



Parent Association Spotlight: Down Syndrome



Oregon is a great place to live if you have a child with Down Syndrome and want to meet others for support, encouragement, and friendship. Regardless of where you live, any of these organizations will be happy to help you connect with another parent. They provide valuable resources, connections, information and activities for families.

- ⇒ [Willamette Valley Down Syndrome Association](#)
- ⇒ [Down Syndrome Association of Southern Oregon](#)
- ⇒ [North Coast Down Syndrome Network](#)
- ⇒ [Northwest Down Syndrome Association](#)
- ⇒ [Down Syndrome Network Oregon](#)

There are a number of other support groups in Oregon who meet more informally. Call us and we can help you find one. If attending a support group isn't your cup of tea, but you would still like to talk to another parent, contact [FACT P2P](#) (888-988-FACT) and ask for a referral to a parent mentor.

FAST FACT:

Approximately 24% of children with special health care needs in Oregon who need a referral have difficulty getting it.

Learn more: www.childhealthdata.org



Contact the
[Oregon Family to Family Health Information Center](#) at
1-855-323-6744

[Stay in touch by joining our mailing list!](#)

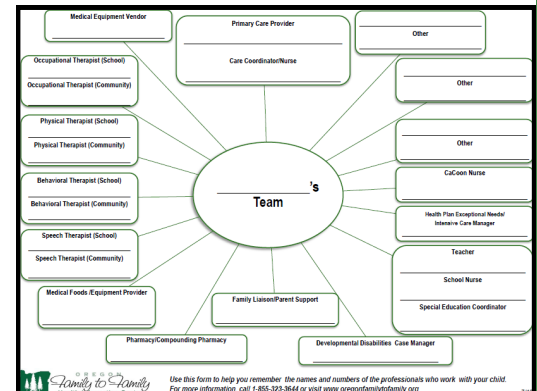
Coordinating the Team

“Who are all these people working with my child?”

Parents tell us that they get overwhelmed at times by the number of professionals that work with their children. Especially in the early years, and when a child has lots of medical needs, there can be many home visitors too. While grateful for the help, parents sometimes feel frustrated with trying to keep straight “who does what” and where they work! One parent told us, “All the home visitors were nice, but they all looked alike to me!”

So to help keep families organized, the OR F2F HIC made up a simple “map” you may find helpful. Click on the box below and you will be taken to a form that you can fill out online, print and post somewhere handy. In addition to your spouse or other caregivers in the family, think about giving one to the other members of your child’s team. If you don’t use a computer, call us at 855-323-6744 and we can mail you a printed version to fill in by hand. We can also customize this form for you, to meet your specific situation.

Use this form to record the names and numbers of the professionals who work with your child!



“Welcome to my Home...I Think”

In 1995, The Parent Connection published a wonderful essay by Sharon Burleson, of Clarksburg West Virginia. It was directed to the many home visitors in her child’s life. Here is an excerpt from that moving essay. To receive a copy of the entire article, give us a call at 855-323-3644 or email contact@oregonfamilytofamily.org

What? Oh, good grief! I forgot your paperwork again! Wait, I know it's here somewhere. I was working on it last week just after the hot water heater burst and right before my husband came home laid off. Wait... I think I wrote on the back when the bank called about the deposit to cover the overdraft. Yeah! I found them! Right behind the peanut butter ... wait, I'll just wipe them off a bit.

You know, I used to be normal. I used to have control of my life, my time, my home. Having a disabled child turned my life upside down. My priorities changed. What I would settle for changed. What I would ask for changed. Who I would accept changed. All that changed because my child needs things and people and ideas and funding. So my life consists of meetings, regulations, documentation and paperwork, social workers and agency people, policies and procedure manuals and administrative decisions, delays and rumors of delays in checks, people not showing up when needed, people quitting, and people showing up when they're not needed.

Please don't judge me. And I'll try not to judge you. You see, in the long run, if I don't measure up I still am his mother. So we're stuck with each other, and I'm willing to try to make the best of it. Help me to grow, help me to become better. Accept me as a person, not some perfect saint. I really DO know my child better than anyone else, so help me express that and put it to best use.

Treatment of Children with Mental Illness

“How do I know if my child’s problems are serious?”

“Will my child get better with time?”

“Is it a good idea to use medications?”

These questions and others like them are answered in a publication from the The National Institute of Mental Health. [You can order a free hardcopy](#) of this publication as well as detailed booklets about ADHD, Anxiety Disorders in Children, Bipolar Disorder in Children, Depression in Children, Brain Development, and Suicide.

Who to Call in Oregon:

If you feel your child is experiencing a mental health crisis, don’t wait! Contact your child’s physician and/or the mental health [crisis line in the county in which you live](#). Most crisis lines are open 24 hours a day and can guide you in getting help. You can also call the [Oregon Family Support Network](#) for more information at **1-800-323-8521**.



Alternate Newsletter Formats Available Upon Request

*Families of children with special needs who do not have internet access may receive this newsletter by mail by calling **1-855-323-6744**.*



Considerations for a Successful Healthcare Transition

Planning for transition from pediatric to adult care takes time—start early!

Independence - young adults should take responsibility for their healthcare by being able to:

- ⇒ make doctor’s appointments
- ⇒ know how to refill prescriptions
- ⇒ understand why they are taking medications
- ⇒ familiarize themselves with their medical history
- ⇒ discuss concerns collaboratively with parents and medical providers

Becoming educated is important so young adults understand their disability or health condition, and the accompanying care needs.

Self-advocacy is an important skill for young adults to master. Self-advocacy can be encouraged through:

- ⇒ modeling self-advocacy in various situations whenever possible
- ⇒ working with young adults to identify opportunities for self advocacy
- ⇒ parents, medical providers, educators, etc. should encourage young adults to understand and advocate for their needs
- ⇒ practicing it in a variety of supportive situations

Communication is the key to young adults getting their needs met by:

- ⇒ discussing future plans and goals of transition (e.g. living arrangements)
- ⇒ talking openly about health-conditions and concerns
- ⇒ exploring vocational and educational plans and opportunities
- ⇒ young adults, parents, and providers should consider needed services (e.g. personal care assistant)
- ⇒ parents and providers demonstrate how to access healthcare services (e.g. filling out insurance forms)



This advice was written by Josiah Barber and reprinted with permission from the Oregon Center for Children and Youth with Special Health Needs. For more information, or to talk with a parent about preparing youth for the transition from pediatric to adult care, call us at 855-323-6744.



Our New Favorite INTERNATIONAL Website for Parents of Children with Special Needs

www.netbuddy.org.uk

Check out this great special needs tip exchange from England! Moms and Dads write in with their most practical tips for managing special needs challenges. There is a little of everything covered, from making friends to managing menstruation. Every parent who writes in a tip is entered into a contest to win gift certificates from the UK’s equivalent of Fred Meyer! If you don’t have internet, but would like to see the tips, give us a call at 855-323-6744 and we can print them out and put in the mail.



Here is a sample tip from Emma, who writes about medicine management:



Use your mobile phone to take a photo of all the medicine bottles / packets the person you care for needs. Simple, but really useful if there’s a sudden admission to hospital or confusion in the pharmacy. You will never be stumped by the milograms per kilogram question again!

The resources on this page are not comprehensive nor does inclusion imply endorsement by the Oregon F2F HIC or the Oregon Health & Science University (OHSU). These resources are intended to be a starting point for further research. The Oregon F2F HIC is a family-led effort, funded by a grant from the Health Resources and Services Administration/Maternal and Child Health Bureau. The F2F is closely affiliated with the Oregon Center for Children and Youth with Special Health Needs (OCCYSHN), located at the Institute on Development & Disability (IDD) at OHSU.