



*Jean Baton Swindells Resource Center
for Children and Families*

My Child's Life Care Notebook and Organizer

The Swindells Center

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503.215.2429
800.833.8899 x52429

Swindells Center at Medford

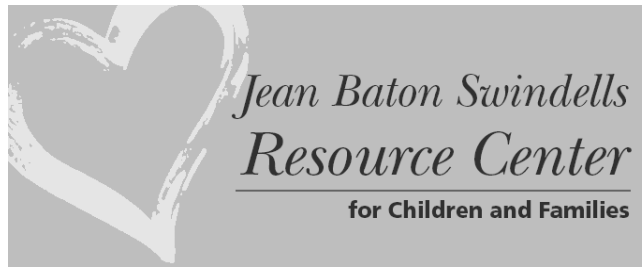
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Medford, Oregon 97504
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This Child Life Care Notebook and Organizer is free to all families of children with disabilities that reside in Oregon. It is intended to help families organize the many pieces 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?

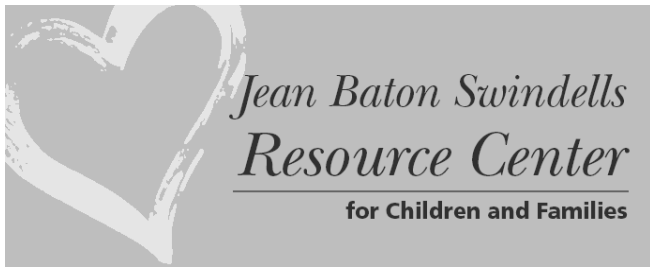
Families in Oregon may order one My Child's Life Care Notebook and Organizer per child with special needs at no cost. Families should call or email the Swindells Center and provide their name, mailing address, phone number and the item they would like to order. Telling us the name and age of your child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

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.

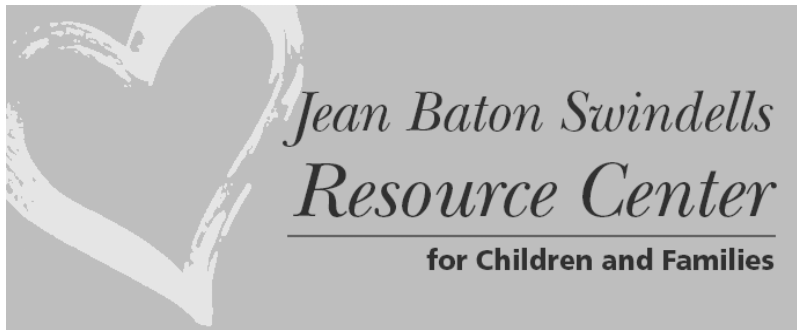
What information do you look up often?

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 1. _____ 2. _____ 3. _____ 4. _____ 5. _____ 6. _____ 7. _____						Current Physicians/Health Care Providers 1. PCP: _____ 2. _____ 3. _____ 4. _____ 5. _____ 6. _____ 7. _____					
Current Medication and Doses 1. _____ 2. _____ 3. _____ 4. _____ 5. _____ 6. _____ 7. _____ 8. _____						Allergies to Medication/Food/Things and what happens with exposure 1. _____ _____ 2. _____ _____ 3. _____ _____ 4. _____ _____					
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:



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? <input type="checkbox"/> English <input type="checkbox"/> Spanish <input type="checkbox"/> Russian <input type="checkbox"/> Vietnamese <input type="checkbox"/> Non Verbal			Interpreter Needed? <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

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



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/>	
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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"> • Does your child have bladder control? <input type="checkbox"/> yes <input type="checkbox"/> no • Does your child have a history of urinary tract infections? <input type="checkbox"/> yes <input type="checkbox"/> no • Does your child have bowel control? <input type="checkbox"/> yes <input type="checkbox"/> no • How often does your child have a bowel movement? <input type="checkbox"/> daily <input type="checkbox"/> every 2-3 days <input type="checkbox"/> 4 days or longer • Does your child have history of constipation / impaction? <input type="checkbox"/> yes <input type="checkbox"/> no • Does your child suffer from diarrhea? <input type="checkbox"/> yes <input type="checkbox"/> no 	
<p>Does your child use laxatives? <input type="checkbox"/> yes <input type="checkbox"/> no (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? <input type="checkbox"/> yes <input type="checkbox"/> no</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? <input type="checkbox"/> yes <input type="checkbox"/> no</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 & 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: _____ _____ _____ _____	
Other Information: _____ _____ _____	



Alphabet Soup Acronym Index

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



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



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





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



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



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



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



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



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



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

