

# News and Resources

November 2021

## for Families of Children and Youth with Special Health Needs

### Smoothing the transition to adult health care

If your youth with special health care needs is approaching adulthood, Oregon Family to Family Health Information Center can help them get ready for the transition to adult health care. With [this worksheet](#), you can check in with your child's pediatric providers.

If your child's health care providers haven't brought it up by age 16 or 17, you can start the conversation with questions like:

- How will you work with us as we transition to a new provider?
- At what age must my child leave your practice and enroll with an adult provider?

A recent [study](#) showed that many Oregon caregivers are unaware of the need to transition to adult providers, leading to gaps in health care coverage.

As always, if you need more information on this topic, contact a [Parent Partner](#).

ORF2FHIC helps families of children, youth, and young adults with special health needs navigate health care and other systems. This newsletter offers up-to-date, practical information and resources. [Contact us](#) to be added to the email list.

Visit our [Facebook page](#) and [website](#). Get more information, talk to a [Parent Partner](#) or schedule a free training: [contact@oregonfamilytofamily.org](mailto:contact@oregonfamilytofamily.org)



### Parent spotlight: Tami

**Q: What have you learned from your child?**

A: Raising a child with different needs has taught me a growth mindset.

For example, at three years of age, he was very intrigued with a computer mouse. Whenever he would go to play with it, I made time for him and - using a hand-over-hand technique - taught him in just one day how to click and drag, click open, and click a window shut.

Now, at 13, he is proficient at electronics and gaming by "just figuring it out." He never ceases to amaze me.

**Q: What is your fondest hope for your child?**

A: For him to dream and follow his passions! I follow his lead now. He surpassed my expectations long ago.

# Finding and funding a service dog

Service dogs have skills to help disabled children and adults with a wide range of activities. These dogs can be trained to alert to seizures, navigate around obstacles, fetch items fallen to the floor, offer a calming presence during sensory overwhelm, and much more.

Service dogs are [not the same as support or assistance animals](#). Service dogs are specifically trained to perform certain tasks. Use of a service dog is protected by the Americans with Disabilities Act, whereas use of support animals is not.

Oregon-based [Dogs for Better Lives](#) trains hearing dogs and autism assistance dogs for children. Nationally, [4 Paws for Ability](#) trains dogs for children with a wider range of needs. [Paws With a Cause](#) trains dogs for youth age 14 and over.

It's important to consider the level of commitment required for a service dog. Wait lists can be years long, and initial fees and ongoing care can be expensive.

Fortunately, there are grant programs to help families afford a furry aide. These include [Canines for Disabled Kids](#) and the [Assistance Dog United Campaign](#).

Find [more information about service animals](#) on our website.



## Supporting siblings of children with special health care needs

Siblings of children with medical complexities have unique roles in their families, and they need special support.

The [Pediatric Palliative Care](#) Coalition and the [Courageous Parents Network](#) developed a toolkit to help parents, caregivers, and medical professionals support these siblings. [The toolkit](#) offers resources, activities, and recommended reading.

## Join the Oregon Commission on Autism Spectrum Disorder

The [Oregon Commission on Autism Spectrum Disorder](#) (OCASD) is actively recruiting professionals, family members and self-advocates for a variety of positions on the commission and its subcommittees.

OCASD's goal is to help all autistic Oregonians experience rich and fulfilling lives. Meetings are currently virtual, so phone or computer access is required. Check out the OCASD website for more information, or visit [this page](#) for details about open committee positions.

OCASD is especially interested in including more people of color, more LGBTQ+ people, and more people who live in rural Oregon.

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