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Written testimony:
February 19, 2015

To:
Joint Committee On Ways and Means
Sub-Committee On Human Services

From:
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RE:
HB 5026, Department of Human Services Budget, Developmental Disability Programs

Dear Representative Nathanson, Senator Bates, and Members of the Committee:

My name is Noelle Sisk and I am from Portland, Oregon.

I am the single mom of 3 and my oldest daughter Olivia is 11 and experiences multiple disabilities including intellectual disability. My first experience with motherhood was "normal" until week 20 in my pregnancy when on my ultra sound to find out she was a beautiful girl also showed she had brain abnormalities. The fear of the unknown was paralyzing.

After having Olivia, I struggled with isolation because of the medical needs that she required. And while well-meaning and loving people helped me and loved me- it was more than most knew how to handle. Instead of play-dates and Gymboree classes- I was at the hospital seeing specialists plus multiple therapy appointments every week. The energy, financial stress and emotional upheaval of this time were devastating.

We struggled with inclusion from the time she was born- in church, community and multiple denials from community preschools.

My connection with our Family Network was the point at which our lives changed. I received support from another parent which was exactly what I needed to change the isolation my children and I were experiencing and learned how to effectively advocate for my daughter.

I received support and education around effective advocacy and navigating special education services. Because of that support, instead of a segregated setting in school and being bussed out of her community, I was able to advocate for my daughter, Olivia, so she could attend her neighborhood school along with her siblings. This has been a life changing experience for her and she is now in the 4th grade in general education with special education support. Her education is rigorous and with high expectations. She has already said she wants to work at Starbucks and own a Mini-Cooper! She expresses this with her iPad that has communication software on it.

I worked for the FACT Family Network for 2 years and have seen first-hand, the amazing changes it brings to families, communities and children who experience disability. Because of this support I now work statewide to make sure children with disabilities receive equitable education, with high expectations and are not excluded or defined by their disability or support needs.

Meaningful support looks different for every family, but no matter what that support may look like in delivery it needs to help parents have a vision for their child's successful future as a member of their community and access a whole life, including employment and living independently.

I believe that if we want this meaningful support to be sustainable than we need to also help our communities know how to include and welcome families whose children have disabilities.

In my role working with the FACT Family Network I made relationships with the Portland Children's Museum. They have written a grant to work with the family network that includes 12 accessibility days with free admission for these families. This has included a free Holiday party for over 300 people, with Santa. This was the first time some of the families ever felt safe coming out to meet Santa. It was an understanding and non-pressuring environment with a Santa that was so kind. Seeing the families have tears in their eyes as they received their first family holiday picture was amazing. It's the beautiful ordinary things we take for granted - and when we can make these beautiful ordinary experiences, that EVERYONE should have access to, happen - it makes us realize how incredibly important this work is!

The Family Network has also done Inclusion and Disability Awareness staff trainings for Intel, Boys and Girls Clubs, School Districts, Confederation of School Administrators, Shriner's, Randall's Hospital, OHSU Students, Portland State University Students, County Developmental Disabilities Program Service Coordinators, Brokerage Personal Agents, The Oregon Home Care Commission and many more community partners.

The amazing partnership in Medford between Families for Community and Alaska Airlines continues to grow and will be hosting another flying simulation next month. This event offers families with children who would benefit from a no stress practice in flying, the opportunity to do just that. And, it provides disability training for TSA and airline employees, which has a far reaching affect.

Many of the Networks are working with YMCA's, corporations supporting Assistive Technology access like AT&T and Verizon, Parks and Rec centers to make sure they are accessible for all kids and families.

It is so important to have the opportunity to continue this work with the communities we live in. It is creating more inclusive communities that are open and accepting to everyone. All people should have an opportunity to give to and receive from the community they live in. This reciprocal relationship is what creates sustainable and strong communities.

Because of the peer to peer support I have received through our family network, from another parent walking this same journey, my daughter won't ever expect to not be included in her school, local daycare, church community or neighborhood. I cannot imagine how secluded her life would look if another parent hadn't helped me to break out of the isolation I was experiencing when I was completely disconnected from our community.

I am so thankful for this support; it has changed my life and more importantly the life of my children. Formal systems are an amazing help- but in a time when everyone is at capacity, having access to peer support to help navigate parenting a child experiencing multiple disabilities has been invaluable. Because of the Family Network support I believe my daughter will graduate with a diploma, be prepared for life-long learning and will be employed in her community and be paid competitive wages.

This is what we want for ALL people. Changing the statistics for adults with disabilities accessing a whole life, I believe, begins with supporting the families to believe this is possible and creating a vision for their child! I ask you to continue fully funding the Family Networks in Oregon; they are building empowered parents who in turn are raising empowered children who then grow up knowing they have access to whole lives as adults who experience disability. Thank you so much for your support and please feel free to contact me for any additional information or support I can offer.

Oregon Consortium of Family Networks

Supporting families to have vision for a whole life for themselves and their children, use services effectively and develop natural support in local communities.

What is OCFN?

6 Full Time Staff
15 Part Time Staff
222 Partners
516 Volunteers

Benefiting more than 7000 people

2011	2015
4 pilot locations	8 non-profit organizations

OCFN available to 75% of Oregon counties and 95% of Oregonians.

"I believe my child will...

GRADUATE WITH A DIPLOMA 72%

LIVE INDEPENDENTLY 75%

HAVE A PAYING JOB 82%

BE SAFE AND HEALTHY 95%

Source: OCFN Evaluation Report 2015

Data also shows that families who have been connected with a Family Network for at least 6 months are more likely to envision this future for their child.

Oregon Consortium of Family Networks (OCFN)

Families building community; Creating futures

Why do we need Family Networks?

Research shows that with the changing demographics of the United States, and dwindling human service budgets, our current systems of support for families with a child who experiences a developmental disability are not sustainable.

- Too few direct support workers,
- Too little funding to sustain the number of individuals with a variety of support needs,
- The reliance on families as the primary source of support is becoming the new reality. In response, it is crucial that sustainable models of support to families who have a child that experiences a disability be explored.

The Oregon Consortium of Family Networks uses public and private resources to encourage strength-based, organic networks of families that help each other and emphasize the power of natural supports in local communities.

OCFN believes that when parents connect with other parents who share a vision of possibility, and help each other find strength, they break the cycle of loneliness and isolation commonly experienced by families of children with disabilities. In turn, their children are more likely to experience a trajectory of empowerment and success within and beyond the disability community.

Who are the Family Networks?

In only four years, OCFN grew from four pilot groups to eight non-profit organizations now available to 75% of Oregon counties representing 95% of Oregonians. The Networks include:

- Central Oregon Disability Support Network (CODSN) (Deschutes, Crook and Jefferson Counties)
- Creating Opportunities (Marion, Polk and Yamhill Counties)
- Family and Community Together (FACT) Family Network (Multnomah, Clackamas and Washington Counties)
- FACT Columbia and Coastal Communities (Clatsop, Columbia, Lincoln and Tillamook Counties)
- Families Connected (Lane County)
- Families for Community (Jackson and Josephine Counties)
- Families Engaging and Thriving Together (FEATT) (Douglas County)
- Reaching Our Communities Combining Our Strength (ROCCOS) Family Network (Lake, Harney, Grant, Wheeler, Gilliam, and Morrow Counties)

Family Networks represent a viable model that uses limited resources to engage social capitol and available community resources to address unmet needs. They employ six full time staff and 15 part time staff in 26 Counties. In the last year, they have been supported by 516 volunteers and 222 community organizations to create local supports and make available resources more accessible to children and families experiencing disability.

More than 7000 Oregonians currently benefit from the Oregon Consortium of Family Networks.