

News and Resources

July 2021

for Families of Children and Youth with Special Health Needs

The OR F2F HIC helps families of children, youth, and young adults with special health needs navigate health care and other systems. This newsletter highlights up-to-date, practical information and resources for families and is published a few times per year. [Contact us](#) to be added to the mailing list.

Moving from Pediatric to Adult Health Care: Now what?

Turning 18 can be an unsettling time in any young person's life. But for youth with special health care needs, it can also often mean finding a whole new roster of medical professionals to replace the pediatric providers. The process can be hard, but not impossible. If your health team members don't bring up the subject of transition around ages 16 or 17, we have created a handy set of questions to help with that conversation. These six questions will get you the basic information you and your teen need in order to plan for transition at age 18. Ask your providers:

- Must we leave your care right at age 18? If not, at what age will the transfer to a new provider take place?
- Will your office make the referral to a new provider? If not, who do you recommend I call?
 - How will you work with me and my youth as we make this transition?
 - How will you work with the *new provider* when the time comes to leave your care?

Check out our [webpage](#) for many more resources and watch this short [video](#) from Nemours Children's Hospital about transition.



Parent spotlight: Amanda

Q: What does a typical day for you look like?

A: A typical day with Ollie involves food, school, people and play. He is a happy kid and uses sign language. He loves plans and so we go over the plan multiple times throughout the day. After school, Ollie likes to call a friend. He has so many friends who enjoy getting a Facetime call from him. He loves playing Wii sports or riding the bus. At night, he'll usually ask for chocolate ice cream and a short show. He is happiest when he's with 'his people.'

Q: What is one thing you wish you would have known when you received the diagnosis?

A: Looking back to when we got Ollie's first diagnosis, I really wish I had known that he would be the happiest person I know. The doctors delivered miserable news that made your stomach turn. Living past babyhood was even a question. Doing anything — ever — was a question. To see Ollie now: vibrant, strong, full of life and love... I wouldn't have worried so much if I could have seen his beautiful future self, back then. He's a light!

Oregon Kinship Navigator helps relatives raising children

In our state, there are 36,000 children being raised by grandparents or other relatives, plus another 2,787 children cared for by kinship foster parents. That's according to the Oregon Kinship Navigator, a free, bilingual resource offering support to non-parent relatives raising children.

Through [a Facebook page](#) and online support groups, OKN offers support and resources for child care, counseling, food resources, mediation, multicultural services, clothing, utility resources and more. They also help navigate Department of Human Services Child Welfare, Supplemental Nutrition Program, Oregon Health Plan and WIC. Visit oregonkinshipnavigator.org for more info.



Your input can improve PT for children with cerebral palsy

The American Physical Therapy Association wants to improve the way children and young adults with cerebral palsy (CP) experience physical therapy (PT).

Parents, caregivers and people with CP aged 18-25 are invited to fill out a survey to help write guidelines on PT treatment for improving mobility for people with CP.

The survey is for those who can stand or walk with or without devices and will take 15 – 30 minutes. Follow this link to participate or pass it on to someone you know who would be interested.

<https://redcap.link/CPMobilityCPG>

Questions: james.hedgecock@childrenscolorado.org.

This is an approved survey: COMIRB #20-29-26

Visit our [Facebook](#) page and [website](#)! For more info, free training, or to be added to our mailing list: contact@oregonfamilytofamily.org

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