Care Needs Program

Care Notebook
List of Pages

Pages to Create a Care Team and Resources List

- ❑ Hospital Information Form
- ❑ Community Health Care/Service Providers:
  - ❑ Medical/Dental
  - ❑ Public Health
  - ❑ Home Care
  - ❑ Therapists
  - ❑ Early Intervention Services
  - ❑ School
  - ❑ Child Care
  - ❑ Respite Care
  - ❑ Pharmacy
  - ❑ Special Transportation
- ❑ Family Information
- ❑ Family Support Resources
- ❑ Help Finding Resources
- ❑ Insurance/Funding Sources
- ❑ Alphabet Soup Acronym Index

Pages to Create a Care Summary: Abilities and Special Care Needs

- ❑ Activities of Daily Living
- ❑ Care Schedule
- ❑ Child's Page—Now and Later
- ❑ Communication
- ❑ Coping/Stress Tolerance
- ❑ Mobility
- ❑ Nutrition
- ❑ Respiratory
- ❑ Rest/Sleep
- ❑ Social/Play
- ❑ Transitions—Looking Ahead

Pages to Keep Track of Appointments and Care

- ❑ Appointment Log
- ❑ Medical/Surgical Highlights
- ❑ Lab Work/Tests/Procedures
- ❑ Growth Tracking Form
- ❑ Equipment/Supplies
- ❑ Notes
- ❑ Medications
- ❑ Diet Tracking Form
- ❑ Hospital Stay Tracking Form
- ❑ Medical Bill Tracking Form
- ❑ Make-a-Calendar

Care Planning Pages

- ❑ Emergency Preparedness for Families of Children with Special Needs
- ❑ Getting to Know Me
- ❑ In Case of Emergency
- ❑ What's the Plan

Hospital Name

Address: _____

City, State, Zip Code: _____ Website: _____

Phone Numbers:

Main Number: _____ Emergency Room: _____

Medical Record Number: _____

- Clinic: _____ Hours/Days of Operation: _____

  Physician: _____

  Contact Person / Title: _____

  Phone: _____ Fax: _____ Email: _____

- Clinic: _____ Hours/Days of Operation: _____

  Physician: _____

  Contact Person / Title: _____

  Phone: _____ Fax: _____ Email: _____

- Clinic: _____ Hours/Days of Operation: _____

  Physician: _____

  Contact Person / Title: _____

  Phone: _____ Fax: _____ Email: _____

Medical / Dental
Community Health Care Providers

- Primary / Community Care Provider: _____

  Office Nurse: _____

  Address: _____

  Phone: _____ Fax: _____ Email: _____

  Website: _____

- Community Hospital: _____

  Medical Record Number: _____

  Address: _____

  Phone: _____ Fax: _____ Email: _____

  Website: _____

- Community Specialty Care Provider: _____

  Address: _____

  Phone: _____ Fax: _____ Email: _____

  Website: _____

- Community Specialty Care Provider: _____

  Address: _____

  Phone: _____ Fax: _____ Email: _____

  Website: _____

- Dentist / Orthodontist: _____

  Address: _____

  Phone: _____ Fax: _____ Email: _____

  Website: _____

Public Health
Community Health Care / Service Providers

- Public Health Department: _____

  Address: _____

  Phone: _____ Fax: _____ Email: _____

  Website: _____

- Public Health Nurse: _____

  Address: _____

  Phone: _____ Fax: _____ Email: _____

- Nutritionist: _____

  Address: _____

  Phone: _____ Fax: _____ Email: _____

- Social Worker: _____

  Address: _____

  Phone: _____ Fax: _____ Email: _____

- Other: _____

  Address: _____

  Phone: _____ Fax: _____ Email: _____

Home Care
Community Health Care / Service Providers

- Home Nursing Agency: _____

  Start Date: _____

  Contact Person: _____

  Address: _____

  Phone: _____ Fax: _____ Email: _____

  Website: _____

- Home Nursing Agency: _____

  Start Date: _____

  Contact Person: _____

  Address: _____

  Phone: _____ Fax: _____ Email: _____

  Website: _____

- Home Nursing Agency: _____

  Start Date: _____

  Contact Person: _____

  Address: _____

  Phone: _____ Fax: _____ Email: _____

  Website: _____

Therapists
Community Health Care / Service Providers

Therapists:

- Occupational Therapist (OT) _____

  Start Date: _____

  Agency: _____

  Address: _____

  Phone: _____ Fax: _____ Email: _____

- Physical Therapist (PT): _____

  Start Date: _____

  Agency: _____

  Address: _____

  Phone: _____ Fax: _____ Email: _____

- Speech-Language Pathologist: _____

  Start Date: _____

  Agency: _____

  Address: _____

  Phone: _____ Fax: _____ Email: _____

Early Intervention Services
Community Health Care / Service Providers

- Developmental Center: _____

  Start Date: _____

  Contact Person: _____

  Address: _____

  Phone: _____ Fax: _____ Email: _____

  Website: _____

- Family Resources Coordinator: _____

  Agency: _____

  Address: _____

  Phone: _____ Fax: _____ Email: _____

School
Community Health Care / Service Providers

- School / Preschool: _____

  Start Date: _____

  Address: _____

  Phone: _____ Fax: _____ Email: _____

  Website: _____

- School Nurse: _____

  Phone: _____ Fax: _____ Email: _____

- Contact Person/Title: _____

  Phone: _____ Fax: _____ Email: _____

- Contact Person/Title: _____

  Phone: _____ Fax: _____ Email: _____

Child Care
Community Health Care / Service Providers

- Child Care Provider: _____

  Start Date: _____

  Contact Person: _____

  Address: _____

  Phone: _____ Fax: _____ Email: _____

- Child Care Provider: _____

  Start Date: _____

  Contact Person: _____

  Address: _____

  Phone: _____ Fax: _____ Email: _____

- Child Care Provider: _____

  Start Date: _____

  Contact Person: _____

  Address: _____

  Phone: _____ Fax: _____ Email: _____

Respite Care
Community Health Care / Service Providers

- Respite Care Provider: _____

  Start Date: _____

  Contact Person: _____

  Agency: _____

  Address: _____

  Phone: _____ Fax: _____ Email: _____

- Respite Care Provider: _____

  Start Date: _____

  Contact Person: _____

  Agency: _____

  Address: _____

  Phone: _____ Fax: _____ Email: _____

- Respite Care Provider: _____

  Start Date: _____

  Contact Person: _____

  Agency: _____

  Address: _____

  Phone: _____ Fax: _____ Email: _____

Pharmacy
Community Health Care / Service Providers

- Pharmacy: _____ Hours/Days of Operation: _____

  Contact Person: _____

  Address: _____

  Phone: _____ Fax: _____ Email: _____

  Website: _____

- Pharmacy: _____ Hours/Days of Operation: _____

  Contact Person: _____

  Address: _____

  Phone: _____ Fax: _____ Email: _____

  Website: _____

- Pharmacy: _____ Hours/Days of Operation: _____

  Contact Person: _____

  Address: _____

  Phone: _____ Fax: _____ Email: _____

  Website: _____

Special Transportation
Community Health Care / Service Providers

- Transportation (to and from medical / therapy appointments)

  Contact Person: _____

  Agency: _____

  Address: _____

  Phone: _____ Fax: _____ Email: _____

  Website: _____

- Transportation (to and from medical / therapy appointments)

  Contact Person: _____

  Agency: _____

  Address: _____

  Phone: _____ Fax: _____ Email: _____

  Website: _____

Family Information

- Child's Name: _____ Nickname: _____
  Date of Birth: _____
  Diagnosis: _____
  Blood Type: _____

  Legal Guardian: _____
  Address: _____
  Phone: _____

Family Members

- Mother's Name: _____
  Address: _____ Email: _____
  Daytime Phone:_____ Evening Phone:_____ Cell: _____

- Father's Name: _____
  Address: _____ Email: _____
  Daytime Phone:_____ Evening Phone:_____ Cell: _____

- Sibling's Name: _____ Age: _____ Name: _____ Age: _____
  Name: _____ Age: _____ Name: _____ Age: _____

- Other Household Members: _____

- Important Family Information: _____

- Language Spoken at Home: _____
  Other Language(s): _____
  Interpreter Needed? Yes: ☐ No: ☐
  Interpreter: _____ Phone: _____

Emergency Contact

- Name: _____
  Address: _____ Email: _____
  Daytime Phone:_____ Evening Phone:_____ Cell: _____

Family Support Resources

- Parent to Parent: _____

  Contact Person: _____

  Address: _____

  Phone: _____ Fax: _____ Email: _____

  Website: _____

- Parent Group: _____

  Contact Person: _____

  Address: _____

  Phone: _____ Fax: _____ Email: _____

  Website: _____

- Religious Organization: _____

  Contact Person: _____

  Address: _____

  Phone: _____ Fax: _____ Email: _____

  Website: _____

- Service Organization: _____

  Contact Person: _____

  Address: _____

  Phone: _____ Fax: _____ Email: _____

  Website: _____

- Counseling Services: _____

  Contact Person: _____

  Address: _____

  Phone: _____ Fax: _____ Email: _____

  Website: _____

(continued)

Family Support Resources

- Division of Developmental Disabilities: _____

  Contact Person: _____

  Address: _____

  Phone: _____ Fax: _____ Email: _____

  Website: _____

- Other: _____

  Contact Person: _____

  Address: _____

  Phone: _____ Fax: _____ Email: _____

  Website: _____

- Other: _____

  Contact Person: _____

  Address: _____

  Phone: _____ Fax: _____ Email: _____

  Website: _____

Finding Resources for Your Child with Special Needs

Having a child with special needs can be a challenge. You may feel confused and overwhelmed. Here you will find descriptions of some of the people that may be of help to you and your family.

Public Health Nurses

Public health nurses work in local health departments. They can answer questions about your child's health, growth and development and help you find local resources.

Children with Special Health Care Needs Coordinators (CSHCN)

CSHCN Coordinators are public health nurses who can provide screening and assessment of your child, refer you to services and resources, provide health information and help you coordinate services. There is a CSHCN Coordinator in every county.

Family Resource Coordinator (FRC)

FRCs provide information about child growth and development, coordinate resources and services for your family, and find screening for your child if you have concerns about his or her development.

Health Care Providers

Your child's doctors, nurses or social workers can also help you find services and resources.

People at Your Child's School

Teachers, school nurses, counselors, or therapists can help your child with medications, equipment, therapies and homework. If your child goes to a private school, you can still get help from the public school system.

Other Parents

Other parents can tell you about their experiences, give you tips, tell you about helpful providers, and give you hope. Parent to Parent www.arcwa.org/parent_to_parent.htm and The Fathers Network www.fathersnetwork.org are two parent-run organizations that provide emotional and informational support to parents.

To find these resources and others in your community:

1. Call the toll-free ASK Resource Line (Answers for Special Kids) at 1-800-322-2588, or visit www.ParentHelp123.org . They can connect you to Family Resource Coordinators, Children with Special Health Care Needs Coordinators, health insurance coverage, parenting support, recreational opportunities, local and national disability-related organizations and adolescent transition care.

2. Call Seattle Children's Resource Line and ask for a copy of *Starting Point*, a free resource guide for Washington families who have a child with special needs: (206) 987-2500, option 3, or toll-free 1-866-987-2500. *Starting Point* is also online at www.cshcn.org.

Create a Contact List for Your Child

Health Care Providers

Name: _____

Phone/Email: _____

Name: _____

Phone/Email: _____

School Contacts

Name: _____

Phone/Email: _____

Name: _____

Phone/Email: _____

Parents

Name: _____

Phone/Email: _____

Name: _____

Phone/Email: _____

Other Important Numbers

Name: _____

Phone/Email: _____

Name: _____

Phone/Email: _____

Name: _____

Phone/Email: _____

Name: _____

Phone/Email: _____

Name: _____

Phone/Email: _____

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Washington State Department of Health

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Insurance/Funding Sources

- Insurance Company: _____

  Policy Number: _____

  Contact Person / Title: _____

  Address: _____

  Phone: _____ Fax: _____ Email: _____

  Website: _____

- Insurance Company: _____

  Policy Number: _____

  Contact Person / Title: _____

  Address: _____

  Phone: _____ Fax: _____ Email: _____

  Website: _____

- Insurance Company: _____

  Policy Number: _____

  Contact Person / Title: _____

  Address: _____

  Phone: _____ Fax: _____ Email: _____

  Website: _____

- Supplemental Security Income (SSI): _____

  Contact Person / Title: _____

  Address: _____

  Phone: _____ Fax: _____ Email: _____

  Website: _____

(continued)

Insurance/Funding Sources

- Other: _____

  Contact Person/Title: _____

  Address: _____

  Phone: _____ Fax: _____ Email: _____

  Website: _____

- Other: _____

  Contact Person/Title: _____

  Address: _____

  Phone: _____ Fax: _____ Email: _____

  Website: _____

Alphabet Soup
Acronym Index

The following index lists a wide variety of acronyms used by professionals who work with families.

ADA	Americans with Disabilities Act
ADD	Attention Deficit Disorder
ADHD	Attention Deficit Hyperactivity Disorder
AIDS	Acquired Immune Deficiency Syndrome
ARC	The Arc: Advocates for the Rights of Citizens with Developmental Disabilities and their families
ARNP	Advanced Registered Nurse Practitioner
CD	Communication Disorders
CDS	Communication Disorders Specialist
CHDD	Center on Human Development and Disability at the University of Washington
CAN	Certified Nursing Assistant
CNS	Clinical Nurse Specialist
CP	Cerebral Palsy
CPS	Child Protective Services
CSHCN	Children with Special Health Care Needs
CSO	Community Service Office, DSHS
DCFS	Division of Children and Family Services
DD	Developmentally Disabled
DDD	Division of Developmental Disabilities, DSHS
DH	Developmentally Handicapped
DMH	Division of Mental Health
DOH	Department of Health
DSB	Department of Services for the Blind
DSHS	Department of Social and Health Services
DVR	Division of Vocational Rehabilitation
ECEAP	Early Childhood Education and Assistance Program
ED	Emotionally Disturbed
EEG	Electroencephalogram
EEU	Experimental Education Unit, CHDD
EFMP	Exceptional Family Member Program (helps military families locate to areas with services)
EKG	Electrocardiogram
EPSDT	Early Periodic Screening, Diagnosis, and Treatment
ESD	Educational Service District
FAPE	Free Appropriate Public Education
FRC	Family Resources Coordinator
HHS	Health and Human Services
HI	Health Impaired or Hearing Impaired
HIPAA	Health Insurance Portability and Accountability Act
HMO	Health Maintenance Organization
HO	Healthy Options, DSHS, Medicaid Managed Care Program
HOH	Hard of Hearing
ICC	Interagency Coordinating Council; county ICC and state ICC.
IDEA	Individuals with Disabilities Education Act
IEP	Individual Education Plan
IFSP	Individual Family Service Plan
IHP	Individual Health Plan
ISP	Individual Service Plan
IRB	Institutional Review Board
ITEIP	Infant Toddler Early Intervention Program
LD	Learning Disabled
LDA	Learning Disabilities Association
LRE	Least Restrictive Environment
MCH	Maternal and Child Health
MD	Medical Doctor

(continued)

Alphabet Soup
Acronym Index

MDT	Multi-Disciplinary Team
MH	Multiply Handicapped
MR	Mentally Retarded
NICU	Neonatal Intensive Care Unit
NORD	National Association of Rare Disorders
OCR	Office of Civil Rights
OFM	Office of Financial Management
OI	Orthopedically Impaired
OSEP	Office of Special Education Programs
OSERS	Office of Special Education and Rehabilitation Services
OSPI	Office of Superintendent of Public Instruction
OT	Occupational Therapy/Therapist
OTR	Licensed and Registered Occupational Therapist
PAVE	Parents Are Vital in Education
P & A	Protection and Advocacy
PHN	Public Health Nurse
PL	Public Law
PT	Physical Therapy/Therapist
PTA	Parent Teacher Association
RCW	Revised Code of Washington (state law)
RD	Registered Dietician
RN	Registered Nurse
RPT	Registered Physical Therapist
SBD	Seriously Behaviorally Disabled
SCHIP	Statewide Children's Health Insurance Program
SEA	State Education Agency
SEAC	Special Education Advisory Council
SEPAC	Special Education Parent/Professional Advisory Council
SLD	Specific Learning Disability
SSA	Social Security Administration
SSI	Social Security Income
STOMP	Specialized Training of Military Parents
SW	Social Work/Worker
TANF	Temporary Assistance to Needy Families
TAPP	Technical Assistance for Parents and Professionals
TASH	The Association for Persons with Severe Handicaps
TBI	Traumatic Brain Injury
TDD	Telecommunication Device for the Deaf
TRICARE	U.S. Department of Defense Health Care System
TTY	Telecommunication Device for Deaf, Hearing Impaired, and Speech Impaired Persons
VI	Visually Impaired
WAC	Washington Administrative Code
WACD	Washington Association for Citizens with Disabilities
WATA	Washington Assistive Technology Act Program
WIC	Women, Infants and Children Supplemental Food Program
WSMC	Washington State Migrant Council
WSSB	Washington State School for the Blind

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Care Summary:
Activities of Daily Living

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

Date: _____

Care Schedule

TIME	CARE
Morning	
Afternoon	

Care Schedule

TIME	CARE
Evening	
Night	

Care Summary:
Child's Page—Now and Later

Use this page for your child's words and thoughts about his or her life now as well as in the future. What are your child's dreams? What does he or she do well now that might give direction for life later? What does your child want to be when he or she grows up?

Date: _____

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Care Summary: Communication

Use this page to write 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: _____

Care Summary:
Coping / Stress Tolerance

Use this page to write 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: _____

Care Summary: Mobility

Use this page to write 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: _____

Care Summary: Nutrition

Use this page to write 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: _____

Care Summary: Respiratory

Use this page to write 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: _____

Care Summary:
Rest / Sleep

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

Date: _____

Care Summary: Social / Play

Use this page to write 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: _____

Care Summary:
Transitions—Looking Ahead

Your child and family may go through or have many transitions, small and large, over the years. Three key transitions are: when your child reaches school age, when he or she nears adolescence, and when your child moves from adolescence into adulthood. 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 of others.

It's not always easy to think about the future. There may be many things, including what has to be done today, that keep you from looking ahead. It may be helpful to take some time 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: _____

Developed in partnership with staff from the Adolescent Health and Transition Project, University of Washington

Appointment Log

DATE	PROVIDER	REASON FOR APPOINTMENT / CARE PROVIDED	NEXT APPOINTMENT

Medical / Surgical Procedures

DATE	PROCEDURE	RESULTS	COMMENTS

Lab Work / Tests / Procedures

DATE	TEST	RESULTS	COMMENTS

Growth Tracking Form

DATE	HEIGHT	WEIGHT	HEAD CIRCUMFERENCE	CHECKED BY

Equipment / Supplies

- Name of Equipment: _____

  Description (brand name, model, size, etc.): _____

  Date obtained: _____ Supplier: _____

  Website: _____

  Contact Person: _____ Phone: _____

  Serial Number: _____

- Name of Equipment: _____

  Description (brand name, model, size, etc.): _____

  Date obtained: _____ Supplier: _____

  Website: _____

  Contact Person: _____ Phone: _____

  Serial Number: _____

- Name of Equipment: _____

  Description (brand name, model, size, etc.): _____

  Date obtained: _____ Supplier: _____

  Website: _____

  Contact Person: _____ Phone: _____

  Serial Number: _____

- Name of Equipment: _____

  Description (brand name, model, size, etc.): _____

  Date obtained: _____ Supplier: _____

  Website: _____

  Contact Person: _____ Phone: _____

  Serial Number: _____

Notes

Medications

Allergies:

Pharmacy: Phone:

MEDICATION	DATE STARTED	DATE STOPPED	DOSE / ROUTE (with or without food?)	TIME GIVEN	PRESCRIBED BY

Diet
Tracking Form

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

Hospital Stay Tracking Form

DATE	HOSPITAL	REASON	NOTES

Medical Bill Tracking Form

DATE	PROVIDER	COST	INSURANCE PAID	DATE PAID	FAMILY OWES	DATE PAID

"MAKE-A-CALENDAR" Month Year

SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY

Emergency Preparedness for Children with Special Needs

"I used to get overwhelmed about emergency preparedness, but once I broke it down into small steps it got easier. Each week I put a few items on my shopping list. Then I got other supplies at second hand stores and the Red Cross. I feel better knowing I'm ready instead of worrying about getting ready". –Parent

In an emergency, we all have to plan to be self sufficient and possibly spend several days without utilities, medical aid or communications.

Three Ways to Get Ready

1. *Think* about your child's special needs in an emergency.
2. *Plan* now for emergencies that can happen in your area.
3. *Pack* an emergency supplies kit.

1. Think about your child's special needs in an emergency.

Consider your child's needs if there was:

- No water
- No electricity, telephone, heat, air conditioning, computer
- No local access to prescription refills or health products
- No refrigeration
- Separation from your family
- Evacuation to a shelter or elsewhere
- Confinement to home
- Limited health care access
- Lack of transportation
- Limited emergency rescue services

2. Planning for Special Needs

❒ Talk with your family about different types of emergencies, how to prepare for them, and how to care for your child with special needs during an emergency.

❒ Talk with your child's doctor or health care team about how to care for your child during different types of emergencies. Develop a plan for how you will communicate with your child's care team during an emergency.

Continued

- ❒ Plan for back up sources of heat, refrigeration, and electricity. Your family can use an emergency shelter for storing medicine, charging equipment, help with medical needs, getting a meal and more. You do not have to be staying in a shelter to use its resources.
- ❒ If your child depends on dialysis or other life sustaining treatment, know the location of more than one facility and find out *their* plans for emergencies and how your child will get treatment, medications etc. Get their emergency contact numbers (these may be out of state).
- ❒ Store extra medicines and equipment at your child's school.
- ❒ Create and practice an escape plan for your home. Are there clear exit paths for a child who uses mobility devices or has vision loss?
- ❒ For each person in the home, keep a pair of shoes stored under their bed to use in an evacuation.
- ❒ Talk to your local police and fire departments to see if they have emergency services or plans for people with special needs.
- ❒ Plan for your child's service animal.
- ❒ Obtain a medical alert and/or identification bracelet for your child.
- ❒ In the event of a disaster, listen to your emergency radio station (710-AM KIRO for King, Kitsap, and North Mason Counties)

Create a Support Network

A support network includes family, neighbors or friends that can help you and your child. They may be your first source of help in an emergency.

- ❒ Tell your support network about your child's special needs and where your emergency supplies are stored.
- ❒ Give a trusted member of your network a key to your house or apartment.
- ❒ Agree upon a system with your neighbors to signal for help if phones and electricity are not working.
- ❒ Show others how to handle your child's wheelchair or other equipment.
- ❒ Talk to other families who have a child with the same condition as your child about ideas and tips.

Continued

3. Pack Emergency Supplies Including:

- ❒ A copy of your child's up to date Emergency Information Form and care plan (sample forms at http://www.cshcn.org/Docs/InCaseofEmergency.doc and http://www.aap.org/advocacy/eif.doc).
- ❒ Current medical information and important records stored in an easy to carry format such as a CD or flash drive. Keep at least one paper copy in a waterproof bag.
- ❒ Two-weeks worth of medical supplies such as syringes, dressing materials, nasal cannulas, or suction catheters.
- ❒ At least a 3 day supply of medications-fourteen days is ideal. It may be a challenge to get extra medications for emergencies, so talk with your child's doctor about how to obtain an extra supply. Keep prescription information in your wallet, car, and survival kit, along with the name, location and phone number of an out of town pharmacy. Ask your doctor or pharmacist how to properly store medication for use in an emergency. In a disaster, if you can't contact your doctor or pharmacy, you can ask for help from emergency responders or staff at emergency shelters or service centers. You can also call your local Red Cross or the Washington State Information Network 211.
- ❒ Back up power support (generator or battery) for electrical medical equipment. Due to deadly fumes, use generators, camp stoves or grills outdoors.
- ❒ Have a way to charge your cell phone without electricity. You can use a car adaptor or crank radio/flashlight that includes a cell phone charger. These are available at home and hardware stores. Look for battery powered or travel versions of medical equipment your child uses.
- ❒ An AC adaptor for your car that can run small electrical equipment such as a nebulizer. Know how long your battery will last while using the adaptor.
- ❒ Manual wheelchair or other non-electric equipment.
- ❒ Extra contact lenses, glasses, and lens supplies.
- ❒ Batteries for hearing aids, communication devices
- ❒ Special dietary foods and supplies
- ❒ Cooler and chemical ice packs for storing medications that must be kept cold.
- ❒ Items that calm or entertain your child.
- ❒ Identification to be carried by each child in case your family gets separated.
- ❒ Proof of service animal status to insure it can go with you into a shelter.

Continued

❒ Pack a smaller "to go" version of items for use in an evacuation. See link below for more information.

Store your supplies in water and pest-proof containers that are easy to get to. Update supplies and emergency contact and medical forms each year and replace water every six months. Store batteries out of devices until ready to use.

Links to Other Emergency Preparedness Resources for Special Needs

- **The American Red Cross**:
  http://www.redcross.org/museum/prepare_org/disabilities/disabilitiesprep.htm
  Includes tips for people with:
  - cognitive disabilities
  - communication disabilities
  - disabilities and medical concerns
  - environmental or chemical sensitivities
  - life support systems
  - mobility concerns
  - psychiatric disorders
  - visual disabilities / hearing loss
  - service animals

- **The Department of Homeland Security**. Instructional video on emergency preparedness for individuals with disabilities and or special needs.
  http://www.ready.gov/america/about/_flash/movie14.html

- **Disability Resource Center**. Emergency preparedness for special needs including specific tips by disability.
  http://www.disabilitypreparedness.gov/ppp/disabil.htm

- **Family Voices.** "Emergencies and Disasters: Keeping Children and Youth with Special Health Care Needs Safe".
  http://www.familyvoices.org/work/caring?id=0004

- **National Hemophilia Foundation.** Individual and family preparedness.
  http://www.hemophilia.org/NHFWeb/Resource/StaticPages/menu0/menu8/menu125/AtAGlanceIndividual.pdf

- **Washington State Department of Health.** Emergency Resource Guide. Includes disability specific planning.
  http://www.doh.wa.gov/phepr/handbook/hbk_pdf/Emer_Res_Guide07.pdf

- **U. S. Department of Health and Human Services.** Helping children with cognitive disabilities cope with disaster.
  http://www.acf.dhhs.gov/programs/add/Sept11/addcoping.html

We wish to thank the Washington State Family to Family Health Information Center, the Family Advisory Board of Seattle Children's Hospital, and the American Red Cross, Serving King and Kitsap Counties.

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Getting to Know Me

My Name:	**Nickname:**
Date of Birth:	**Today's Date:**
A Little About Me:	
My Strengths: (things that are easy for me)	
My Challenges: (communication, feeding, learning, mobility, social, energy, behavior)	
My Life in the Community: (school, childcare, place of worship, my favorite places)	
My Home and Family Information:	
My Diagnosis (Diagnoses):	
My Overall Health:	
My Prior Surgeries, Procedures, Lab/Diagnostic Studies:	

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Getting to Know Me

My Name:	**Nickname:**
Date of Birth:	**Today's Date:**
My Current Medicines/Doses:	
My Allergies:	
Things to Avoid: (food, activities, and procedures)	
My Equipment/Assistive Technology: (braces/orthotics, walker, wheelchair, communication device, home O_2, insulin pump, nebulizer, suction)	
Other Things I'd Like You to Know About Me:	
Ways You Can be Helpful to Me:	

Copies of this form are available at http://www.cshcn.org

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In Case of Emergency

Today's Date: _____

CHILD'S INFORMATION		
Name:	**Nickname:**	
Birth Date:	**Primary Language/Communication:**	
Home Address:		
Parents/Guardians:	**Relationship:**	**Home #:** **Other #'s:**
Diagnosis:		

Medications	Dose	Time

Allergies:		
Emergency Contact:	**Relationship:**	**Phone #'s:**

PHYSICIAN INFORMATION		
Primary Doctor:	**Phone:**	**Fax:**
Specialist:	**Phone:**	**Fax:**
Specialist:	**Phone:**	**Fax:**
Insurance:		

HOSPITAL INFORMATION	
Name: **Address:**	**Phone:** **ER Phone:**

PHARMACY INFORMATION	
Name: **Address:**	**Phone:**

OTHER
Most Important Things to Know About My Child in an Emergency:

Copies of this form are available at http://www.cshcn.org

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Washington State Department of Health
Children with Special Health Care Needs Program

Center
8/07

What's the Plan?

Child's Name:	**Date of Birth:**	**Provider:**
Parent's Name:		**Today's Date:**
Questions/Concerns: What do I want to talk about today?		
What do I hope to have happen?		
Next steps? What needs to be done?		
Who will do this?		
By when? (time frame)		
How will we follow-up?		

Copies of this form are available at http://www.cshcn.org

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Washington State Department of Health
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