



The Affordable Care Act

The United States Supreme Court recently upheld the ACA, but what does this mean for families of children and youth with special health care needs?

Our partners at the [Catalyst Center](#) remind us that families of children with complex health care needs risk financial hardships if they don't have good health care.

The ACA provides a "safety net" for families. Now private insurance companies may not deny or limit coverage to a child under age 19 based on a pre-existing condition. Also children up to age 26 can now stay on their parents' plans.

[Learn more](#) about what the Affordable Care Act will mean for families of children with special needs.

FAST FACT:

Among children with special health care needs in Oregon, 37% with functional limitations have health conditions that cause financial problems for their families.

Learn more:

www.childhealthdata.org



Contact the

[Oregon Family to Family Health Information Center](#) at

1-855-323-6744



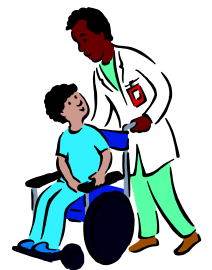
[Stay in touch by joining our mailing list!](#)

Resources and Information for Families of Children and Youth with Special Health Care Needs

Is Your Child with Special Needs a Member of Healthy Kids? *Important changes in Oregon Health Care*

Starting later this summer, Oregon Health Plan clients will have a new type of health plan. Your physical, mental, and dental health care plans will now be working together in what is being called a Coordinated Care Organization or "CCO." The changes will be "behind the scenes" and will not affect your daily care. For now, families need to know the following:

- Some OHP clients will enroll in a new plan as soon as August 1, 2012. Others will enroll September 1, October 1 or November 1, 2012.
- You will get a letter 30 days before the change takes place, but there is nothing you will need to do. The letter will include the name of your new CCO and more information about your new plan.
- Your Oregon Health Plan benefits will stay the same.
- Your doctor will stay the same.
- Your medical ID card will stay the same.



— Health Care Transition —

When your child is too old for the pediatrician...what next?

If your child is 12 or older, it is not too soon to start thinking about the future. Your child's pediatrician can work with you and your child to identify an adult provider and can develop a care plan for a smooth transition when your child turns 18. These are just a few tasks for parents and teens to consider before age 17:



- Learn about the health care funding options that are available to adults.
- Discuss your child's legal rights and responsibilities upon turning 18.
- Develop a transition plan within the IEP that includes both health and vocational goals.
- Explore SSI eligibility.
- Explore continuing education options and accommodations if required.
- Help your child understand his or her own health care needs, medications, and what to do in an emergency.
- When possible, have your child go into the examining room by him/herself to practice interacting with the doctors and nurses.

To receive more tips about transition, or to speak with a Family Liaison to coach you on what is involved, call the OR F2F HIC at 855-323-6744.



Transitioning to College or Work?

Here are just a few ideas for youth with special health needs who will be graduating soon and transitioning to college or a work program.

Needy Meds Scholarships A listing of 117 scholarships for youth with special health care needs who reside in any state.

Scholarships, Support, and More from Incight, an Oregon program that supports young individuals with disabilities to achieve their educational, employment, and independence goals.

Leadership Training and Internships from Emerging Leaders Northwest, an information and guidance center for people with disabilities aged 13–30.

No internet? Call the OR F2F HIC for this information to be mailed to you.



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.

Travel Tips from “Complex Child”

The following tips are from Chicago mom Susan Agrawal, who is the editor of the Complex Child E-Magazine. [Read the full article here](#), or call us at 1-855-323-6744 for a reprint.

It can be incredibly isolating to have a child who cannot leave home, not only for the child, but for the entire family. It takes a bit of creativity, but you can travel without ever leaving home.

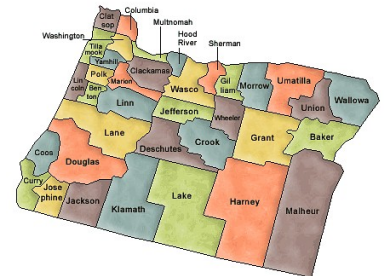
- Your child can't see the world? Bring the world to him/her with travel videos and books about places and things
- Want to take your child to the zoo? Hire an exotic pet party company to bring animals to your home for your child to pet
- Want your child to see the stars? Get a big paper box and recreate the constellations
- Want your child to hear live jazz? Call up a high school or college and ask if they would consider playing for your child
- Want your child to “go to school?” they can participate with a computer and webcam. They can sing during story time, tell a story, listen to the teacher and follow along with lessons, all from home
- Taking a day trip with your other children? Take a lot of pictures and videos to share when you get home or “bring along” your child by using a service like Skype from your smart phone.



Oregon Family to Family Health Information Center Begins Second Year of Outreach to Families

The OR F2F HIC is pleased to report that in its first year, we served over 200 individual families, 88 professionals, and participated in 70 community activities all around the state of Oregon! Over 40 parents attended the recent “Regional Family Gatherings” in the communities of Ontario, Pendleton, Enterprise, Newport, Salem, and Seaside! We shared stories and refreshments, and learned about the systems and services our kids need. Although our stories and circumstances were different, our goals are the same: to improve our kids’ futures!

We are thankful to our partners, [The Swindells Centers](#), the Family Navigators at OHSU: Carol Criswell and Laura Wilson. As well as our dedicated Family Liaisons around the state: Shelly Gilman (Ontario), Diane Dieni (Gearhart), Tracie Skinner (Coos Bay), Aaron Bowman (The Dalles), and Tami Montemayor, Dee Tafolla, and Teresa Gomez (Salem).



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 Child Development and Rehabilitation Center at OHSU.