

News and Resources

October 2021

for Families of Children and Youth with Special Health Needs



Parent spotlight: Maria

“I thought having a child that experienced a disability was going to mean I had to let go of my hopes and dreams I had for her before knowing her diagnosis. Instead, I learned I did not have to let go of my hopes and dreams. I learned that Down Syndrome did not define my daughter. It’s a part of her, but not all of her. She, like any other individual, has unique characteristics that define her.”

Maria is the Bilingual Programs Coordinator at [NW Disability Support](#).

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 mailing list.

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

Tips on finding the right wheelchair

October’s Table Talk is [Selecting a Pediatric Wheelchair](#)

Join us on Zoom
Tuesday, October 26
11:45 a.m.-1 p.m.

Hear about the process from experienced families and a physical therapist. Learn about things to consider when choosing a chair, and get tips and tricks from those who have recently gone through the process.

This Table Talk is also [offered in Spanish](#)
Thursday, October 21, 6-7:30 pm
Both sessions are **FREE**.

Resource for rare diseases

Get help for little-known conditions! Access supports the [Genetic and Rare Diseases Information Center](#) - or call their hotline. English and Spanish at 1-888-205-2311.

Pick the right supports for your new adult

When a child turns 18 — whether or not they have a disability — they are a legal adult with all responsibilities and freedoms.

If your young adult will need more help, there are several possible legal options. Traditional guardianship — in which a court declares a person incapacitated — may not be the only choice. Disability Rights Oregon notes there are many alternatives to guardianship, including:

- Family/community Supported Decision Making
- Advance Directives
- Declaration for Mental Health Treatment
- ISP team-appointed health care advocates
- Powers of Attorney
- Representative Payees

Read more about the options on the [Disability Rights Oregon](#) website, or at [The Arc of Oregon](#). Also check ORF2FHIC's website for [resources for those ages 18-26](#). You'll find information on housing, transition guidance, and job supports.



Recommended podcasts: “Autism in Black” and Sex Education for All with Amy Houtrow

A series by East Coast mom Maria Davis-Pierre offers intersectional information rarely found elsewhere.

[Autism in Black](#) has episodes on transitioning to adulthood, emotional regulation, homeschooling, estate planning and many other issues. Davis-Pierre is a Black mother of a daughter with autism as well as a trained mental health therapist. Her passion for working in this field stems from her personal journey with ASD when her daughter received the diagnosis at a very early age.

Also, check out an episode of the American Academy of Pediatrics podcast featuring Dr. Amy Houtrow, a pediatrician who experiences a disability and

specializes in disability issues. Houtrow says teaching children about sexual health is critical.

Houtrow notes that even children and teens who aren't able to move their muscles still have sexual thoughts and feelings. “It might be expressed differently. But it's there,” she said on [Episode 76](#).

Start the podcast at 13:25 to hear Houtrow's advice on how parents and health care providers can talk to disabled youth about sexual health and safety.

If you would like to recommend a book or podcast, email us at contact@oregonfamilytofamily.org

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