

News and Resources

September 2021

for Families of Children and Youth with Special Health Needs

School's in session! Even health care has IEP goals

Managing one's own health care is a learned skill. Good news: That means it can be included in a public school's Individual Education Plan.

Your young person can start learning the information and processes they need to be able to manage parts of their health care and advocate for themselves at the doctor's office.

Start by taking [this quiz](#) at GotTransition.org. It will break down health care into steps, like: "I know what to do when I run out of medicines" or "I can name 2-3 people who can help me... in an emergency."

Depending on the quiz results, you and your teen can then ask the IEP team to include these [new goals](#), like: "By the end of the IEP cycle, student will call their doctor or pharmacy to ask about medication refills with __% accuracy."

Help your teen take charge of their health care needs — and take some of those items off your plate. Transitioning young people with special health needs to adulthood can be complicated. Let OR F2F HIC help break it down with [more resources for transition](#) on our website.

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



Take care of yourself and others in these overwhelming times

Feeling stressed? You're not alone. The Oregon Family Support Network is hosting an online training with an expert in trauma and perseverance.

Laura van Dernoot Lipsky, founder and director of The Trauma Stewardship Institute, will coach parents through strategies to cope with stress in this age of overwhelm.

Hurry. It's Wednesday, Sept. 8 from 8:30 to 10:30 a.m.

Register [here](#) or check out <https://ofsn.org> for more details.

Juggling all the balls: A new resource for caregivers



OK, so your child has a care coordinator, or two, or five. But how do you coordinate the coordinators?

Enter [this handy form](#) from OR F2F HIC. Print off this form and fill it out to get a handle on just how many care coordinators, service coordinators, case managers, social workers and other folks there are acting as a point of contact. This could be at your child's primary care office, their specialty clinic, the insurance company, the school, any government programs, and even charity organizations.

With a single sheet as a reference guide, you can easily share your child's care network with your teams. It's also a handy reference to keep in a notebook for other caregivers, such as a spouse, grandparents or paid support. It helps when everyone can be on the same page.

Call the Oregon Family to Family Health Information Center for more information about working with care coordinators: 855-323-6744 or 503-931-8930 (Spanish).

Family Organization Spotlight: Tourette Association

Erica Gordon, co-founder of the Tourette Association of America's Oregon chapter, says the best way to combat the mainstream stigma of her daughter's syndrome is with facts.

"It's just often misunderstood," Gordon says. Tourette Syndrome is surprisingly common. The [CDC finds](#) that 1 out of every 162 children have symptoms but only half of those may have a formal diagnosis.

Also, the vast majority of those children (83 percent) have other conditions, like ADHD, OCD or anxiety. "Oftentimes the co-morbidities are more impactful than the tics in adulthood," Gordon says. She adds that finding her "village" has changed so much for her as a parent. There are already 175 families in the Oregon support group. "It's really nice to share the good, the bad, and the ugly," she says. "It feels good, too, to love people through their journey." To join the support group, email ts.salemor@gmail.com. To support the cause, like their [Facebook page](#).



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