



*Jean Baton Swindells Resource Center  
for Children and Families*

# My Child's Life Care Notebook and Organizer

**The Swindells Center**

830 NE 47<sup>th</sup> Ave  
Portland OR 97213  
503.215.2429  
800.833.8899 x52429

**Swindells Center at Medford**

840 Royal Avenue Suite C  
Medford, OR 97504  
541-732-5958

**Swindells Center at Hood River**

1151 May Street  
Hood River, OR 97031  
541-387-8920

**Swindells Center of Central Oregon**

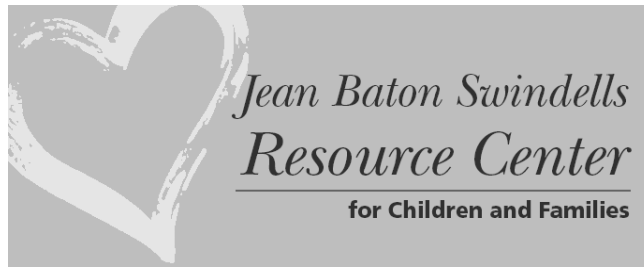
412 SW 8th Street  
Redmond, OR 97756  
541-526-1448

**Swindells Center at the Coast**

321 SE 3rd Street  
Toledo, OR 97391  
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This Child Life Care Notebook and Organizer is free to all families of children with disabilities that reside in Oregon. It is intended to help families organize the many pieces of their child's life in the simplest manner possible. Whether your child has a complex medical or developmental or mental health diagnosis, you are in charge of the information you need to have with you when you have appointments.

The Swindells Center staff searched national, regional, and local resources for the best information and with the careful guidance of parents and providers, developed these pages to make it easier to share information with educators, therapists and family. We appreciate the parents, grandparents, family members and foster parents who shared their perspectives, knowledge, and experiences during this project.

The following agencies, programs and individuals contributed to this project through direct involvement or example:

*Jean Baton Swindells Resource Center for Children and Families* Family Advisory Board.  
The Swindells Center families, children and visitors.  
Staff of the Providence Neurodevelopmental Center for Children  
Nursing staff at the Center for Medically Fragile Children

The following agency notebooks were a valuable resource  
National Center of Medical Home Initiatives for Children with Special Needs;  
Los Angeles Medical Home Project Parent Notebook  
Center for Children with Special Needs: A Program of Children's Hospital & Regional Medical Center of Seattle, Washington.  
The Center for Infants and Children with Special Needs: Children's Hospital Medical Center of Cincinnati and The Arc of Hamilton County.  
Children's Hospitals and Clinics, Minneapolis and St. Paul, MN

**Care Notebook and Organizer Trainings:** If you would like additional assistance in learning how to organize and use this notebook, please contact the Swindells Center for further information.

#### **Can Oregon Families order a copy?**

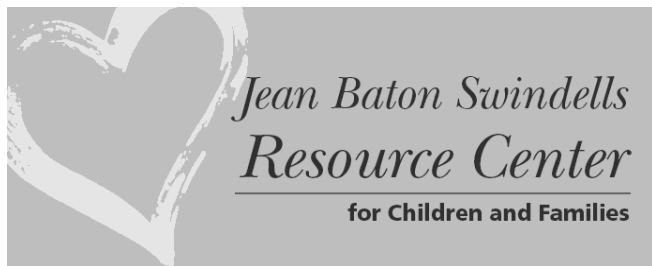
Families in Oregon may order one My Child's Life Care Notebook and Organizer per child with special needs at no cost. Families should call or email the Swindells Center and provide their name, mailing address, phone number and the item they would like to order. Telling us the name and age of your child or children also helps us send updated pages or information to you.

The Swindells Center: 503.215.2429 or 1.800.833.8899 ext: 52429 [Swindells@providence.org](mailto:Swindells@providence.org)

#### **What about orders outside of Oregon State?**

Currently our funding only supports the production of notebooks for families in Oregon. For orders out-of-state, the My Child's Life Care Notebook and Organizer cost \$20 each. Contact Anne Saraceno for more information at 503.215.2429.





## **This Life Care Notebook and Organizer can make life a little easier!**

This child's life care notebook and organizer was developed by Swindells Center Family and Professional Advisory Board members and staff members to help families of children with disabilities keep track of many important pieces of information regarding their child's care and day-to-day needs.

As you care for your child, you get paperwork, forms, letters and other items that you may not know where to keep or how to use. This life care notebook and organizer is intended to help you keep and share information with others who are members of your family, as well as those on the education and healthcare team.

### **Use your Notebook and organizer to:**

- Share your child's routine, preferences, and needs with family members and friends.
- Track changes in your child's medicines or treatments.
- Keep recent evaluations and appointment schedules in one easy spot.

This includes information regarding your child's medical, educational and/or legal history.

### **Helpful hints about using the Child Life Care Notebook and Organizer**

Keep this notebook where it is easy to find, taking it with you to all doctor, therapy and school appointments.

Add new information whenever there is a change in your child's daily routine, schedule or treatment. Medical offices can copy evaluation reports, immunization records, and

specialist reports and give them to you to insert into the notebook.

### **How to set up the Notebook and Organizer**

Gather your paperwork and information you have about your child. This could include prescription slips, medical records, summary of hospital stays, your child's school reports and IEP/ISP and informational pamphlets.

### **Look through the pages of My Child's Life Care Notebook**

Which of these pages could help you keep track of information about your child's health or care?

Chose the pages you like. Place the remainder in the back of the folder for possible future use. You can download additional pages from the Swindells Center website if you need to.

### **Decide which information about your child is most important to keep in the notebook and organizer.**

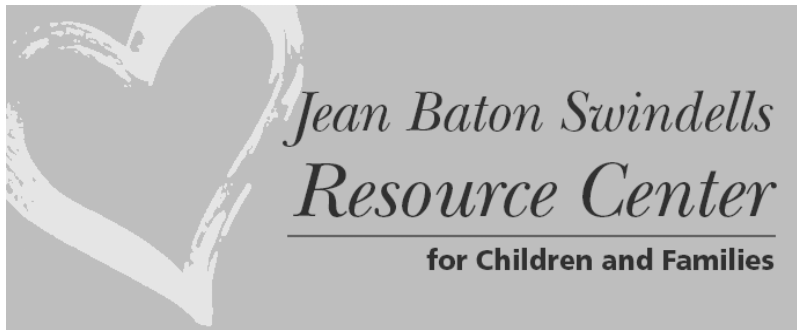
What information do you look up often?

What information might others looking after your child need?

### **Put the Child Life Care Notebook together.**

- Please personalize the cover, use your child's photo or artwork!
- Everyone has a different way of organizing information. The only important thing is to make it easy for YOU to locate them.
- Tabbed dividers: create your own information sections.
- Pocket dividers: store reports and loose materials.
- Plastic Pages: Store business cards, insurance cards and photographs





## A Parent's Perspective

I appreciate it when you:

Remember that it is normal and healthy to sometimes feel anger and denial when I grieve my child's illness.

Realize that I am struggling to regain my balance in a confusing and challenging situation.

Recognize that my child's health needs don't erase the other real life challenges all families face: bills, job stressors, plumbing issues and not enough time in any day.

Listen when I tell you there is something wrong. I know my child. Help me solve the puzzle until we both understand what is going on. Telling me my child will outgrow it only frustrates me and it could be harmful to my child.

Help me to be a competent partner in healthcare. I have to be. My child relies on me for everything.

Help me find the information I need to understand my child's condition. Send me to resource centers or other providers if you need to. Tell me what books and articles are the good ones. The more I know about my child, the more I can enjoy and work with my child.

Realize you can't tell me too much about my child's condition. I may not absorb it all at once, so you may have to repeat yourself.

Help me enjoy the smallest of successes and recognize my child's limitations for what they are.

Keep me informed about everything, even referrals. Call me, send me a note, and let me know that my child has not been forgotten or lost in a tangle of procedural tape.

See my whole child, not just the diagnosis.

Work with the other professionals providing care for my child. We each hold only one piece of the puzzle.

I don't think these are too much to ask for. Do you?



## Medical Information Summary

Name						Date of Birth					
Diagnosis/Problem List						Current Physicians/Health Care Providers					
1. _____						1. PCP: _____					
2. _____						2. _____					
3. _____						3. _____					
4. _____						4. _____					
5. _____						5. _____					
6. _____						6. _____					
7. _____						7. _____					
Current Medication and Doses						Allergies to Medication/Food/Things and what happens with exposure					
1. _____						1. _____					
2. _____						_____					
3. _____						2. _____					
4. _____						_____					
5. _____						3. _____					
6. _____						_____					
7. _____						4. _____					
8. _____						_____					
Antibiotic Prophylaxis? yes <input type="checkbox"/> no <input type="checkbox"/>						Medication:					
Immunizations											
Dates						Dates					
DPT						HEP B					
Polio						Varicella					
MMR						TB					
HIB						Other					

Clinical Summary and Comments:

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## My Child's Hospital and Medical Clinic Information

Hospital Name/Phone: \_\_\_\_\_ Emergency Room Phone: \_\_\_\_\_

Hospital Name and Location			
Medical Record #		State	Zip
Primary Care Doctor:			
Phone		Fax	

Medical Clinic Name and Location			
Medical Record #		State	Zip
Physician/Therapist(s):			
Treatment Type:			
Phone		Fax	

Medical Clinic Name and Location			
Medical Record #		State	Zip
Physician/Therapist(s):			
Treatment Type:			
Phone		Fax	



# Medical History

Birth History Unknown

Name	Date of Birth
Pregnancy / Birth History	Smoker <input type="checkbox"/> yes <input type="checkbox"/> no Type/Amount _____
Used alcohol during pregnancy	<input type="checkbox"/> yes <input type="checkbox"/> no Type/Amount _____
Used recreational drugs during pregnancy	<input type="checkbox"/> yes <input type="checkbox"/> no Type/Amount _____
Complications / illnesses during pregnancy:	
Birth Weight ___ lbs ___ oz	Length ___ inches

## Family History

Family History Unknown

Family History of Difficulties Similar to My Child's

Problem	Name	Relation

## Family History of Other Problems

Problem	Name	Relation
Allergies		
Arthritis		
Heart Conditions		
Feeding		
Stomach/Bowel		
Hearing Loss		
Learning /slow learner		
Mental Retardation		
Developmental Delay		
Mental Illness		
Emotional/Behavioral		
Breathing Problems		
Seizures		
Speech and Language		
Kidney and Bladder		
Eyes/Vision		
Family Death /Cause		
Diabetes		
Autism Spectrum		
Genetic		
Stroke		





## My Child's Information

Personal Information	Name	Nickname	Date of Birth	Social Security #		
				(optional)		
	Primary Language?			Interpreter Needed?		
	<input type="checkbox"/> English <input type="checkbox"/> Spanish <input type="checkbox"/> Russian <input type="checkbox"/> Vietnamese <input type="checkbox"/> Non Verbal			<input type="checkbox"/> Yes <input type="checkbox"/> No		
	Child Lives with:					
	<input type="checkbox"/> Biological Family <input type="checkbox"/> Extended Family <input type="checkbox"/> Adoptive Family <input type="checkbox"/> Foster Family <input type="checkbox"/> Group Home <input type="checkbox"/> Other:					
	Name(s)	Address	City	State	Zip	
	Family Email:					
Legal guardian(s)	Name / Relationship	Address	Phone(s)			
			(   )			
			(   )			
			(   )			
			(   )			
			(   )			
Emergency Contact	Contact Name / Relationship		Phone(s)			
			(   )			
			(   )			
Primary Providers	Primary Doctor	Location	Phone			
			(   )			
	Preferred Hospital	Location	Phone			
			(   )			
	School	Location	Phone			
		(   )				



# Our Family Information

Other Family Members	Name / Relationship		Phone(s)		
Siblings	Name		Age	Gender	
				<input type="checkbox"/> M <input type="checkbox"/> F	
				<input type="checkbox"/> M <input type="checkbox"/> F	
				<input type="checkbox"/> M <input type="checkbox"/> F	
				<input type="checkbox"/> M <input type="checkbox"/> F	
				<input type="checkbox"/> M <input type="checkbox"/> F	
Other Household Members	Name/ Relationship				
Pets					



# Medical Visit Check Sheet

My child's name is: \_\_\_\_\_ Today's Date: \_\_\_\_\_

Reason for today's visit:


My biggest concerns are:


Weight: \_\_\_\_\_

Height: \_\_\_\_\_

Current Medications:


Doctor's Notes / Today's Diagnosis:


Medication and Instructions:


Follow up Plan:


\_\_\_\_\_  
Physician / Provider Signature



## Medical / Dental Speech / OT / PT/ Therapists

<b>Primary Care Provider</b>					
Date of First Visit		Medical Record #:			
Office Address		State	Zip		
Phone:	Fax:				
<b>Preferred Hospital</b>					
Date of First Visit		Medical Record #:			
Address		State	Zip		
Phone:	Fax:				
<b>Developmental Pediatrician</b>					
Date of First Visit		Medical Record #:			
Office Address		State	Zip		
Phone:	Fax:				
<b>Dentist / Orthodontist:</b>					
Date of First Visit		Medical Record #:			
Office Address		State	Zip		
Phone:	Fax:				
Date of First Visit		Medical Record #:			
Office Address		State	Zip		
Phone:	Fax:				
Date of First Visit		Medical Record #:			
Office Address		State	Zip		
Phone:	Fax:				
Date of First Visit		Medical Record #:			
Office Address		State	Zip		
Phone:	Fax:				



## Medical / Dental Speech / OT / PT/ Therapists

Date of First Visit				Medical Record #:	
Office Address				State	Zip
Phone:			Fax:		
				Medical Record #:	
Address				State	Zip
Phone:			Fax:		
Date of First Visit				Medical Record #:	
Office Address				State	Zip
Phone:			Fax:		
Date of First Visit				Medical Record #:	
Office Address				State	Zip
Phone:			Fax:		
Date of First Visit				Medical Record #:	
Office Address				State	Zip
Phone:			Fax:		
Date of First Visit				Medical Record #:	
Office Address				State	Zip
Phone:			Fax:		
Date of First Visit				Medical Record #:	
Office Address				State	Zip
Phone:			Fax:		
Date of First Visit				Medical Record #:	
Office Address				State	Zip
Phone:			Fax:		



# Medication Information



Pharmacy: \_\_\_\_\_ Phone: \_\_\_\_\_

Date Start/End	Medication Name	Dose/Route	Prescribed By
	You can place the prescription tag/label here	Tips for giving this to my child	



## My Child's Daily Routine

Time	Directions and Hints for Success	
Morning Routines	Signs my child is ready to get out of bed	
	What my child does first in the morning	
	Favorite Clothing	
	Where shoes are usually hiding	
	Songs that make dressing easier	
	Toys that make mornings better	
	For Breakfast my child usually eats	
	Foods to Avoid	
	Usual length of time to eat	
	Signs my child is full	
	Ways to encourage better eating	
	Places my child is not allowed in the house	
	How to calm my child	



Time	Directions and Hints for Success	
Daytime Routines	We take a walk (time/where/ directions)	
	Favorites songs to listen to	
	Favorite shows to watch	
	Favorite books to read	
	Signs my child is needing a nap or quiet time	
	Nap times (hints for success)	
	Snack times (hints for success)	
	For Lunch, my child usually eats	
	Foods to Avoid	
	Usual length of time to eat	
	Signs my child is full	
	For Dinner, my child usually eats	
	Foods to Avoid	
	Usual length of time to eat	
	Signs my child is full	
	Ways to encourage better eating	



Time	Directions and Hints for Success	
Evening Routines	How my child sleeps through the night	
	Signs my child is ready for sleep	
	Bedtime ritual and toys	
	What to avoid in the bedroom	
	What my child wears to sleep	
	What helps my child fall asleep	
	What cues help keep my child in bed	
Medication Routines		
	What are the best methods for giving medication	
	Where the medications are kept	



Time	Directions and Hints for Success	
Entertainment	TV rules	
	Radio rules	
	Music rules	
	Computer Game rules	



# My Child's Communication

How my child communicates	
Tools that help my child communicate	
Gestures my child uses to show fear	
Gestures my child uses to show hunger	
Gestures my child uses to show need for toileting	
Gestures my child uses to show _____	
Gestures my child uses to show: _____	
Gestures my child uses to show _____	



# My Child's Mobility

	Directions and Hints for Success
How my child moves about	
Tools/Equipment that help my child move about successfully	
Actions my child can take without assistance	
Activities my child needs assistance with	
Positioning information and routines	
Transfer information and routines	
<hr/> <hr/>	
<hr/> <hr/>	



## My Child's Rest and Sleep Patterns

How my child sleeps	
Tools/Equipment that help my child sleep successfully	
Rituals that help my child sleep through the night	
Security/Comfort objects that help my child sleep	
Positioning information and routines	
Medication information and schedule	
<hr/> <hr/>	
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## My Child's Social/ Play Information

How my child show's affection	
How my child show's fear	
How my child plays with other children	
My child's favorite activity with others	
What helps my child cooperate with other children	
What helps my child transition from one task to another	
My child's favorite activity with other children	
_____ _____	





# School Information



School / Preschool					
Teacher/Grade					
Days Attending	Monday AM/PM	Tuesday AM/PM	Wednesday AM/PM	Thursday AM/PM	Friday AM/PM
Address					
Phone			Fax		

School Nurse			
Phone		Fax	

Contact Person / Title			
Phone		Fax	

School Transportation Information			
Company Name		Phone	
Contact Person			
Cues for Successful Scheduling			





## Transportation for My Child

School Transportation Information			
Company Name			
Contact Person			
Cues for Successful Scheduling		Phone	Fax

Medical Appointment Transportation Information			
Company Name			
Contact Person			
Cues for Successful Scheduling		Phone	Fax

Medical Appointment Transportation Information			
Company Name			
Contact Person			
Cues for Successful Scheduling		Phone	Fax





## Early Intervention Services

County Educational Service District			
Start Date			
Contact Person			
Address			
Phone		Fax	

Family Resources Coordinator			
Start Date			
Contact Person			
Address			
Phone		Fax	

Teacher/Therapist			
Start Date			
Contact Person			
Address			
Phone		Fax	

Teacher/Therapist			
Start Date			
Contact Person			
Address			
Phone		Fax	



## Skin Concerns

Does not apply to my child

Name	Date of Birth
<p>What is the overall condition of your child's skin?</p> <p><input type="checkbox"/> good    <input type="checkbox"/> dry    <input type="checkbox"/> rashes    <input type="checkbox"/> bruises    <input type="checkbox"/> bed sores    <input type="checkbox"/> wounds</p>	
<p>How do you treat skin problems?</p> <hr/> <hr/> <hr/>	
<p>My child uses the following hair product(s):</p>	
<p>My Child uses the following skin care product(s):</p>	
<p>Other helpful items for skin care for my child</p>	



# Seizure Conditions

Does not apply to my child

Name	Date of Birth
Does your child have seizures? <input type="checkbox"/> yes <input type="checkbox"/> no If yes, please describe typical seizure activity: (frequency, duration, type of body movement, and any color changes that occur) _____ _____	
How often does your child have seizures? <input type="checkbox"/> more than 1x a day <input type="checkbox"/> weekly <input type="checkbox"/> monthly	
How do you treat a seizure that lasts longer than 5 minutes? _____ _____ _____	
What seizure medications has your child tried in the past, but is not currently taking? <input type="checkbox"/> Depakote <input type="checkbox"/> Depakene <input type="checkbox"/> Dilantin <input type="checkbox"/> Felbatol <input type="checkbox"/> Gabitril <input type="checkbox"/> Lamictal <input type="checkbox"/> Phenobarbital <input type="checkbox"/> Tegretol <input type="checkbox"/> Topiramate <input type="checkbox"/> other _____	
Does your child have a vagal nerve stimulator? <input type="checkbox"/> yes <input type="checkbox"/> no	
What diagnostic studies has your child had? (Please include date and result of study) <input type="checkbox"/> MRI _____ <input type="checkbox"/> CT Scan _____ <input type="checkbox"/> EEG _____	
Is your child currently on, or has your child ever been on, the Ketogenic Diet? <input type="checkbox"/> yes <input type="checkbox"/> no If yes, when? -----	
Does your child have a VP shunt? <input type="checkbox"/> yes <input type="checkbox"/> no If yes, what was the date of its last revision? _____	



## Sensory & Ability Information

Name		Date of Birth		
Vision	Last Date Tested	By whom	Where	
	Results if known: _____ <input type="checkbox"/> Glasses <input type="checkbox"/> Contact lens <input type="checkbox"/> Prosthesis <input type="checkbox"/> Other _____			
Hearing	Last Date Tested	By whom	Where	
	Test Type / Results : _____			
	Test Type / Results : _____ <input type="checkbox"/> Wears Aids <input type="checkbox"/> Right Ear <input type="checkbox"/> Left Ear <input type="checkbox"/> Both Ears			
Mobility / Orthotics	Brace	Type	Orthotist	
	Wheel Chair	Measured by		Last Date Measured
	Walker	Type	Orthotist	Provided by
Jacket				



Communication	<input type="checkbox"/> Computer <input type="checkbox"/> Sign Language (ASL) <input type="checkbox"/> Communication Board <input type="checkbox"/> Interpreter Services <input type="checkbox"/> Lip Reads <input type="checkbox"/> Communication Book <input type="checkbox"/> Sign Language (English) <input type="checkbox"/> Other _____
Developmental Screening	<p>At what age level is your child functioning:</p> <p>Cognitively: _____ Date Tested: _____</p> <p>By Whom: _____</p> <p>Motor: _____ Date Tested: _____</p> <p>By Whom: _____</p>
Ambulation	<input type="checkbox"/> Walks independently <input type="checkbox"/> Walks with assistance <input type="checkbox"/> Walks with walker / brace etc <input type="checkbox"/> Non-ambulatory <input type="checkbox"/> Uses wheelchair with assist <input type="checkbox"/> Motorized <input type="checkbox"/> Uses wheelchair w/o assist
Transfer Directions	<p>Transfer Directions:</p> <input type="checkbox"/> Independent <input type="checkbox"/> With assist <input type="checkbox"/> Equipment type: _____



## Equipment / Supplies

Name of Equipment			
Description of Equipment			
Details		Date Obtained	
Supplier			
Phone		Fax	

Name of Equipment			
Description of Equipment			
Details		Date Obtained	
Supplier			
Phone		Fax	

Name of Equipment			
Description of Equipment			
Details		Date Obtained	
Supplier			
Phone		Fax	

Name of Equipment			
Description of Equipment			
Details		Date Obtained	
Supplier			
Phone		Fax	





## Child Care (Respite and/or Home Care Providers)

Provider/Agency			
Schedule			
Contact Person			
Address			
Phone		Fax	

Provider/Agency			
Schedule			
Contact Person			
Address			
Phone		Fax	

Provider/Agency			
Schedule			
Contact Person			
Address			
Phone		Fax	

### Preferred Alternate Staff

Provider			
Schedule			
Contact Person			
Address			
Phone		Fax	



## Toileting (Bowel and Bladder)

Does not apply to my child

Name	Date of Birth
<ul style="list-style-type: none"> <li>• Does your child have bladder control? <span style="float: right;"><input type="checkbox"/> yes    <input type="checkbox"/> no</span></li> <li>• Does your child have a history of urinary tract infections? <span style="float: right;"><input type="checkbox"/> yes    <input type="checkbox"/> no</span></li> <li>• Does your child have bowel control? <span style="float: right;"><input type="checkbox"/> yes    <input type="checkbox"/> no</span></li> <li>• How often does your child have a bowel movement?  <span style="margin-left: 20px;"><input type="checkbox"/> daily    <input type="checkbox"/> every 2-3 days    <input type="checkbox"/> 4 days or longer</span></li> <li>• Does your child have history of constipation / impaction? <span style="float: right;"><input type="checkbox"/> yes    <input type="checkbox"/> no</span></li> <li>• Does your child suffer from diarrhea? <span style="float: right;"><input type="checkbox"/> yes    <input type="checkbox"/> no</span></li> </ul>	
<p>Does your child use laxatives? <span style="float: right;"><input type="checkbox"/> yes    <input type="checkbox"/> no</span> (Check all that apply)</p> <p style="margin-left: 40px;"> <input type="checkbox"/> colace            <input type="checkbox"/> lactulose            <input type="checkbox"/> milk of magnesia  <input type="checkbox"/> mineral oil        <input type="checkbox"/> senna    <input type="checkbox"/> miralax            <input type="checkbox"/> other _____ </p>	
<p>Does your child use suppositories or enemas? <span style="float: right;"><input type="checkbox"/> yes    <input type="checkbox"/> no</span></p> <p style="margin-left: 40px;"> <input type="checkbox"/> bisacodyl (dulcolax)        <input type="checkbox"/> saline enema        <input type="checkbox"/> phosphate enema  <input type="checkbox"/> glycerin adult? Pediatric? Or infant? (Fleets)        <input type="checkbox"/> other _____ </p>	
<p>Does your child have a toileting program? <span style="float: right;"><input type="checkbox"/> yes    <input type="checkbox"/> no</span></p> <p>If yes, please describe: _____</p> <p>_____</p> <p>_____</p>	



## Breathing Problems

Does Not Apply To My Child

Name	Date of Birth	Social Security #
<p>Does your child have a tracheotomy?    <input type="checkbox"/> Yes    <input type="checkbox"/> No</p> <p>Brand &amp; Size _____</p>		
<p>How often does your child need oxygen?    <input type="checkbox"/> never    <input type="checkbox"/> intermittently    <input type="checkbox"/> continuously</p>		
<p>Does your child have history of breathing problems?    <input type="checkbox"/> yes    <input type="checkbox"/> no</p> <p style="padding-left: 40px;"> <input type="checkbox"/> asthma                      <input type="checkbox"/> pneumonia                      <input type="checkbox"/> CF                      <input type="checkbox"/> tuberculosis         </p> <p style="padding-left: 40px;"> <input type="checkbox"/> apnea (not breathing)                      <input type="checkbox"/> other _____         </p>		
<p>Check if your child uses:</p> <p style="padding-left: 40px;"> <input type="checkbox"/> Ventilator: type _____    <input type="checkbox"/> CPAP machine    <input type="checkbox"/> monitor    <input type="checkbox"/> pulse oximeter         </p> <p>Setting information: _____</p> <p>_____</p>		
<p>What kind of breathing treatments or medications does your child require ?</p> <p style="padding-left: 40px;"> <input type="checkbox"/> Albuterol nebulizer? Or Puffs ?                      <input type="checkbox"/> suctioning                      <input type="checkbox"/> clapping (CPT)         </p> <p style="padding-left: 40px;"> <input type="checkbox"/> Intal nebulizer? Or Puffs?                      <input type="checkbox"/> mist                      <input type="checkbox"/> oxygen         </p> <p style="padding-left: 40px;"> <input type="checkbox"/> Liters                      <input type="checkbox"/> Provental nebulizer? Or Puffs?         </p> <p style="padding-left: 40px;"> <input type="checkbox"/> Pulmicort                      <input type="checkbox"/> Thairapy vest                      <input type="checkbox"/> other _____         </p>		



# Comfort / Pain

Does not apply to my child

Name	Date of Birth
Does your child have pain concerns? <input type="checkbox"/> Always(daily) <input type="checkbox"/> Often (less than daily) <input type="checkbox"/> not at all	
What would best describe your child's usual pain level? <input type="checkbox"/> mild <input type="checkbox"/> moderate <input type="checkbox"/> severe	
What do you do to resolve your child's pain? _____ _____ _____	
Does your child take medications(s) to control pain? <input type="checkbox"/> yes <input type="checkbox"/> no	
If yes, please explain: _____ _____ _____	
<input type="checkbox"/> Please refer to Medication Information Sheet for further details	
Has your child ever caused injury to self? <input type="checkbox"/> yes <input type="checkbox"/> no (Example: skin breaks, biting, hitting, etc)	
If yes, please what kind? _____ _____ _____	
What do you use / do to prevent injury? Please describe: _____ _____ _____ _____	





## Heart problems

Does not apply to my child

Name	Date of Birth
Name of Heart Condition:	
<p>Has your child had surgery for a heart problem?      <input type="checkbox"/> yes      <input type="checkbox"/> no</p> <p>Date of surgery      _____</p> <p>Did the surgery correct the problem?      <input type="checkbox"/> yes      <input type="checkbox"/> no</p>	
<p>Does your child have a pacemaker?      <input type="checkbox"/> yes      <input type="checkbox"/> no</p> <p>Does your child have/take any medications regularly for the heart?      <input type="checkbox"/> yes      <input type="checkbox"/> no</p> <p>If yes, please describe:</p> <p>_____</p> <p>_____</p> <p>_____</p>	
<p>Other information: _____</p> <p>_____</p> <p>_____</p> <p>_____</p>	





# Muscle / Bone Issues

Does not apply to my child

Name	Date of Birth
<input type="checkbox"/> spasticity (tight) <input type="checkbox"/> "floppy" <input type="checkbox"/> contractures <input type="checkbox"/> scoliosis <input type="checkbox"/> broken bones : explain _____	
Does your child have a baclofen pump? <input type="checkbox"/> yes    Si <input type="checkbox"/> no	
Has your child had orthopedic (bone) surgery? <input type="checkbox"/> yes <input type="checkbox"/> no If yes, please explain: _____ _____ _____ _____	
<b>Other Information:</b> _____ _____ _____	



## Alphabet Soup Acronym Index

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



A	
<b>AAC</b>	Alternative Augmentative Communication
<b>AAD</b>	Adaptive Assistive Devices
<b>AAMR</b>	American Association on Mental Retardation
<b>ABA</b>	Applied Behavior Analysis
<b>ABE</b>	Adult Basic Education
<b>ACB</b>	American Council of the Blind
<b>ACCH</b>	Association for the Care of Children's Health
<b>ADA</b>	Americans with Disabilities Act
<b>ADD</b>	Attention Deficit Disorder or Administration on Developmental Disabilities (Agency)
<b>ADHD</b>	Attention Deficit Hyperactivity Disorder
<b>ADM</b>	Average Daily Membership
<b>ADR</b>	Alternative Dispute Resolution
<b>AED</b>	Academy for Educational Development
<b>AFB</b>	American Federation for the Blind
<b>AFT</b>	American Federation of Teachers
<b>AIDS</b>	Acquired Immune Deficiency Syndrome
<b>AIR</b>	American Institute for Research
<b>ALJ</b>	Administrative Law Judge
<b>AOTA</b>	American Occupational Therapy Association
<b>APR</b>	Annual Performance Report
<b>APTA</b>	American Physical Therapy Association
<b>ARC</b>	Advocates for the Rights of Citizens with Developmental Disabilities and their families
<b>ARNP</b>	Advanced Registered Nurse Practitioner
<b>ASD</b>	Autism Spectrum Disorder
<b>ASDC</b>	American Society for Deaf Children
<b>ASA</b>	Autism Society of America
<b>ASHA</b>	American Speech-Language-Hearing Association
<b>ASL</b>	American Sign Language
<b>AT</b>	Assistive Technology
<b>ATA</b>	Alliance for Technology Access
<b>ATRA</b>	American Therapeutic Recreation Association
<b>AYP</b>	Adequate Yearly Progress



<b>B</b>	
<b>BASIS</b>	Basic Adult Skills Inventory System
<b>BD</b>	Behaviorally Disabled or Behavior Disorder
<b>BMP</b>	Behavior Management Plan
<b>BIA</b>	Bureau of Indian Affairs or Brain Injury Association
<b>BIAO</b>	Brain Injury Association of Oregon
<b>C</b>	
<b>CA</b>	Chronological Age
<b>CADRE</b>	Coalition for Alternative Dispute Resolution
<b>CAPD</b>	Central Auditory Processing Disorder
<b>CASA</b>	Court Appointed Special Advocate
<b>CCD</b>	Consortium for Citizens with Disabilities
<b>CD</b>	Communication Disorders
<b>CDRC</b>	Child Development and Rehabilitation Center
<b>CCN</b>	Community Connections Network
<b>CDS</b>	Communication Disorders Specialist
<b>CEC</b>	Council for Exceptional Children
<b>CFR</b>	Code of Federal Regulations
<b>CHADD</b>	Children and Adults with Attention-Deficit/Hyperactivity Disorder
<b>CIL</b>	Center for Independent Living
<b>CLE</b>	Center for Law and Education
<b>CMFC</b>	Center for Medically Fragile Children
<b>CMA</b>	Certified Medication Assistant
<b>CNA</b>	Certified Nursing Assistant
<b>COSA</b>	Confederation of Oregon School Administrators
<b>CP</b>	Cerebral Palsy
<b>CPRC</b>	Community Parent Resource Center
<b>CPS</b>	Child Protective Services
<b>CSHCN</b>	Children with Special Health Care Needs
<b>CSPD</b>	Comprehensive System of Personnel Development





<b>D</b>	
<b>DARTS</b>	Day and Residential Treatment Services
<b>DB</b>	Deaf Blind
<b>DCD</b>	Department of Community Development
<b>DCFS</b>	Division of Children and Family Services
<b>DD</b>	Developmental Delay or Developmental Disability
<b>DDD</b>	Division of Developmental Disabilities, DSHS
<b>DDPC</b>	Developmental Disabilities Planning Council
<b>DH</b>	Developmentally Handicapped
<b>DHR</b>	Department of Human Resources
<b>DHS</b>	Department of Human Services
<b>DMH</b>	Division of Mental Health
<b>DOE</b>	Department of Education
<b>DOH</b>	Department of Health
<b>DSB</b>	Department of Services for the Blind
<b>DSHS</b>	Department of Social and Health Services
<b>DSM</b>	Diagnostic and Statistical Manual of Mental Disorders
<b>DVR</b>	Division of Vocational Rehabilitation
<b>E</b>	
<b>ECEAP</b>	Early Childhood Education and Assistance Program
<b>ECSE</b>	Early Childhood Special Education
<b>ED</b>	Emotionally Disturbed
<b>EEC</b>	Education Evaluation Center (at WOU)
<b>EEG</b>	Electroencephalogram
<b>EHA</b>	Education of the Handicapped Act (now IDEA)
<b>EKG</b>	Electrocardiogram
<b>EI</b>	Early Intervention
<b>ELL</b>	English Language Learner
<b>EPSDT</b>	Early Periodic Screening, Diagnosis, and Treatment
<b>ERIC</b>	Educational Resources Information Center
<b>ESD</b>	Education Service District or Extended School Day
<b>ESEA</b>	Elementary and Secondary Education Act
<b>ESL</b>	English as a Second Language
<b>ESY</b>	Extended School Year (k – 12)
<b>EYS</b>	Extended Year Services (ECSE)
<b>F</b>	
<b>FAPE</b>	Free Appropriate Public Education
<b>FAS</b>	Fetal Alcohol Syndrome
<b>FBA</b>	Functional Behavior Assessment or Analysis
<b>FBLA</b>	Future Business Leaders of America
<b>FERPA</b>	Family Education Rights and Privacy Act
<b>FMLA</b>	Family Medical Leave Act
<b>FRC</b>	Federal Resource Center



<b>G</b>	
<b>GAPS</b>	Guardianship, Advocacy and Protective Services
<b>GED</b>	General Educational Development
<b>H</b>	
<b>HHS</b>	Health and Human Services
<b>HI</b>	Health Impaired or Hearing Impaired
<b>HKLB</b>	Healthy Kids Learn Better
<b>HMO</b>	Health Maintenance Organization
<b>HOH</b>	Hard of Hearing
<b>HS</b>	Head Start or High School
<b>HUD</b>	Housing and Urban Development



<b>I</b>	
<b>IA</b>	Instructional Assistant
<b>I &amp; R</b>	Information and Referral
<b>ICC</b>	Interagency Coordinating Council; county ICC and state ICC
<b>IDA</b>	International Dyslexia Association
<b>IDEA</b>	Individuals with Disabilities Education Act
<b>IEE</b>	Independent Educational Evaluation
<b>IEP</b>	Individualized Education Program
<b>IFSP</b>	Individualized Family Service Plan
<b>ILC</b>	Independent Living Center
<b>IQ</b>	Intelligence Quotient
<b>ISP</b>	Individual Service Plan
<b>J</b>	
<b>JRP</b>	Juvenile Rights Project
<b>JTPA</b>	Job Training and Partnership Act
<b>L</b>	
<b>LD</b>	Learning Disability
<b>LDA</b>	Learning Disabilities Association
<b>LEA</b>	Local Education Agency (school district)
<b>LEP</b>	Limited English Proficiency
<b>LICC</b>	Local Interagency Coordinating Council
<b>LICWAC</b>	Local Indian Child Welfare Advocacy Board
<b>LPN</b>	Licensed Practical Nurse
<b>LPTA</b>	Licensed Physical Therapy Assistant
<b>LRE</b>	Least Restrictive Environment
<b>M</b>	
<b>MAA</b>	Medical Assistance Administration
<b>MCH</b>	Maternal and Child Health
<b>MD</b>	Medical Doctor or Muscular Dystrophy
<b>MDA</b>	Muscular Dystrophy Association
<b>MDT</b>	Multi-Disciplinary Team
<b>MFCU</b>	Medically Fragile Children's Unit
<b>MH</b>	Multiply Handicapped
<b>MR</b>	Mentally Retarded
<b>MRI</b>	Magnetic Resonance Imaging
<b>MS</b>	Multiple Sclerosis



<b>N</b>	
<b>NAEP</b>	National Assessment of Educational Progress
<b>NAEYC</b>	National Association for the Education of Young Children
<b>NAMI</b>	National Association for the Mentally Ill
<b>NAPVI</b>	National Association for Parents of Children with Visual Impairments
<b>NASBE</b>	National Association of State Boards of Education
<b>NASDSE</b>	National Association of State Directors of Special Education
<b>NASP</b>	National Association of School Principals
<b>NCD</b>	National Council on Disability
<b>NCIL</b>	National Council on Independent Living
<b>NCPIE</b>	National Coalition for Parent Involvement in Education
<b>NCLD</b>	National Center for Learning Disabilities
<b>NDSC</b>	National Down Syndrome Congress
<b>NEA</b>	National Education Association
<b>NFB</b>	National Federation for the Blind
<b>NICU</b>	Neonatal Intensive Care Unit
<b>NICHCY</b>	National Dissemination Center for Children with Disabilities
<b>NICWA</b>	National Indian Child Welfare Association
<b>NORD</b>	National Organization for Rare Disorders
<b>NPND</b>	National Parent Network on Disabilities
<b>NPRM</b>	Notice of Proposed Rule Making
<b>NWAF</b>	Northwest Autism Foundation



<b>O</b>	
<b>O &amp; M</b>	Orientation and Mobility
<b>OAC</b>	Oregon Advocacy Center
<b>OAR</b>	Oregon Administrative Rules
<b>OCD</b>	Obsessive Compulsive Disorder
<b>OCDC</b>	Oregon Child Development Coalition
<b>OCDD</b>	Oregon Council on Developmental Disabilities
<b>OCDD</b>	Local Interagency Coordinating Council
<b>OCR</b>	Office for Civil Rights
<b>ODC</b>	Oregon Disabilities Commission
<b>ODD</b>	Oppositional Defiant Disorder
<b>ODE</b>	Oregon Department of Education
<b>OrFIRST</b>	Oregon Families Information Referral Services and Training
<b>OFM</b>	Office of Financial Management
<b>OFSN</b>	Oregon Family Support Network
<b>OHI</b>	Other Health Impaired
<b>OI</b>	Orthopedically Impaired
<b>OrPTI</b>	Oregon Parent Training and Information Center
<b>ORS</b>	Oregon Revised Statute
<b>OSB</b>	Oregon School for the Blind
<b>OSD</b>	Oregon School for the Deaf
<b>OSE</b>	Office of Special Education
<b>OSEP</b>	Office of Special Education Programs
<b>OSERS</b>	Offices of Special Education and Rehabilitative Services
<b>OSLP</b>	Office of Student Learning and Partnerships
<b>OT</b>	Occupational Therapy / Therapist
<b>OTR</b>	Licensed and Registered Occupational Therapist
<b>OVSA</b>	Oregon Very Special Arts
<b>OYA</b>	Oregon Youth Authority



<b>P</b>	
<b>P &amp; A</b>	Protection and Advocacy
<b>PASS</b>	Plan for Achieving Self Support
<b>PAVE</b>	Parents Are Vital in Education
<b>PBIS</b>	Positive Behavior Interventions and Supports
<b>PBS</b>	Positive Behavior Support
<b>PCC</b>	Providence Child Center
<b>PDD</b>	Pervasive Developmental Disorder
<b>PECS</b>	Picture Exchange
<b>PHN</b>	Public Health Nurse
<b>PIRC</b>	Parent Information and Resource Center
<b>PL</b>	Public Law
<b>PLP</b>	Present Level of Performance
<b>PNCC</b>	Providence Neurodevelopmental Center for Children
<b>PT</b>	Physical Therapy / Therapist
<b>PTA</b>	Parent Teacher Association
<b>PTI</b>	Parent Training and Information Center
<b>PTO</b>	Parent Teacher Organization
<b>R</b>	
<b>RCW</b>	Revised Code of Washington (state law)
<b>RN</b>	Registered Nurse
<b>RTI</b>	Response to Intervention



<b>S</b>	
<b>SACSE</b>	State Advisory Council for Special Education
<b>SAS</b>	Supplemental Aids and Services
<b>SAT</b>	Scholastic Aptitude Test
<b>SBD</b>	Seriously Behaviorally Disabled
<b>SCSHN</b>	Services for Children with Special Health Needs
<b>SDI</b>	Specially Designed Instruction
<b>SDS</b>	Self Directed Supports
<b>SE</b>	Special Education
<b>SEA</b>	State Education Agency
<b>SEAC</b>	Special Education Advisory Council
<b>SECC</b>	Special Education Child Count
<b>SED</b>	Serious Emotional Disturbance
<b>SEPAC</b>	Special Education Parent / Professional Advisory Council
<b>SHHH</b>	Self Help for the Hard of Hearing
<b>SIB</b>	Self Injurious Behavior
<b>SIG</b>	State Improvement Grant
<b>SLC</b>	Structured Learning Center
<b>SILP</b>	Semi Independent Living Program
<b>SLD</b>	Specific Learning Disability
<b>SLP</b>	Speech-Language Pathologist
<b>SSA</b>	Social Security Administration
<b>SSDI</b>	Social Security Disability Income
<b>SSI</b>	Supplemental Security Income
<b>SW</b>	Social Work / Worker
<b>T</b>	
<b>TAPP</b>	Technical Assistance for Parents and Professionals
<b>TASH</b>	The Association for Persons with Severe Handicaps
<b>TBI</b>	Traumatic Brain Injury
<b>TDD</b>	Telecommunication Device for the Deaf
<b>TTY</b>	Telecommunication Device for Deaf Teletypewriter
<b>U</b>	
<b>UAP</b>	University Affiliated Program
<b>UCP</b>	United Cerebral Palsy Associations
<b>V</b>	
<b>VI</b>	Visually Impaired
<b>VR</b>	Vocational Rehabilitation
<b>VSA</b>	Very Special Arts
<b>W</b>	
<b>WIC</b>	Women, Infants and Children Supplemental Food Program
<b>WISC-R</b>	Wechsler Intelligence Scale for Children Revised
<b>WRRC</b>	Western Regional Resource Center
<b>Y</b>	
<b>YLF</b>	Youth Leadership Forum
<b>YTP</b>	Youth Transition Program

