

Co-Chairs and Members of the Committee.

My name is Heidi Robinson and I live in Hillsboro with my husband and 3 children, ages 13, 11 and 7. I am here to urge you to prioritize funding for Developmental Disability Services, and more specifically in Regional Family Networks.

Before you meet tomorrow as a committee to vote on funding for Regional Family Networks, I would like to share a more complete story of how Family Networks have changed and impacted my family's life.

My 11-year-old daughter, Izzy, was born with a rare genetic syndrome called Kabuki Syndrome. She experiences Intellectual and Developmental Disabilities and a wide range of health issues because of her syndrome. We moved to Oregon when Izzy was 5 from another state. When we moved, we had to transfer 11 different medical specialties, weekly Physical/Occupational/Speech/Feeding/Vision Therapy appointments, reapply for Division of Developmental Disability services with a new state, transfer Early Intervention services and prepare for Kindergarten. We knew no one and were completely overwhelmed, drowning in doctor appointments, and felt totally isolated.

Izzy's doctor at Phoenix Children's recommended that I look up our state's Family Network for support when we got settled, so it was one of the first things I did. I signed up for one of their all-day workshops called Transitioning to Kindergarten. I was given a wealth of information about IEP's, inclusive education, creating a one-page profile for Izzy's teachers and planning a vision for Izzy's future.

Our family network became my family's go-to resource. I attended workshops, used their support line and we attended their community events. They provided us with resources, helped my family build connections and taught me how to create and build a network of support in our community. Family networks work to remove barriers between the disabled community and the world around them that is not always welcoming. They taught me how to fight and remove barriers for my daughter. They offered peer-delivered support and lived experience, having walked the same journey with their children who experience disability.

It is overwhelming the spaces and places that feel unwelcome or closed to you when you experience a disability. It would be so easy for us to slip into a path of isolation, because community does not just happen for Izzy, the way it did with my boys. In so many activities and places she was not welcomed or included, or we were told she could not participate.

Our Family Support Network taught me that it was ok for me to challenge systems and people who exclude Izzy and her peers. I learned how to start conversations and work with teachers and community leaders to create rich opportunities, use imaginative supports and have Izzy's voice and dreams recognized and encouraged. In teaching me to have high expectations for Izzy, it forced me to have

high expectations of those around me. When Izzy wanted to participate in the after-school club at her school, the initial answer was no. When I asked why, I was told a SPED student had never participated in the after-school club before. And our conversation began from there: *What barriers can we remove so Izzy can participate? What does the school need to support Izzy? How can we make it happen?* In the end, it required very little adaptations for Izzy to participate and was done so easily. It merely required conversation and an open mind. My family network taught me to advocate for my daughter, to refuse to let Izzy exist on the margins because something has never been done before or because it may require more effort or a new way of thinking to find a way to include her.

Izzy is now (pre-covid) active in Girl Scouts, Activity Days (a program at her church for young girls, ages 8-12), is a member the Flying Stars Vaulting Team, a competitive horseback riding vaulting team. She swims, plays sports, takes dance classes and attends community day camps in the summer. Our family network has played a vital role in how we have fought to create a whole life for Izzy, where she is actively involved in her school and community.

Family network funding was cut last year in a special session. This lack of support for our disabled community is devastating. The family network is who I would normally turn to with questions about CDL, returning to hybrid learning, questions about accessing DD services during quarantine and more. With funding cut, our family networks have either shut down or are running on a skeleton crew and cannot support the needs of their community. It feels like someone told me I was going to be running a marathon for the next year, while carrying my 3 kids. Then, as I was about to start, they cut my legs out from under me.

Family networks are the support system for so many families and the loss is making us feel more isolated and weakened than ever before. Family Networks provide essential lifelines to Oregonians with disabilities and their families during these very uncertain times. Please fund these vital programs to ensure these vulnerable people have the supports they need when they need them.

-Heidi Robinson, Hillsboro, Oregon