



Got Transition?

Reaching the age of 18 presents many opportunities and challenges for young adults with or without special health needs. But for parents of teens with intellectual disabilities, this transition time may be stressful as families have questions about how their loved one will manage his or her own health care.

Questions to consider as your child's 18th birthday approaches:

- How is our child involved in making decisions about his or her own health?
- How do we find a primary care provider who understands (or is willing to learn about) our child's special needs?
- What is guardianship? what support will my young adult need to manage his or her medications or other health routines?

Some resources to get you started:

- Attend a [free webinar](#) to learn more about how youth can be involved in their own health care decisions.
- Read a family story of transition [here](#).
- Learn more about [guardianship](#).

Contact an Oregon F2F HIC Family Liaison to discuss the ins and outs of transition. Call 855-323-6744.

FAST FACT:

Nearly 30% (an estimated 35,225) of Oregon children with special health care needs have asthma.

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!**

When Insurance Won't Pay: Family to Family Ideas

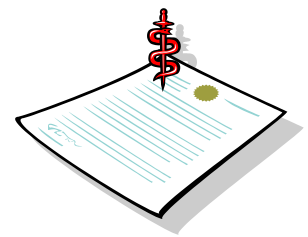
It is common for children with special needs to require services, supports, equipment, therapies, medications, and other items that are not covered by any health insurance plan or government program. Many families have used these strategies (thank you to [The Arc of Illinois](#) for many of these great ideas!):

- Ask the vendor or provider if they will offer a discounted price or rate if you pay cash.
- Find other families and share the cost of hiring a therapist for group therapy sessions.
- Check with your employer, community groups and houses of worship for local grant funding options.
- Try a personal fundraising site to raise donations from friends and family. Some sites to consider: www.youcaring.com; www.gofundme.com; gogetfunding.com; <http://www.personalpaypal.com>
- Apply for all possible government programs even if you do not think you are eligible. Many providers will offer payment on a sliding scale to families who can show a rejection letter from a government program.
- Go www.oregonhelps.org to see which programs you might be eligible for.
- Ask your child's care coordinator, home visiting nurse, therapist, or school representative about scholarships or funds they are aware of.
- Ask local high school, college, or community service clubs if they can raise funds for your child's needs as one of their community service activities.
- Ask your child's therapist if his or her professional organization has a scholarship fund you can apply for.
- Accept offers of help from friends and neighbors – make up a list of things they can help with (examples: running errands, rides to appointments, help with chores, respite, babysitting, lawn care, meal preparation, pet care, etc).
- Look into [Medical Savings Accounts](#) where you can bank pre-tax dollars for uncovered medical expenses.
- Use your local health department, Federally Qualified Health Center, or School-Based Health Center to find out if your child can receive free or low-cost immunizations, well-child care or other services.



AND...talk to your tax preparer to see if you are eligible for :

- [Oregon State tax exemption](#) for a dependent child with a disability
- [Earned Income Tax Credit](#) for your child
- [Deductions](#) for your child's out-of-pocket medical expenses



For more information, contact us at 1-855-323-6744.

Children with UNIQUE Health Conditions

www.rarediseaseday.us

Rare Disease Day is celebrated on the last day of February each year. All around the United States and the world, families of children and youth with rare conditions are doing what they can to raise awareness about rare conditions and disorders.

Oregon parents, you can join the event by:

- [View a family video](#) and submit your own!
- Share your family's [story](#).
- [Teach others](#) about what it means to have a rare disorder
- [Recommend](#) your child's physician as a rare disease expert





Your Child's Medications

Understanding Mental Health Meds:

If your child is taking medication for ADHD, Depression, or Bipolar disorder, you may wish to download the following guides, or call us at the OR F2F HIC and we will send you a copy. These guides are provided by The American Psychiatric Association, and the American Academy of Child and Adolescent Psychiatry:

- [Medication Guide for Treating ADHD](#)
- [Medication Guide for Treating Depression](#)
- [Medication Guide for Treating Bipolar Disorder in Children and Adolescents](#)

Keeping Track of Multiple Meds:

There are a number of medication systems you can use to keep track of a complex medication schedule, the parents at the Complex Child Newsletter recommend using one called My Med Schedule, which can be downloaded to your smart phone. [Read about MyMedSchedule here.](#)



How to Get Help Paying for Meds:

Many drug companies have programs that will help families pay for medications. You can often save hundreds of dollars using coupons, discount cards and free samples. One of the best resources to find these programs is www.NeedyMeds.org. If you need help finding more affordable medications, talk to your child's pediatrician, your care coordinator through the health plan, or call one of the OR F2F HIC Family Liaisons at **1-855-323-6744**

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**.*

School-Based Health Centers (SBHCs) Help all Oregon Children Get the Health Care They Deserve

A valuable (but sometimes overlooked) resource in Oregon is our network of 63 School-Based Health Centers. Last year, more than 20,000 children and youth received quality health care services at their schools. School-Based Health Centers:

- provide **quality primary health care** (physical exams, diagnosis and treatment of illness, treatment of minor injuries, and vision and dental screenings)
- are **conveniently located** in a school setting where students spend much of their day
- are **well-staffed** with a receptionist, nurse, and a clinical provider (nurse practitioner, physician assistant, or physician)- some SBHCs also have qualified mental health professionals
- provide **health education** such as obesity counseling and tobacco prevention
- can provide students with **mental health services**, such as grief therapy, help with peer pressure, bullying and suicide

SBHCs help families by:

- providing services to students **even if they cannot pay** or do not have insurance
- providing services to students immediately so parents don't have to miss work and **children don't have to miss school**

SBHCs are in 63 elementary, middle and high schools across 21 Oregon counties, and new programs will be opening in Washington, Clackamas, and Columbia Counties later this year.

To find the SBHC in your community, [click here](#), or call 503-813-6400.



In the News

One of our favorite newsletters is [Disability Scoop](#), which provides daily news of interest to the developmental disabilities community. This article is taken from their December 12, 2012 edition:

Disability Caregiving Can Be Health Hazard, Study Finds

By Shaun Heasley



Parents of children with developmental disabilities are experiencing health consequences stemming from their caregiving responsibilities, a first-of-its-kind [study](#) suggests.

For the study, researchers followed a group of 35 parents of children with developmental disabilities and a control group of 30 other moms and dads. All of the parents wore a blood pressure monitor for 24 hours and each responded to questions about themselves, their stress level, the types of behaviors their child displays and the extent of support they receive from others.

Overall parents of kids with developmental disabilities reported a higher level of perceived stress, more challenging behaviors and less social support. What's more, the parents of kids with special needs had higher blood pressure on average at all points during the 24-hour period, the study indicates.

"We found these parents, who were mostly caring for children with autism and Down's syndrome, were more stressed and had less social support had higher blood pressure than other parents," said Stephen Gallagher of the University of Limerick in Ireland who led the study. "More importantly it was reporting of lower social support that seemed to explain the higher blood pressure in these caring parents." The study is the first to directly measure and compare the blood pressure of these two groups of parents, researchers said.

Gallagher and his colleagues said the findings highlight the need for better supports for caregivers.

[Read the rest of the article here](#), or call 855-323-6744 for a reprint.