To: Rep Nosse; Sen Beyer; Sen Gelser; Sen Hansell; Rep Hayden; Rep Salinas; Rep Schouten; Rep Stark; JWMHS

Exhibits; Sen Johnson; Sen Steiner Hayward; Rep Rayfield

Subject: A plea for compassion and common sense

Date: Wednesday, July 22, 2020 9:17:41 PM

### Dear Committee Members,

My name is Carolyn Martin and I'm a resident of Clackamas, OR. I understand you are considering budgetary cuts to the Oregon DD Coalition. Please do not eliminate the Family to Family Networks and Family Support program funding from the DD Services Budget. There is so much painful uncertainty everywhere right now and it would be tragic to add more stress to families who need help the most.

We're counting on all of you to find it in your hearts to support these family programs. What is this state without an investment in families?

Sincerely, Carolyn Martin

- Carolyn A. Martin, Ph.D.

"All my life I have tried to find the truth and make it beautiful." – Sting

Poetry editor, <u>Kosmos Quarterly</u>: journal for global transformation

Visit my <u>author's website</u>.

To: Rep Nosse; Sen Beyer; Sen Gelser; Sen Hansell; Rep Hayden; Rep Salinas; Rep Schouten; Rep Stark; JWMHS

Exhibits; Rep Rayfield

Cc: OregonDDC@gmail.com

Subject: Budget cuts and support services

Date: Thursday, July 23, 2020 7:44:35 AM

My Name is Camille Hewett, I live here in Eugene Oregon and have since my son was born in 2015. To make a long story short my son was diagnosed with Autism and the journey has been difficult in so many ways. Special needs children are at higher risk for injury, foster care and death. Removing these services could be disastrous and incredibly harmful, neurodivergent people but especially children NEED the extra support. Please do not eliminate the Family to Family Networks and Family Support program funding from the DD Services Budget. Families need continual access to systems of support during this pandemic and this is not the time to eliminate these programs.

Thank you and have a wonderful day. -Camille Hewett.

To: Rep Nosse; Sen Beyer; Sen Gelser; Sen Hansell; Rep Hayden; Rep Salinas; Rep Schouten; Rep Stark; JWMHS

Exhibits; Sen Johnson; Sen Steiner Hayward; Rep Rayfield

Cc: RobNosse@oregonlegislature.gov

Subject: SAVE Family to Family Networks & Family Supports Funding in DD Services Budget

**Date:** Thursday, July 23, 2020 8:19:18 AM

Attachments: OCFN 2020 Fact Sheet.png

Christian.png

Good morning, thank you for taking time to read our family's story! I am writing to you from our family home in Wilsonville Oregon in Clackamas County.

I am the wife and proud mom of 3 children 24, 19 and 15. It also so happens that my eldest son, Christian, experiences a developmental disability. Our family has personal experience with being part of our local Family to Family Network (FACT Oregon).

Before we were a part of a Family to Family Network we spent many of Christian's younger years in isolation and were stuck in "disability world". Meaning that our family spent all of our time navigating systems that included medical, therapeutic, educational, and human services and were unable to see Christian's future or help him to dream big dreams and figure out what he wanted for his future.

At 14 months old when Christian received his rare chromosome developmental disability diagnosis we were told that "most boys like your son are in institutions, take him home and love him and hope for the best".

Fast forward to today! Christian graduated high school with an extended diploma, he spent three years in his local school district transition program where he developed life skills and work skills. In the last 3 months of the transition program Christian was working part time, three days a week at a local car dealership. With the money that Christian earned at the car dealership he saved up enough money to fulfill his dream. All he talked about after graduation was going on a vacation with his family to Hawaii. He lived that dream (see picture attached). He paid for his airfare, accommodation and the activities that he wanted to do there. At 23 Christian chose to move out of our family home and into Adult Foster care, close to us. Christian is now employed part time by Levey Restaurants Inc. Prior to COVID-19 he was working at the Portland Moda Center and Providence Park where he was thriving (what 24yr old man who is sports crazy wouldn't want to watch all the Portland Trail Blazer Games and Portland Timbers games while working)? He lives in a home with three roommates that are his age and he is happy and content.

I am sharing Christian's story with you because I feel that without Family to Family Networks our family would not have had the vision for Christian. We would not have been able to understand how to support him in areas of self-determination, or teach him self-advocacy skills or how to support him as he made important life decisions that were person-centered.

As with all my children Christian has the same wants and desires of all young people his age. We are extremely grateful that the Family to Family Networks were able to bring us out of that isolated disability world that we were swirling in. Our family's life is better for it, Christian's life is better for it as we were able to support and encourage Christian to be the best he can be.

In addition to the benefits Family to Family Networks brought to Christian they also taught me, as a mother, to be a better advocate for my child and to follow my passion, leading me into the work that I now have been doing for 6 years. Advocating on behalf of all families that have a child with a disability is my passion. Telling Christian's story and inspiring other families that their son or daughter is also able to have a meaningful life, be a part of and give back to their community.

I now work for a Family to Family Network! I believe we make a difference and that we provide something case management entities can't. Peer to Peer support with shared life experience. An extended hand when the disability world is overwhelming. A grassroots approach that is localized to the needs of the family. It's not tied to procedure and forms and red tape and a system that is ever changing. It's personal and powerful. It's connecting families to resources and someone who will listen when your world feels like it is falling apart, someone who understands.

I am asking that you maintain our current funding of \$1.3 million. This will continue to support families that come along behind mine to receive the same vital vision for their son or daughter.

I have attached an info-graphic for you to review as well as a short video from other families that feel like ours about our Family to Family Networks.

https://www.youtube.com/watch?v=R-gaE0vs1dQ&feature=youtu.be&fbclid=IwAR2\_GvoqmK4-Si00Q9-NuvKCawVrFh-ILUg\_V1NhNIubi52qjp9hvB0vgl4

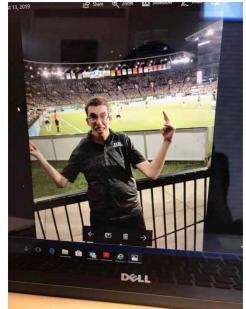
Sincerely the Cavarno Family,
Take care and stay safe,
Jenny Cavarno
Program Manager,
CODSN (Central Oregon Disability Support Network)
Office (541) 548-8559 or Cell (503) 869-4793

I work part time if you need immediate assistance or support please contact our office at 541-548-8559 or <a href="mailto:info@codsn.org">info@codsn.org</a>



Christian's Helicopter Ride. Hawaii 2018.
Dream Come True!

This is Christian he works the timbers games. After the season is over he is going to work at the Moda Center for the blazer games.



We are efficient and effective. **OCFN represents 12,250 families and 1,800 community partners** across 20 counties for an investment of \$1.3 million per biennium. Continue this investment in the resilience of families and their children's future.

In times of crisis, everyone needs their peers. Without a structure to connect families with children with disabilities to each other, they struggle to find one another. OCFN has been essential in helping families and communities work together to build a future where all people live full lives, use services effectively, and support each other.

# How is OCFN leveraging peer support during this crisis?



Maintaining connections between families virtually while supporting partners remotely



Responding to state systems' need to understand the experience of families



Identifying gaps in resources and leveraged community partners to address them



Connecting families directly with information, resources and coping strategies that work



Helping families avoid crisis through connection, training and advocacy

"I just needed another mom, to know I wasn't alone in this." - OCFN founding member

Our data\* tells us:

# 4 out of 5

Community partners feel better able to engage families with disability

# 82% of families

"Believe my child will work at a paying job"

# 86% of families

"Believe my network makes my family's life better"

# 3 out of 4

Families now feel able to focus on their child's strengths

# What have families been saying about OCFN?

"OCFN strengthens my family to build connections and supports we need to raise our children at home." "Family networks **build community capacity** to support
and welcome people and families
who experience disability."

"OCFN has helped us **refine natural supports** to live a whole life and reduce the need for paid services during COVID-19."

Maintaining our current funding of \$1.3M will allow us to continue this vital work in 20 Oregon counties.

To: Rep Nosse; Sen Beyer; JWMHS Exhibits
Subject: Central Oregon disability support funding
Date: Wednesday, July 22, 2020 7:36:59 PM

Please do not eliminate the Family to Family Networks and Family Support program funding from the DD Services Budget. Families need continual access to systems of support during this pandemic and this is not the time to eliminate these programs. Theses services are essential especially here in Central Oregon! Please do t cut their budget who helps families like mine find support for school and many more for our special kids! I am a voter, citizen, mother, and Essential worker who has to rely on these services for my child and also use them to help other families like mine. Please don't cut these important funds!

Thank you, Karina Millenheft Advocate for my child and other moms like me.

To: <u>JWMHS Exhibits</u>

Subject: Funding for Regional Family Networks in the Developmental Disabilities Services Budget

**Date:** Wednesday, July 22, 2020 4:04:55 PM

Attachments: 2019 CO Annual Update.pdf

Dear Joint Committee Members,

My name is Tahleah Clark. I am writing to ask my Legislature to continue funding current service levels for Regional Family Networks in the DD Services Budget. I sent emails last month, and I am concerned this is still on the cut list.

My husband, Timothy, and I live in Keizer with our 2 children. Our son is 8 years old, going into 3rd grade, and has Autism. Our daughter is 6 years old, going into 1st grade, and has epilepsy and a provisional Autism diagnosis. Our Regional Family Network, Creating Opportunities, has been responsive to the changing needs of families like mine, during this COVID pandemic. With their support, my family feels less isolated because we have connected with other families who understand. We connect with these families daily, and our children have video chats. This experience is priceless during these uncertain times.

Creating Opportunities Family Network has made a positive difference in my life and my family's. When we first discovered Creating Opportunities, my family was lost and isolated. We were struggling to navigate this new world after our son's autism diagnosis. After hearing about the Regional Family Network from another parent, we began signing up for several, if not all, of the training sessions, workshops, and community events offered. We were welcomed with warm open arms. We've been guided, encouraged, lifted up, and heard! We feel more comfortable being a part of our local community. We meet several families, repeatedly, at events. My children are excited to see their friends and always run into each other's arms every time they see one another. The marriage workshops have helped my husband and I strengthen our communication skills, and reassure us that we are not alone in these struggles.

We are now better equipped to navigate complex service systems. We know we can call anytime we are confused or concerned. Because of our Regional Family Network, my family is no longer in crisis, and we definitely feel a greater sense of hope about our children's futures.

We have been supported in advocating for our children at school and in the community. We've had issues with our son's IEP, and not being heard. There is nothing more powerful than an advocate by your side at an IEP meeting. Last year, our son was the victim of bullying on the playground, resulting in painful injuries. Creating Opportunities Family Network was there for us and our son. Now our son has confidence to stand up to bullying, and report bullying to an adult.

Thank you for considering what the Regional Family Support Network means to our family. I would love to discuss this with you further via a phone or video call.

I have also attached a copy of the annual update for Creating Opportunities.

Sincerely,

Tahleah Clark





## 2019 Annual Update

1,804 Regional Family Network Members 1,368 Facebook Likes



### **Connecting Families**

## **Regional Family Network Event Highlights**

Family Paint Studio Party • Valentine's Day Party • Celebrating Achievements Awards Gala Sensory Friendly Carousel • Mom's Day at Oregon Garden • Summer Swap • Miniature Golf Sharing the Weight Blanket Party • Pumpkin Patch with WVDSA & ASO Parents Night Under the Stars • Parents Night at the Planetarium • New Year Prep Party



## Strengthening Families

## **Family Training Event Highlights**

- Alternatives to Guardianship with The Arc Oregon Guardianship Advocacy & Planning Services
- Behavior Supports in Salem Keizer Schools with Salem Keizer School District
- Building Independence in the Classroom & Community with Salem Keizer School District
- Create a Color Life for Your Family
- Creating Leaders Parent Leadership Class of 2019
- Diagnosis Discussions with Providence Swindells Resource Center
- Discussions with a Doctor
- Finding Balance for Parents: Self Care and Relaxation Strategies
- Finding Hope in Moments of Crisis with Kathy Schnebly of Natural Discoveries
- How to Start a Social Club with Oregon Council on Developmental Disabilities
- Maximizing Developmental Disabilities Services with Polk County DD Services and Yamhill DD Services
- Raising a Self-Advocate with Oregon Self-Advocacy Coalition
- **RESPECT Healthy Boundaries** by Providence Swindells and Autism Society of Oregon
- Safe & Secure Symposium with The Arc Oregon, Autism Society of Oregon, Providence Swindells, Oregon Family to Family Health Information Center, Willamette Valley Down Syndrome Association, Natural Discoveries, and Oregon Family Support Network
- Sensory Strategies for Home with Providence Swindells and Willamette Valley Down Syndrome Association
- Showcase Your Student's Strengths with Dallas School District
- Strengthening Marriage While Nurturing Your Child with Special Needs Workshop
- The Power of Personal Profiles
- The Power of Words and How they Impact Children with Dallas School District
- Transition to Adulthood by FACT Oregon with Salem Keizer School District
- Transition to High School by FACT Oregon with Salem Keizer School District
- What to do if Bullying Happens with Salem Keizer School District
- Your Journey Begins with Salem Health, Natural Discoveries and Marion Polk Early Learning Hub



## 2019 Annual Update

December 30, 2019 • Page 2



# Strengthening Communities Community Building Highlights

- Presentation to Marion County Youth & Family Crisis Services
- Presentation to Oregon Family Workforce Association
- Presentation to Mental Health Clinicians
- Presented Custom Disability Awareness Training to 17 Local Librarians



# Building Collaboration Systems Advocacy Highlights

- Marion-Polk Family Resources, Support & Training (FRST) Group Coordination
- Special Education Advisory Committee Leadership for Salem-Keizer Schools and Dallas School District
- Oregon's Developmental Disabilities Services Vision Advisory Group
- Community Service Integration Team Meeting Participation
- Provided Dozens of Local Families Individual Support, Consultation and Advocacy Assistance



## **Contracted Program Coordination**

- Regional Family Network Marion, Polk & Yamhill Counties
  - Contracted by the Oregon Department of Human Services, Office of Developmental Disability Services and the Oregon Council on Developmental Disabilities to strengthen families and communities.
- **Employer Resource Connection** Clatsop, Tillamook, Lincoln, Marion, Polk, Yamhill, Linn, Benton & Lane Contracted by the Oregon Home Care Commission to offer resources to those who employ PSWs.
- GO Project Statewide
  - Contracted by the Oregon Developmental Disabilities Coalition to support legislative advocacy.
- Alliance for Early Intervention Statewide
   Contracted by the Oregon Council on Developmental Disabilities to promote advocacy for EI/ECSE services.



### **Contact Information**

- **Phone**: 503-559-0424 Voice/Text
- Email: support@creatingops.org
- Website: www.creatingops.org
- Facebook: @2CreateOpportunities
- Address: 462 17<sup>TH</sup> Street NE Salem OR 97301
- **501(c)(3)** Non-Profit Organization Tax ID: 46-5073171

To: <u>JWMHS Exhibits</u>
Subject: Consideration

**Date:** Thursday, July 23, 2020 10:30:54 AM

### Hello,

My name is Brianna Childs, and I live in Central Point. We have a 6 year old with non verbal autism.

I am writing to request that you please not eliminate the Family to Family Networks and Family Support program funding from the DD Services Budget. Families need continual access to systems of support during this pandemic and this is not the time to eliminate these programs.

As a stay at home mom to a special needs child who just entered school last year, I have utilized Family Networks to gather much needed information navigating special education. During this time of constant change due to Covid 19, I look to them even more for guidance and support, as well as the encouragement of fellow parents in my position.

Thank you for your time and consideration.

Sincerely, Brianna Childs

Sent from my iPhone

To: <u>JWMHS Exhibits</u>
Subject: DD funding

**Date:** Wednesday, July 22, 2020 7:31:29 PM

My name is Cynthia Munford and I'm from Salem Oregon. My daughter and my family depend on family support programs like Creating Opportunities. Now, more than ever, we need to provide support and connection to families.

Thank you, Cynthia

Sent from Yahoo Mail on Android

To: Rep Nosse; Rep Salinas; Sen Beyer; Sen Gelser; Sen Hansell; Rep Hayden; Rep Schouten; Rep Stark; Sen

<u>Johnson; Sen Steiner Hayward; Rep Rayfield; JWMHS Exhibits</u>

Cc: <u>Oregon Developmental Disabilities Coalition; Laura Dahill; jeffrey davis</u>

**Subject:** DD Services Budget

**Date:** Wednesday, July 22, 2020 5:58:16 PM

Dear Human Services Ways and Means Subcommittee and Chairs of the Joint Ways and Means Committee,

My name is Lesli Takasugi, and both my husband Jeffrey Davis and I live in Eugene, Oregon with our 8 year-old daughter, Mukti. We are writing to you to emphasize the importance of continuing funding for Family to Family Networks and Family Support Programs here in Oregon. As we all know first-hand, this period in our lives is filled with a high level of uncertainty, fear and stress. Each and every family is challenged in their own ways, but disability families like ours particularly depend on the support and guidance received during this time from family networks and support programs, such as Families Connected of the Arc of Lane County. This is not the time to eliminate this support for families with children who experience a disability.

On a personal level, Families Connected has allowed me to stay connected with other parents who are experiencing similar challenges during this time. We not only encourage one another, offer advice, and stay current on disability news affecting our children, but we are able to share information about resources: i.e. which doctors work safely during this time with our children, which videos help us to creatively find ways to help our children wear masks, which organizations are offering free boxes of food, where we can find responsible caregivers and tutors to help our children transition both socially and academically....the list is endless.

We cannot stress the value of these programs enough, nor of the individuals who work within them. Prior to the pandemic, I learned a great deal on how to envision a positive future for my daughter where she can be an active and contributing member of her community. Through an invaluable training program led by one of the directors of *Families Connected*, I also learned how to effectively navigate her rights during the IEP process.

We **love** our state of Oregon, and with the information and resources that are shared amongst families via these networks and support programs, Oregon is creating stronger, more informed families who care about one another. Eliminating the second year of funding for these two programs would eliminate the programs, themselves. This is not consistent with the Guiding Principles outlined in the **2020 Ways and Means Co-Chair Rebalance Plan**. Taking these programs away from us is *disabling* us in a way that affects how we raise our children, interact with other families, and contribute to our beautiful communities. My daughter is smart, funny, loving and incredibly creative. Her friends in the disability world each have similar amazing qualities.

Please continue to support the integrity of our families in how we grow, how we become more educated, confident, connected, empowered, and how we help our

children do the same. **Oregon deserves that**.

With respect and gratitude,

Lesli M. Takasugi Jeffrey Davis

To: Rep Nosse; Sen Beyer; Sen Gelser; Sen Hansell; Rep Hayden; Rep Salinas; Rep Schouten; Rep Stark; JWMHS

Exhibits; Sen Johnson; Sen Steiner Hayward; Rep Rayfield; OregonDDC@gmail.com

Subject:DD Services budget: Family to family NetworksDate:Wednesday, July 22, 2020 3:15:45 PM

My name is Tony Iannetta. I live in Oregon City and run the Good Roots Food Bank and Garden in Milwaukie.

As a grandfather of 2 special needs granddaughters I am pleading with you!

Please do not eliminate the Family to Family Networks and Family Support program funding from the DD Services Budget. Families need continual access to systems of support during this pandemic and this is not the time to eliminate these programs. Connection and support with other families have been vital in helping my Down Syndrome granddaughter's family to learn to advocate for her inclusion and the opportunity for her to reach her fullest potential. I believe this kind of support and community building will give her the best opportunity to become a productive citizen and contributor to our society. As administrator of a Food Bank affiliated with the Oregon Food Bank, I see so much need and so much pain and uncertainty on the faces of our clients. Networks like the Family to Family Networks are vital in the building of a fair, just and inclusive society.

Thanks for considering my point of view, Tony Iannetta Good Roots Food Bank and Garden

Sent from my iPhone

To: <u>JWMHS Exhibits</u>
Subject: Dds services

**Date:** Wednesday, July 22, 2020 10:37:05 PM

Hi my name is Margaret Nelson I have two special needs sons that get developmental disability services please do not cut the family support services especially in these trying times are even harder for these kids they need support now more than ever the funds for the family support services provides things like swings to help kids calm down and regulate themselves when they are overwhelmed and having to stay at home all the time is even harder for them because they don't fully understand everything going on in our world now they just know that they are even more isolated than normal so we as families of special need kids need the items they can help provide for our kids even more now like weighted vests and weighted blankets if you have never looked up anything that could help a special needs child know that if you put special needs, autism, adhd, or anything else the price is at least doubled and most families with special need kids can't afford the things that they know will help them be able to cope with all the extra stimulation and noise that's too much for them to handle for a whole day These kids thrive on routine and their routine is gone because even the things we usually do in the summer If you take away the family support funding you are sentencing these kids to even more setbacks

Sent from my iPhone

Sent from my iPhone

To: JWMHS Exhibits; Rep Nosse; Sen Beyer; Sen Gelser; Sen Hansell; Rep Hayden; Rep Salinas; Rep Schouten; Rep

Stark; Sen Johnson; Sen Steiner Hayward; Rep Rayfield

Cc: MCCORMICK Mike R; TENINTY LILIA; COMMISSION OregonDisabilities

Subject:Disability Family Support SystemDate:Thursday, July 23, 2020 1:05:48 AM

My name is Lisa Kingsley and I reside in Salem, Oregon.

I would like to request that you continue funding (even if at a reduced level) to support the regional family support programs who are critical in helping families like mine access care.

My daughter experiences severe disability. She is a young adult now who lives in a group home, has friends, enjoys spending time with her younger sister, and is looking forward to finding a job in the near future. Her future is bright and I feel optimistic about the path she is on.

Her current prospects are so bright in part due to the support we received through individual parent support, group activities with other families, support groups, and training provided by our local family support network.

I have private insurance and was not aware of the early intervention, in home care, therapy, occupational therapy supplies, and other services available to my family. In fact I was told by several agencies that there was nothing available to us.

Before we found help, my husband and I were told by a caseworker that we should give our daughter up to the state so she could get the care she needed. We were encouraged to send her to live in a facility for the rest of her life. We were told that being charged with child abandonment would be preferable to keeping her at home, and that single parents are able to get more services, so we should divorce to get her care.

After she was hospitalized for several months, a co-worker, who's child has very similar issues, helped me get in contact with a family support network that directed us to the appropriate agency and helped us get testing and assistance so we could continue caring for her at home.

Once we began getting support, we learned of a group of other parents who met and helped each other through the tough stuff and celebrate the victories (no matter how small). We learned

how to choose between different therapies, describe our needs, and ask for the help we needed. The most important things I learned were that we are not alone on this journey; how to talk about our challenges without crying; and most of all, I learned about our strength as parents, a family, and a community.

Trainings on a variety of topics from how to access care, encouraging independence, estate planning, lhow to care for ourselves and each other, hiring in home support workers and having a great working relationship with them, personal safety, accessing care, pre-planning for police and fire interventions, and more helped us use a variety of supports to not only survive, but to grow as a community.

Without the relatively small amount of funds provided to our regional family support network

and their partnership with other non-profit organizations, agencies, and families, we would not have been able to keep our daughter in our home. I can only imagine how much more costly providing housing for just her in a residential or facility program would have been than providing a reasonable amount of funds to provide regional support for my entire region. Imagine how much more it will cost to not provide these services to families across the state.

I am so thankful that they're were available when I needed them and will cheer with families all across Oregon when you direct Oregon Department of Human Services Office of Developmental Disability Services to continue these important relationships by returning funding to their budget for the family support networks.

Sincerely,

Lisa Kingsley

To: Rep Nosse; Sen Beyer; Sen Gelser; Sen Hansell; Rep Hayden; Rep Salinas; Rep Schouten; Rep Stark; JWMHS

Exhibits; Sen Johnson; Sen Steiner Hayward; Rep Rayfield; OregonDDC@gmail.com

**Subject:** Don"t cut family networks!

**Date:** Wednesday, July 22, 2020 11:11:56 PM

#### Hello,

My name is Sarah Matichuk and I live in Medford. I am writing to you today to express concern for the future of my Family Network, Bridging Communities. I have four children and our youngest has autism. Bridging Communities has provided my family the opportunity to find and navigate needed resources, develop friendships and support systems, and keep from feeling isolated – especially during this time of COVID-19.

Please do not eliminate the Family to Family Networks and Family Support Program funding from the DD Services Budget. Families need continual access to systems of support during this pandemic, and this is not the time to eliminate these programs. I am available to speak to you, should you have any questions.

Thank you for your time and consideration, Sarah Matichuk Medford, Oregon 541-499-0500

To: Rep Nosse; Sen Beyer; Sen Gelser; Sen Hansell; Rep Hayden; Rep Salinas; Rep Schouten; Rep Stark; JWMHS

Exhibits; Sen Johnson; Sen Steiner Hayward; Rep Rayfield

Cc: <u>OregonDDC@gmail.com</u>

**Subject:** essential programs for families who need support

**Date:** Thursday, July 23, 2020 9:54:01 AM

I am a pediatric occupational therapist in Portland and work with families who have children with disabilities. These families not only face the associated challenges of caring for a child with special needs, who may require near continual care, but also endure additional barriers to community engagement. Many caregivers experience financial constraints due to medical other care expenses and are frequently limited in their capacity to work due to the availability of experienced childcare services for children with special needs. Isolation is not uncommon and parents need to be able to connect with other parents with shared experiences. Social access is a social determinant of health. Parents also need to have access to equipment that makes functional participation in life more possible for their children. The Family to Family Networks and Family Support Programs have great impact on families and are so needed, especially in these challenging times we are currently all experiencing, but are likely felt much more deeply by families who are impacted by disability.

Please do not eliminate the Family to Family Networks and Family Support program funding from the DD Services Budget. Families need continual access to systems of support during this pandemic and this is not the time to eliminate these programs.

Warmly,

Sarah Reppenhagen, MS, OTR/L Pediatric Occupational Therapist Gather & Grow gatherandgrowpdx.com (503) 683-7700

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www.factoregon.org



July 20, 2020

Joint Committee On Ways and Means Subcommittee On Human Services

Co-Chair Senator Lee Beyer, Co-Chair Representative Rob Nosse, and members of the committee,

I write this afternoon as a parent of a young man experiencing intellectual/developmental disability (IDD) and as the executive director of FACT Oregon, the Office of Special Education Programs federally designated parent training and information center (PTI) for Oregon and one of ODDS funded Family to Family Networks.

FACT Oregon's mission is to empower Oregon families experiencing disability in pursuit of whole lives in their community. Through services created "by families for families," we have helped thousands of families each year navigate barriers, create a culture of inclusion, and demonstrate that a whole life is possible for their child experiencing disability. The outcome of our work is engaged families with high expectations for their child and a vision for the future, in other words, families that dream big dreams! Dreams of graduating with a diploma, earning a paycheck, and living in community.

Families know all too well the importance of living within a budget, and we fully appreciate the predicament you are in to try to support Oregon living within its budget. But with that in mind, I ask for your support for Family to Family Networks as you consider various budget reduction proposals that have been put forward when you convene in a second special session later this week. Specifically, there is a proposal that the second year of funding for the Family to Family Networks be eliminated, which would result in a savings of \$667,372. To be clear, taking a reduction of this amount at the point we are in the biennium would effectively mean that this program would be eliminated in its entirety.

Since its original funding started in 2012, Family to Family Networks have proven to be a tremendously effective resource in supporting parents and family members of individuals experiencing I/DD. Within the catchment area served by our organization alone (comprising seven counties, including Multnomah, Clackamas, Washington, Columbia, Clatsop, Tillamook and Lincoln), we serve over 8,000 families, and there are 10 Family to Family organizations in total across the state that serve over 12,250 families and almost 1800 community partners.

Many people don't realize that parents and family members are the *largest*, *least resourced/funded*, *provider* pool supporting individuals experiencing I/DD, and they typically provide this support across an individual's entire *lifespan* (birth to death). The FINDS Survey (Family & Individual Needs for Disability Community Report, 2018) found that 80% of individuals with I/DD live with a caregiver who is their family member. While an individual may be an agency or providers customer, client, or case, they are also our child, adult child or family member.

In our peer delivered support model, costing vastly less than formal supports, we ground parents in appreciation that disability is a natural part of the human condition (DD Act PL 106-402-OCT. 30, 2000) and introduce the importance of person-centered planning and self-determination – key values at the bedrock of DD services. We are the most effective and efficient way to secure that families have access to training,

resources, and support navigating one of many behemoth systems they will intersect with on their journey in disability.

While this is a general fund only program, the results it achieves in exchange for an extremely modest investment should warrant special consideration of its unique worth. Moreover, application of the following "Additional Guiding Principles" the Ways and Means Co-Chairs stated they would be using to rebalance the budget should also result in a closer look at this uniquely impactful and effective program, namely:

- 1) "Review programs and services to prevent reductions from creating or exacerbating barriers to underserved and marginalized communities and Oregonians" (individuals with disabilities and their families are consistently among the underserved and marginalized communities in Oregon).
- 2) "Evaluate programs and services for efficacy and cost-savings," (as discussed above, these programs have been proven to be extremely cost-effective and efficient).
- 3) "Evaluate and consider the long-term impact of reductions" (as stated by DHS/ODDS in its budget reduction proposal, if the Family to Family Networks are eliminated and there are no organizations that are able to refer families to community resources and supports, families are more likely to seek additional formal Medicaid funded services, which would likely be more expensive for the system in the long run).

Please see that we secure this resource for families who already do much, with so little.

Sincerely,

Roberta Dunn

Executive Director, FACT Oregon

Roberto M Dum

To: Rep Nosse; Sen Beyer; Sen Gelser; Sen Hansell; Rep Hayden; Rep Salinas; Rep Schouten; Rep Stark; JWMHS

Exhibits; Sen Steiner Hayward; Rep Rayfield

Subject: Families connected DD funding

Date: Thursday, July 23, 2020 10:57:00 AM

### Greetings:

My name is Cindy Corcoran and I have been a lane county foster parent since 2006 serving many youth! We have been honored to open our home to multiple children who have trauma and disabilities to varying degrees. We have been able to adopt five and have three biological.

We have been able to access Families Connected here for many different activities and services over the years and have been very grateful.

"Please do not eliminate the Family to Family Networks and Family Support program funding from the DD Services Budget. Families need continual access to systems of support during this pandemic and this is not the time to eliminate these programs."

Our children, weather they be foster, adopted, or bio have been able to participate inclusively with other children like them and in a way that they can be successful thanks to Families Connected.

This program, among others like it, are creating a bridge for children and adults with disabilities and is very important to our community- and world!

Cindy Corcoran

To: <u>JWMHS Exhibits</u>
Subject: Family Network

**Date:** Thursday, July 23, 2020 11:09:46 AM

### Hi,

I am Rebecca Burleigh and live in Bend, Oregon.

Please do not eliminate the Family to Family Networks and Family Support program funding from the DD Services Budget. Families need continual access to systems of support during this pandemic and this is not the time to eliminate these programs. I believe in this program personally because I see the program feeding lotos of people who would otherwise go hungry.

Thanks, Rebecca

\_\_

Rebecca Burleigh M.A.T. Certified K-8 teacher, Multiple Subjects Certified Orton-Gillingham Tutor 541-408-6029

www.abcdtutoring.org

To: Rep Nosse; Sen Beyer; Sen Gelser; Sen Hansell; Rep Hayden; Rep Salinas; Rep Schouten; Rep Stark; JWMHS

Exhibits; Sen Johnson; Sen Steiner Hayward; Rep Rayfield

Subject: Family Services and budget cuts

Date: Thursday, July 23, 2020 11:57:13 AM

Good afternoon:) My name is Teri Estes and I work for an agency that supports people with disabilities. I am asking that you please not make cuts to the Family to Family Networks and Family Support Program.

My 11 yr old niece experiences developmental delays and struggles with many sensory difficulties. She does not qualify for Medicaid. I do not know if her parents have ever accessed funding through these programs but I do know that there must be many other families who rely on them.

Please do not cut these life lines for families already struggling in these difficult times. Thank you:)

Be Well~ Teri Estes Resource and Benefits Specialist Partnerships in Community Living, Inc. estest@pclpartnership.org 503-838-2403 x 322



Expand the horizons and enhance the quality of life of those we support.

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To: <u>JWMHS Exhibits</u>

**Subject:** Family Support Networks

**Date:** Thursday, July 23, 2020 1:34:10 AM

#### Hello,

My name is Lynne Mason and I live in West Salem. I have a 16 year old son living with Down Syndrome.

I understand that you are meeting to discuss the upcoming budget for services that affect families like ours, and I want to urge you to keep the funding for our family networks. We families of people with developmental disabilities live in a world of isolation that others don't understand or see, often forgotten or overlooked. Family support networks help to keep us from slipping through the cracks, and connect us with each other so we can fight the isolation which is a big factor in most of our lives. This is especially important now during the pandemic when families in general are under extraordinary stress. We are also trying to cope without our usual supports, such as school, daycare, and support workers. The family networks are a lifeline.

Also, families know what families need. Our family has been allotted a certain number of hours per month for a personal support worker, but I struggled for years to find suitable workers to fill the position, so they often went unused (and I picked up the slack). But last year I heard about a network called Creating Opportunities with a program to teach me the fundamentals of how to hire and train a worker for my son, and I am still in that program now but it has already given me the skills I needed to hire and retain a wonderful support worker that I know I can really count on and trust. I don't know how we would have gotten through this stay at home period without her!

Who would have thought that something as simple as "boss skills" could stand between a family and their access to services? Somebody who had been there and learned the hard way. Please vote to keep on funding our family support networks.

Thank you, Lynne

Sent from my iPhone

To: <u>JWMHS Exhibits</u>

Subject: Family to Family Network Funding

Date: Wednesday, July 22, 2020 5:44:56 PM

Attachments: Outlook-ne1qnfho.png

### To Whom It May Concern,

My name is Stacy Fields, and I live in Eagle Point, Oregon with my husband and our two boys. Our youngest son, Richmond, is 8 and experiences disability. Richmond will be entering 3<sup>rd</sup> grade next year and loves to draw comic books, play Legos, and ride his scooter.

Richmond experiences autism, which can look different depending on the individual. For him, this mainly affects his communication skills. It was a long road getting that diagnosis, but he's currently doing well. Richmond is verbally communicating more than ever, and I can see that the future is bright for him.

Much of my child's success can be attributed to being connected to our Family to Family Network, which is a part of the Developmental Disabilities Services budget. Without the connections and guidance from other families in similar situations, we would have remained isolated and unaware of the services and supports available to us. Family Network has also allowed us to avoid crises by connecting with and following other families that are a few steps ahead on similar journeys. This peer to peer support has also been instrumental in helping my husband and I develop a vision for our child's future that is full of education, employment, and social opportunities. For us, Family to Family Network has reduced strains put on our family, the community, and systems in the future.

Please do not eliminate the Family to Family Networks and Family Support funding from the DD Services Budget. Families like mine need continual access to systems of support during this pandemic, and this is not the time to eliminate these programs.

For us, disability has brought diversity to our lives. We believe that disability is natural. Richmond should have the same access to the community that his brother has, and Family Network is the reason we were able to find and access that community.

Thank you for your considerations, and for your time. Feel free to contact me with any questions.

Sincerely, Stacy Fields (541) 621-2116



Subject: Family to Family Networks and Family Support Date: Thursday, July 23, 2020 11:16:10 AM

Attachments: <u>image006.png</u>

image007.png

### To whom it may concern;

My name is Olivia Duffy and I live in Portland, OR. Please do not eliminate the Family to Family Networks and Family Support program funding from the DD Services Budget. Families need continual access to systems of support during this pandemic and this is not the time to eliminate these programs.

### Family to Family Networks

The Value of Family to Family Networks:

- Reach more than 12,250 families throughout Oregon
- Provides an immediate safety net for children who fall through the cracks of formal service systems
- Families are connected with other families with shared experiences which alleviates isolation, averts crisis, builds resiliency and a positive trajectory for the child's future
- Offers an array of supports to families not available in any other part of the DD Services System
- Flexible and responsive to families, especially as many families continue to quarantine due to their children's health conditions
- See the Oregon Consortium of Family Networks Video | Fact Sheet

This is not the time to eliminate funding for Family to Family Networks when it is vital for families to stay connected to systems of support during this pandemic when they are experiencing higher degrees of isolation, fear and stress. Please keep \$665,000 in the DD Services Budget for the remainder of biennium to protect Family to Family Networks.

### Family Support Program

The Value of Family Support:

- Allows DD Services to provide a small amount of annual flexible funding for purchases of goods and/or services that benefit children with Intellectual or Developmental Disabilities who are not enrolled in Medicaid-funded DD services.
- General funds allow flexibility as has been especially helpful since COVID when the State was able to offer Expanded Family Support Funds to purchase items for the child related to their disability and the state of emergency.

This is not the time to eliminate Family Support Funding when alternate types of support are needed when especially as families are faced with additional challenges imposed by COVID. Please keep \$540,000 in the DD Services Budget for the remainder of biennium to preserve the Family Support program.

Eliminating the second year of funding for these two programs would eliminate them completely which is not in alignment with Guiding Principles outlined in the 2020 Ways & Means Co-Chair Rebalance Plan. These General Fund programs are critical to supporting families of children experiencing disability and must be preserved so that Oregon continues to be a place where families are supported to raise their children in their home.

Best wishes, Olivia Duffy Administrative Assistant Pronouns: she/her D: 503-935-5243



Click here for CPI's COVID-19 updates and resources. We're in this together.

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Rep Nosse; Sen Beyer; Sen Gelser; Sen Hansell; Rep Hayden; Rep Salinas; Rep Schouten; Rep Stark; JWMHS To:

Exhibits; Sen Johnson; Sen Steiner Hayward; Rep Rayfield

Cc: OregonDDC@gmail.com

Family to Family Networks and Family Support program funding Subject:

Thursday, July 23, 2020 10:52:58 AM Date:

image006.png Attachments: image007.png

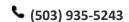
To whom it may concern;

My name is Patricia Cantlon. I live in Portland and currently work for a nonprofit supporting adults with DD.

We are living in very challenging and uncertain times. The COVID pandemic continues to impact nearly every aspect of our lives at home and in our communities. I understand that adjustments need to be made to the budget, but please do not eliminate the Family to Family Networks and Family Support program funding from the DD Services Budget. Families need continual access to systems of support during this pandemic and this is not the time to eliminate these programs.

Thank you,

Trish Cantlon **Executive Assistant** Pronouns: she/her D: (503) 935-5249













Assisting people with disabilities to live empowered, self-determined lives through community connections.

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To: Rep Nosse; Sen Beyer; Sen Gelser; Sen Hansell; Rep Hayden; Rep Salinas; Rep Schouten; Rep Stark; JWMHS

Exhibits; Sen Johnson; Sen Steiner Hayward; Rep Rayfield

Subject: Family to Family Networks are crucial Date: Wednesday, July 22, 2020 4:56:47 PM

Dear members of the Ways and Means Committee,

Just last week, I was in a Zoom meeting for Oregon parents of "Twice Exceptional" children (children with disabilities and giftedness) in which several parents remarked that the system fails to inform families about resources available to them and that they, more often than not, hear about useful supports from other families in their communities.

Thank goodness we have the Family to Family Networks! The parents in these networks volunteer their peer support, lived experience, and resources to each other. Parents in the Family to Family Networks, for example, teach each other how to advocate for school services, share the names of doctors who treat their children with respect, and offer emotional support and practical advice for supporting children with similar disability experiences.

Please fund the Family to Family Networks in the Developmental Disabilities Services Budget for the remainder of the year and biennium. I would wager that these networks more than pay for themselves in preventing crises (requiring more intensive and expensive services). A fellow parent who understands not only the joys and frustrations of learning how to best support one's child, but who is also willing to listen with generous time and heart, is invaluable to a struggling family.

As a parent who has relied on my local Family to Family Network for many needs, I request that you continue to fund this crucial service.

Thank you for your consideration and for representing all Oregonians.

Sincerely, Alexis Reed Parent and DD Behavior Professional

Alexis Reed, CPCC
Positive Behavior Consultant and Trainer
for the Developmental Disabilities Community
541-520-6241
https://alexisreed.com

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To: JWMHS Exhibits; Rep Nosse; Sen Beyer; Sen Gelser; Sen Hansell; Rep Hayden; Rep Salinas; Rep Schouten; Rep

Stark; Sen Johnson; Sen Steiner Hayward; Rep Rayfield

Subject: Family to Family Networks Funding

Date: Thursday, July 23, 2020 12:19:04 PM

My name is Patrice Qualman and my family is from Grand Ronde, OR. I understand that funding for Family to Family Networks in the DD Services Budget is under threat of being eliminated. I would like to urge you to vote no on this issue. As the parent of someone who experiences an Intellectual/Developmental Disability, having the support of a family network, even during the best of times, much less during our current pandemic crisis, is vital to our family's well-being. To have an organization like Creating Opportunities, that connects families that already feel isolated due to various disability diagnoses, offer relevant trainings, advocacy, and at times, a shoulder to lean on, is invaluable in my opinion. Please don't take this support away from a demographic that already feels under-supported.

Thank you for your time and consideration, Patrice Qualman Grand Ronde, OR

# **Testimony 7/23/2020**



My name is Noelle Sisk and I want to share with you why funding the second year of Family Networks is so important and critical to me, my family and my daughter who experiences intellectual disabilit

My daughter Olivia is 16 years old and is in highschool now.

My experiences raising her have been hard. Not because she experiences disability but because of the systems we have had to navigate and the lack of understanding of inclusion by community, schools, and places of faith.

As a baby, we were at the hospital at least 3 times a week. She was denied access to preschool from 3-5 in the community due to her disability and we were left with only ECSE.

She was told she couldn't attend her neighborhood school in kindergarten due to her disability and they wanted to bus her across town out of our neighborhood because they had services there. Because of the support I received from the family network in my area, I knew that I had

rights and was able to advocate for her to be in her neighborhood school with support there. Because of the support of our family network, she is now a sophomore in highschool in her neighborhood school. She has a full life because of how the network supported me. It is isolating raising a child with significant needs. Formal supports are wonderful but the friendship, training, and advocacy supports these networks provide, is what has supported me to be the advocate I am today for Olivia. In the formal support model parents are barraged with the deficits that their child has due to their disability, but the support the family network gives teaches parents to have high expectations, dreams and that disability is a natural part of being a human.

We are preparing for Olivia's second major surgery in a couple weeks. I am so thankful for the friends and support that our Network has provided me during this time. It is giving me the support I need to keep going when I am able to connect with other parents who have gone through this and the amazing advice, support and service they provide my family at this time.

I would like to close with my belief that supported parents raise stronger, more resilient children. This system of support is what I am relying on during this time of unexpected crisis due to Covid. Our Oregon families and children are experiencing such loss and isolation. As a parent of 4 and a school district employee I see both professionally and personally that our children with disabilities are having higher and higher levels of anxiety and depression. If you eliminate the 2nd year of Family Network funding I need you to understand that you are eliminating the program and services that these organizations provide to myself and over 12,000 families in Oregon. Please understand that these networks are more than a support group. I have learned incredible ways to advocate for my daughter Olivia that have changed the trajectory of her life. She wants to go to college, and she wants to live on her own with support and work in the community and now she is becoming an incredible advocate for herself. This is a support all our families need, especially in this time of crisis. Please do not eliminate family networks in a time when Oregon Families raising children with disabilities need them the most.

Thank you so much.

Noelle Sisk

To: Rep Nosse; Sen Beyer; Sen Gelser; Sen Hansell; Rep Hayden; Rep Salinas; Rep Schouten; Rep Stark; JWMHS

Exhibits; Sen Johnson; Sen Steiner Hayward; Rep Rayfield; OregonDDC@gmail.com

**Subject:** Funding for Family Networks

**Date:** Wednesday, July 22, 2020 9:26:23 PM

Hello, my name is Larissa Meany, and I live in Central Point. I am writing to you today to express concern for the future of my Family Network. I am the parent of a disabled child. Several years ago I went through Strong Start training provided by my local family network, Bridging Communities. This training connected me to other families with similar life experiences. It also taught me about the history of disability rights and how to effective advocate for my daughter. I have taken this knowledge and passed it on to so many other parents and families. I have also connected many families with Bridging Communities, my local Family Network. Being the parent of a disabled child can be incredibly isolating. Family Networks bring families together, provide resources and decrease isolation.

Please do not eliminate the Family to Family Networks and Family Support Program funding from the DD Services Budget. Families need continual access to systems of support during this pandemic, and this is not the time to eliminate these programs. I am available to speak to you, should you have any questions.

Thank you for your time and consideration,

NAME Larissa Meany

**CITY Central Point** 

PHONE # 541-261-5259

To: Rep Nosse; Sen Beyer; Sen Gelser; Sen Hansell; Rep Hayden; Rep Salinas; Rep Schouten; Rep Stark; JWMHS

Exhibits; Rep Rayfield

 Cc:
 OregonDDC@gmail.com

 Subject:
 Funding for Family Supports

**Date:** Wednesday, July 22, 2020 3:57:50 PM

## Hello,

First, I would like to begin with a warm thank you for taking time to read my email. I know time is valuable and like me, your to do list is probably way too long. So, I will do my best to keep it short and sweet.

Second, I truly appreciate that you recognize how important parent feedback is. I am a mother of three wonderful, active, and loving boys. My name is Lacey Leppo and I live in Eugene.

Now this is where things get serious. We love our community and also depend on the resources it has to offer. In fact it was a large part of why we moved our family to Lane County seven years ago. Our older two boys face life with challenges that make inclusion difficult. The programs at stake of being cut, provide opportunities for inclusion and commodity not otherwise found in the community. Having supports that understand the complex needs of the families they are supporting, is critical for the well being of parents and their kids. Our families need our support systems to survive, thrive, and everything in between. They are the stitching holding our lives together by threads.

So, I ask of you, please do not eliminate the Family to Family Networks and Family Support program funding from the DD Services Budget. Families need continual access to systems of support during this pandemic and this is not the time to eliminate these programs.

We need more supports, not less.

And again, thank you for your time.

Kindly,

Lacey Leppo

To: JWMHS Exhibits; Rep Nosse; Sen Beyer; Sen Gelser; Sen Hansell; Rep Hayden; Rep Salinas; Rep Schouten; Rep

Stark; Sen Johnson; Sen Steiner Hayward; Rep Rayfield

Subject: Funding for Family to Family Networks

Date: Thursday, July 23, 2020 6:47:03 AM

## Good morning legislators:

I am Keith A White, MD from Salem, OR. I am writing to ask you to please continue funding for Family to Family Networks in the DD budget. This is especially important that this is not the time (if ever) to consider reducing or eliminating this funding. Creating Opportunities of Salem, a Family to Family network has been instrumental in educating me and helping me provide for my 21 year old son, Ryan, who has been completely disabled since birth by a congential brain deformity.

Before my contact with Creating Opportunities I was lost and confused about securing public benefits, trust accounts and bank accounts available from the State of Oregon and the federal government for my helpless son. Through the information, guidance, special programs and referrals made by Creating Opportunities I have now been successful, as have the many other families that I have seen, at securing public and private benefits and special trust and banking accounts to protect my son's future. I could expand on this with several examples, but I respect your limited time. I would be willing to do so at your request.

Sincerly,

Keith A White, MD Family Physician

To: JWMHS Exhibits; Rep Nosse; Sen Beyer; Sen Gelser; Sen Hansell; Rep Hayden; Rep Salinas; Rep Schouten; Rep

Stark; Sen Johnson; Sen Steiner Hayward; Rep Rayfield

**Subject:** Funding for Family to Family networks in DD budget

**Date:** Tuesday, July 28, 2020 12:13:25 PM

I understand the pandemic has pushed our economy into a recession and there is much in the future that is unknown. I am asking that you **do not** eliminate funding for the <u>Regional Family Networks</u> in the <u>DD budget</u>.

I have worked in the Marion County Disability Community for 38 years and you can believe me when I say we need this program. I am currently a board member for the Marion, Polk and Yamhill County Family network, Creating Opportunities, who has over 1800 members who are supported or provide support to our local families that no other agency does or can provide. Because of our flexible funding we have been able to continue our services during this pandemic with modifications.

I joined this board because I was employed at the EasterSeals Children's Therapy Center when it closed and heard first hand from families how their support and services had once again been taken away, reduced or scattered and how there was nowhere for the families to go that understood the stress and problems their family live with daily with no rest.

Then <u>Creating Opportunities</u> arrived and families once again know they have support and understanding that is not tied to a disability service but to a group of people who truly understand their needs because <u>Creating Opportunity staff</u> are parents of special needs children too. The work this agency does for our local families is outstanding and needed now more than ever as many families are currently unable to access needed support and services. We need your help to continue these services during this pandemic and the recovery process.

We need this program to provide families with knowledge and support to keep their special needs child in the family home even in crisis, to save state money but also save the families so they can continue to provide care.

We need this program to help families whose child would otherwise fall through the cracks as he is just no disabled enough to meet criteria but is not succeeding at home or school or in the community.

And we need this program to help other agencies provide better communication and services to our families.

With the family network everyone wins: families, children, agencies and the budget.

Thank you for your time and consideration. Please call if you have questions.

## **Kathy Schnebly CTRS**

Movement Consultant Developmental Disability Trainer Keizer, Oregon 503-678-0200

The world in which I was born is just one model of reality.

Other people (cultures, religions, abilities, Sexuality race) are not failed attempts at being me.

But rather another unique manifestation of the human experience

From: To:

JWMHS Exhibits; Rep Nosse; Sen Beyer; Sen Gelser; Sen Hansell; Rep Hayden; Rep Salinas; Rep Schouten; Rep Stark; Sen Johnson; Sen Steiner Hayward; Rep Rayfield

Subject: Funding for Family to Family Networks

Date: Wednesday, July 22, 2020 8:32:44 PM

Hello, my name is Laurie Erickson. I work with Oregon Family Support Network. I provide support to families who have a child in crisis or a parent who is overwhelmed by the complex needs of their child. I am also the parent of a child who was once in crisis. My son who is a young adult now, lives with autism, ADHD, psychosis (schizophrenia), food allergies and a hernia in his esophagus. My son started seeing his "imaginary friends" by the time he was 7. At the same time he started vacillating between homicide and suicide, this would last until he was 13. At least twice he made plans to kill another student at school. I worked tirelessly to ensure my son did not hurt another child or himself and today he has a group of friends, he occasionally dates, and he is slowly working on developing his adult life skills; an accomplishment that I used to fear would never happen. I know two young children, from different families, whose primary diagnoses are identical to my son, living here in Salem. My son is not alone.

Professionally I have worked with scores of families whose children were suicidal and/or homicidal. I realize the pandemic is a deeply troubling time across the world and our state. If people like me are not funded to help families in crisis, several things are likely to happen. First, the number of families involved with police will probably go up. Children tend to act out more when they are in crisis and parents are more easily overwhelmed to start with, having to address schooling and sometimes job loss along with social distancing issues. Addressing the needs of a child already social-distancing and lonely, then adding self harm and/or suicidal ideation, this crisis can be too much for parents. This increases the likelihood that more families will be separated, putting some children in foster care. This will create a greater financial burden on the State of Oregon. Other children may end up in juvenile detention, find themselves in and out of mental health institutions, running the risk of being exposed to Covid19 or they may complete suicide. I think all of these paths create an even greater burden for not only the families, but for the community and for the State of Oregon.

First, let's be practical, all of these choices will cost the same and probably more money than it would cost to continue to support families. Second, once a child completes suicide their friends and aquaintences are more likely to attempt to follow in their friends footsteps. Suicide is deeply traumatic and has a deep, depressing impact on the survivors, who can include more than just family. We need to protect our children, all children. When I am old, and need to be cared for, the children of today will be responsible for that care. I want them to think of my care as a priority, but I don't expect that to happen if their care is not a priority today and in the near future. What kind of citizens do we want? I implore you, as an advocate, for more than 20 years, and as the mother of a survivor; PLEASE do NOT cut funding. Thank you for your time and consideration in this matter.

Sincerely, Laurie Erickson

Laurie Erickson--pronouns, she, her, hers Family Support Partner-Marion County Oregon Family Support Network 4275 Commercial St. SE Suite 180 Salem, OR 97302

Direct Line: 503-302-9290 Office: 503-363-8068 Fax: 503-390-3161

Practice does not always make perfect, often times, practice makes progress. Sometimes this progress comes in tiny movements forward. Tiny movements are still acts of moving, and they matter.





----- Forwarded message ------

From: rae lyn jones

Date: Thu, Jul 23, 2020 at 12:35 PM

Subject: Letter
To: Catherine Myers
Cc: Sarah Owens

Hello,

My name is Rae Lyn Jones from West Linn, Oregon. My 11 year old son, Liam has a profound disability and is medically fragile. We depend upon the funds available through Family to Family Networks and Family Support program funding from the DD Services Budget to help supplement the care needed to keep our disabled son and our family healthy. Our son Liam requires 100% assistance accessing all activities of daily living.

As Liam's mother, I am his primary care provider. Without this extra funding the added burden of care put on myself could easily compromise my ability to provide an appropriate level of care as well as compromise my own health. If I were unable to provide care then the cost of care for Liam would significantly increase, not to mention the emotional cost to everyone in the family. Cutting these funds that have proven to be a lifeline for families such as mine during a pandemic would have detrimental results. My family has depended on these services, more now than ever so we can continue to keep our son safe and our family safe.

Budget cuts against vulnerable populations-people with disabilities causes them to experience less full lives, which social institutions then offer as a reason for making the further decision to deny these already-disadvantaged, vulnerable individuals essential benefits. Please don't reduce funding and remove this essential and necessary means that keeps our family safe.

Kind regards,

Rae Lyn Jones



To: Rep Nosse; Sen Beyer; Sen Gelser; Sen Hansell; Rep Hayden; Rep Salinas; Rep Schouten; Rep Stark; JWMHS

Exhibits; Sen Johnson; Sen Steiner Hayward; Rep Rayfield; OregonDDC@gmail.com

Subject:DD Services budget: Family to family NetworksDate:Wednesday, July 22, 2020 3:15:45 PM

My name is Tony Iannetta. I live in Oregon City and run the Good Roots Food Bank and Garden in Milwaukie.

As a grandfather of 2 special needs granddaughters I am pleading with you!

Please do not eliminate the Family to Family Networks and Family Support program funding from the DD Services Budget. Families need continual access to systems of support during this pandemic and this is not the time to eliminate these programs. Connection and support with other families have been vital in helping my Down Syndrome granddaughter's family to learn to advocate for her inclusion and the opportunity for her to reach her fullest potential. I believe this kind of support and community building will give her the best opportunity to become a productive citizen and contributor to our society. As administrator of a Food Bank affiliated with the Oregon Food Bank, I see so much need and so much pain and uncertainty on the faces of our clients. Networks like the Family to Family Networks are vital in the building of a fair, just and inclusive society.

Thanks for considering my point of view, Tony Iannetta Good Roots Food Bank and Garden

Sent from my iPhone

To: Rep Nosse; Sen Beyer; Sen Gelser; Sen Hansell; Rep Hayden; Rep Salinas; Rep Schouten; Rep Stark; JWMHS

Exhibits; Sen Johnson; Sen Steiner Hayward; Rep Rayfield; OregonDDC@gmail.com

Subject: DD Services Budget: Family to Family Networks funding

**Date:** Wednesday, July 22, 2020 3:25:23 PM

My name is Wendy lannetta and I live in Oregon City, Oregon. I have a granddaughter with Down syndrome and I am concerned about the Family to Family Network funding being eliminated from the DD Services budget.

My daughter and granddaughter have benefited greatly from the support and connection they have had over the years by being able to connect to other families navigating disability and having support. Particularly at this time of living through a pandemic where my granddaughter is one of the most vulnerable, the support my daughter receives is essential in helping her navigate her difficult life circumstances with other families experiencing the same situation. I know that you face difficult choices in where to make cuts in the budget, this is NOT an area that should be considered to be removed, too many vulnerable people will be hurt by eliminating the Family to Family Network. These families are already in an uphill climb in life, please protect their connection and support with others facing obstacles for their children and their families. Isolation and stress are daily struggles for these families, and the current state of our country and the world have multiplied their fears for the future of their children. Family to Family networks are an essential source of information, connection and community building for my daughter and her family. I hate to think of her and so many others being left to cope without the support that they get from this community.

Please consider keeping \$665,000 in the DD Services Budget for the remainder of biennium to protect Family to Family Networks!

Thank you for your time,

Wendy lannetta 503-806-3514 From: To:

Subject: Keep Regional Family to Family Network Funding!

**Date:** Thursday, July 23, 2020 9:04:18 AM

## Good Morning!

My name is James Bennett and I am a Service Team Coordinator with Partnerships in Community Living, Inc. (PCL), a large non-profit organization that serves people who are intellectually and developmentally diverse. I live in Corvallis and work in the Marion, Polk, Linn, and Benton Counties. This is a crucial time for families to stay connected with their local resources during this pandemic as the capacity for provider organizations like PCL with Direct Support Professionals (DSPs) and Personal Support Workers (PSWs) are limited.

When interviewing families who are interested in supports, I frequently see how families are struggling and do not have a starting point and do not understand how to be an Employer of Record and hire their own workers what the process is like, and what tools to use. The funding for Regional Family Networks provides this individualized time and tailored tools for families to learn and feel confident about their knowledge of the systems we work within as well as how to manage supports for their family.

I strongly encourage you to support the Regional Family to Family Network funding so people we support and their families will continue to receive great quality supports and resources during this difficult time.

Thank you for your consideration.

Best.

James Bennett, MSW Service Team Coordinator with PCL

James Bennett, MSW
Service Team Coordinator
Individualized Services (Youth Transition/Tapestry Outreach)
Partnerships In Community Living, Inc.

Work: (503) 569-7541



Expand the Horizons and Enhance the Quality of Life of Those We Support.

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To: Rep Nosse; Sen Beyer; Sen Gelser; Sen Hansell; Rep Hayden; Rep Salinas; Rep Schouten; Rep Stark; JWMHS

Exhibits; Sen Johnson; Sen Steiner Hayward; Rep Rayfield

**Date:** Wednesday, July 22, 2020 8:27:26 PM

## Dear Representatives and Senators:

My name is J.R. Estes and I am the mother of an amazing 11-year old whose medical diagnosis causes significant developmental delay. I am also a University professor and researcher dedicated to improving public policy. I am writing my first advocacy letter because eliminating the Family to Family Networks and Family Support Program funding from the Developmental Disabilities Services Budget would be regressive and cause harm to our state's most vulnerable citizens. This would be its effect if we were not in the middle of a pandemic.

Once schools closed in March, my daughter's educational aid disappeared and we still have not received communication from the Special Education Department of Portland Public Schools about where that support went. However, I did receive information from my area Family to Family Network, FACT (Families and Community Together), within the week summarizing the Oregon Department of Education's decisions as well as a resource sheet followed by regular updates and relevant webinars.

Growing up here and working in higher education the last 15 years, I know worthy programs are regularly pitted against each other. What is different about these programs is that for a relatively small investment, the relational family-to-family model creates social benefits impossible to measure because each educated and supported family/community member then shares that with another, and so on, and so on. Family to Family Networks and our state's other Family Support programs epitomize the concept of a public good. They are a shared expense among many that has a benefit to us all.

This is the paragraph where I share a personal anecdote of how our daughter and family have benefited from FACT. I wish I could distill the profound difference FACT resources and programming makes in our lives into one example, but I can't. Because without the parent education and support that FACT and related family support programs provide, I can't imagine how we would have remained a family.

Please follow the guiding principles of the 2020 Ways & Means Co-Chair Rebalancing Plan and continue to support these essential and effective services.

Sincerely,

J.R. Estes, Ph.D.

Associate Professor





4275 Commercial St. SE, Ste. #180 | Salem, OR 97302 503 363 8068 | admins@ofsn.org http://ofsn.org | Twitter; @OregonFSN | Like us on Facebook! www.reachoutoregon.org | 1 833 REACH-OR

July 27, 2020

Co-Chair - Senator Elizabeth Steiner Hayward Co-Chair - Senator Betsy Johnson Co-Chair - Representative Dan Rayfield Members of the Joint Ways & Means Committee

RE: JWM Budget Reduction Detail List

Dear Co Chairs Senator Flizabeth Steiner Hayward, Senator Betsy Johnson, Representative Dan Rayfield, and members of the Joint Ways & Means Committee.

I am writing to request that Ways and Means restore funding to items. No 119 and 120 in the Joint Ways and Means Budget Reduction Detail List, under DHS, Developmental Disablities.

These particular items are related to Family Networks and Family Supports in the Developmental Disabilities system for children and families.

Oregon's Family Networks and related family support services are often a lifeline to families when we don't have the added burden of COVID-19 and its impacts to all Oregon families. However, now their support and services are needed more than ever.

As the Executive Director of Oregon Family Support Network, I am deeply concerned around the idea of cutting family supports at any level, especially during the COVID-19 pandemic. As a 501(c)3, Oregon Family Support Network has been providing family support services for over 25 years for parents raising children and youth experiencing complex mental health needs. We know first-hand what a lifeline family support can be for parents. Oregon Family Support Network has served thousands of families across the state. The role and value of parent/family support being provided by those with lived experience has demonstrated added value in any system where these supports have been engaged. As an example:

- 1. Parents have direct access to in person/or virtual support in real time.
- Parents are able to receive support and information from parents who have an understanding
  of their experience often times being a few steps ahead in their own journey, enough to coach
  and assist others in accessing the right services and supports.
- 3. Having family support that allows parents to connect with one another around their experiences and needs has proven to be so valuable, especially now when the COVID 19 pandemic has made finding information about resources even more challenging. Family Networks are often able to stay on top of changes in resources that are available, and can quickly inform a community of families about those changes and help them navigate what they are needing.

The Family Networks slated for cuts in the Joint Ways and Means Budget Reduction Detail List Section: DHS/Developmental Disabilities on p. 11, items 119 and 120, will leave a significant gap in the system that thousands of families throughout the state rely on for the very type of support and information described above, plus so much more.

This is not the time to defund these services. In fact, families who engage with the Family Networks are really hurting right now. They are struggling with housing, employment/unemployment, food security, childcare, and adapting to online school with children and youth who have significant needs. When considering these added stresses and strains while caring for a child or youth experiencing significant disabilities, this becomes the most inopportune time to even consider such cuts.

Oregon Family Support Network values the very services and resources available to families because of the work being done by the Family Networks. We ask the Committee to reconsider these cuts and give families something to hang onto right now.

Let families raising children with disabilities know that you are truly there for them and are committed to supporting their needs even through these difficult times.

Please restore line item 119 and 120 in the Joint Ways and Means Budget.

Sincerely,

Sandy Bumpus, Executive Director

To: JWMHS Exhibits; Rep Nosse; Sen Beyer; Sen Gelser; Sen Hansell; Rep Hayden; Rep Salinas; Rep Schouten; Rep

Stark; Sen Johnson; Sen Steiner Hayward; Rep Rayfield

Subject: Family to Family Networks in the DD services budget - Please save funding and do not eliminate them!

**Date:** Thursday, July 23, 2020 8:26:26 AM

Hello, my name is Alec Hansen, and I live in Redmond, Oregon. I am writing to you today to express concern for the future of my Family Network. Our family has been connected to the Central Oregon Disability Support Network(our local family network) since its inception. Our Family Network has provided our family the opportunity to find and navigate needed resources, trainings on how to help our daughter live a full meaningful life in her community, connect with other families so we are not so isolated – especially during this time of Covid-19. This program has been a lifeline for our family!!

Please do not eliminate the Family to Family Networks and Family Support Program funding from the DD Services Budget. Families need continual access to systems of support during this pandemic, and this is not the time to eliminate these programs. I am available to speak to you, should you have any questions.

Thank you for your time and consideration,

Alec Hansen (Victoria's Dad) Redmond, Oregon Subject: FW: "Save Family to Family Networks& Family supports Funding in DDServices Budget:

**Date:** Monday, July 27, 2020 10:37:16 AM

From:

**Sent:** Monday, July 27, 2020 10:32 AM **To:** jwmhs.exhibits@oregonlegislature.gov

**Cc:** Rep.RobNosse@oregonlegislature.gov; Sen.LeeBeyer@oregonlegislature.gov

**Subject:** "Save Family to Family Networks& Family supports Funding in DDServices Budget:

My name is Dena Keppen and I am a pediatric physical therapist in Klamath Falls. Oregon. I work for Sky Lakes Medical Center, treating children with special needs.

Many of the families on my caseload benefit from the services provided by the Family Support Network. We live in an area that has many economic challenges and the Family Support Network assists families in navigating these very challenging times.

I would like to respectfully request you continue funding to this very essential and beneficial program to the families of our community.

Sincerely,

Dena Keppen MS,PT

To: Rep Nosse; Sen Beyer; JWMHS Exhibits; Sen Johnson; Sen Steiner Hayward; Rep Rayfield;

OregonDDC@gmail.com; Sen Gelser; Sen Hansell; Rep Hayden; Rep Salinas; Rep Schouten; Rep Stark

**Subject:** Please do not cut funding to family support programs for students with disabilities

**Date:** Wednesday, July 22, 2020 5:54:58 PM

Dear Ways and Means Committee and Legislative Fiscal Office Members,

My name is Niels Pasternak and I have been working as a Special Education Teacher in Eugene, Oregon for the last 14 years. During my career I have mostly worked with students who experience moderate to severe impacts from their disabilities and have worked as a Life Skills teacher. I also earned my administrative license and I worked as an ESY administrator for multiple years. I am currently the chair of the OEA Special Education Committee.

During the time that I have supported students with disabilities I have also worked in collaboration with Families Connected, Directions Services, Developmental Disabilities Services, OVRS, The Pearl Buck Center, supported employment agencies such as Alternative Work Concepts, and The Arc of Lane County as a volunteer and in a professional capacity. One of the things I did as a volunteer was to partner with The ARC and Families Connected in order to host a job skills and person centered planning training class that lasted nine weeks for individuals with developmental disabilities and their families. This class was very successful all the students who attended were able to apply the skills they learned to find paid internships or jobs afterwards. Families Connected Also host multiple social activity nights for people with disabilities and their families and these have been positive experiences and very popular in our community for several years.

Throughout the time I have worked in collaboration with these agencies I have always been impressed by the passion and generosity of the people I have worked with and their willingness to put the needs of people with disabilities first in the ongoing struggle for equity. Mahatma Ghandi once said "A nations greatness is measured by how it treats it's weakest members" and so I am writing to you today to say please do not eliminate the Family to Family Networks and Family Support program funding from the DD Services Budget. Families need continual access to systems of support and these networks provide people with disabilities and their families and opportunities to learn, grow, network, and socialize that they would not otherwise get. These networks save lives by preventing isolation and fostering human connections for people who experience exceptionalities and who need help in these areas. This need is even greater during this pandemic and students with disabilities and their families are already being impacted in more negative ways and more severely during distance learning. It It would be a horrible mistake to eliminate these programs which are respected, appreciated, and utilized often in our community.

Sincerely,

Niels Pasternak Sped Teacher at SEHS Chair of the OEA Special Education Committee

To: Rep Nosse; Sen Beyer; Sen Gelser; Sen Hansell; Rep Hayden; Rep Salinas; Rep Schouten; Rep Stark; JWMHS

Exhibits; Sen Steiner Hayward; Rep Rayfield

Subject: Please do NOT eliminate the Family to Family networks and Family Support programs from DD Budget

**Date:** Thursday, July 23, 2020 10:36:29 AM

Hello all,

My name is Chalice Savage and I live in beautiful Cottage Grove, I'm running for City Council at Large in the next general election and I have a son with a Developmental Disability.

I am writing to ask you to PLEASE do NOT eliminate the Family to Family Networks and Family Support Programs from the DD Budget. Families like mine need this continual access to systems of support during this pandemic and this is NOT the time to eliminate these programs.

My son lost access to his school, his special education supports and his personal support workers (they all quit because he often requires personal contact and we could not guarantee the 6 feet distancing). Programs like FAMILIES CONNECTED at the ARC of Lane County have been our saving grace during this pandemic time. They have been able to reach out virtually and offer amazing tips and tricks in a way that no other program has been able to do. In healthier times this was the only group I felt we could meet up with and be accepted into due to the nature of my son's disability. We could see Santa, play at the park and do arts and crafts. This is not something that he could do in any other environment.

I encourage you all to please keep programs like this funded and I would even go further and ask for more funding. My son should have the right to be accepted in society and without these programs he doesn't have the proper supports to keep him engaged socially.

Please feel free to call or email me anytime. I would love to talk to you more about why I feel this is necessary.

Chalice Savage

Vote Chalice Savage for Vision, Integrity and Compassion Cottage Grove, OR 97424

541-301-1700 cell/txt chalicesavage@gmail.com

To: Rep Nosse; Sen Beyer; Sen Gelser; Sen Hansell; Rep Hayden; Rep Salinas; Rep Schouten; Rep Stark; JWMHS

Exhibits; Sen Johnson; Sen Steiner Hayward; Rep Rayfield; OregonDDC@gmail.com

Subject: Please do not eliminate the Family Networks and Family Support Program funding from the DD Services

Budget

**Date:** Wednesday, July 22, 2020 10:49:32 PM

Hello, my name is Crystal Rowbotham, and I live in Medford Oregon. I am writing to you today to express concern for the future of my Family Network. It is because of these programs that my family was able to find a community of like-minded families experiencing similar social situations. we felt very alone in the world after our son was diagnosed with ASD. In the last two years, these programs have given us friends and second families to share the life of a special needs family that is not recognized in a lot of social programs. without them we would not have been able to know about the different programs available for my son and the different challenges that special needs families face. together they helped ease the stress and events that are common for special needs families that are not discussed outside the world of special needs. because of the courage and encouragement from these meetings and groups, I am able to be a parent advocate for my local early childhood education and special education council and for the early learning services council to help make the voices of special needs families heard more in the community. Our Family Network has provided meaningful coping techniques and resources for day to day and extraordinary situations for each family that experiences special needs in our community. the classes are beyond valuable. the friendships are rare since parents of non-special needs kids don't always know how much of a struggle having a child with challenges can be these are vital programs for families. we need these programs to provide the opportunity to find and navigate needed resources, develop friendships and support systems, and keep from feeling isolated especially during this time of Covid-19.

Please do not eliminate the Family to Family Networks and Family Support Program funding from the DD Services Budget. Families need continual access to systems of support during this pandemic, and this is not the time to eliminate these programs. I am available to speak to you, should you have any questions.

Thank you for your time and consideration,
Crystal Rowbotham
Medford Oregon
541-324-1953
(Arthur at an Easter Event for Autism Society of Oregon 2019)



To: Rep Nosse; Sen Beyer; Sen Gelser; Sen Hansell; Rep Hayden; Rep Salinas; Rep Schouten; Rep Stark; JWMHS Exhibits;

Sen Johnson; Sen Steiner Hayward; Rep Rayfield

Subject: Please do not eliminate the Family Networks and Family Support program funding from the DD Services

Budget. Families need continual access to systems of support during this pandemic and this is not the time to eliminate

these programs."

**Date:** Thursday, July 23, 2020 10:26:05 AM

#### Good Morning,

My name is Natasha DeSantis and I am from Eugene Oregon. I am writing this email to ask Please do not eliminate the Family to Family Networks and Family Support program funding from the DD Services Budget. Families need continual access to systems of support during this pandemic and this is not the time to eliminate these programs. Family Networks and the Family Supports are very important for families on a every day basis when there are already limited supports for those that need these services, and it is even more crucial for the health and safety of these children and their families during this pandemic. I know that our state is in a budget deficit, but I ask you to please reconsider taking from one of the most vulnerable population who already face struggle daily and have very little support and services. Below I have added some important bullet points from the Oregon DD Coalition. I urge you again to think about what it would do to these children and their families if this was no longer available to them. These children and their families need you to fight for them and be their voice. Thank you for taking the time to read this email.

Family to Family Networks

## The Value of Family to Family Networks:

- Reach more than 12,250 families throughout Oregon
- Provides an immediate safety net for children who fall through the cracks of formal service systems
- Families are connected with other families with shared experiences which alleviates isolation, averts crisis, builds resiliency and a positive trajectory for the child's future
- Offers an array of supports to families not available in any other part of the DD Services System
- Flexible and responsive to families, especially as many families continue to quarantine due to their children's health conditions
- See the Oregon Consortium of Family Networks Video | Fact Sheet

# Family Support Program

## The Value of Family Support:

 Allows DD Services to provide a small amount of annual flexible funding for purchases of goods and/or services that benefit children with Intellectual or Developmental Disabilities who are not enrolled in Medicaid-funded DD services.

• General funds allow flexibility as has been especially helpful since COVID when the State was able to offer Expanded Family Support Funds to purchase items for the child related to their disability and the state of emergency.

I appreciate everything you do and will continue to due for the vulnerable populations of Oregon.

Thank you! Natasha DeSantis

1240 Charnelton St. Eugene Or, 97401 Office-541-284-5070 Cell-541-228-7122 Fax-541-284-5067

NDesantis@fullaccess.org

In an effort to be compliant with Governor Kate Brown's Stay at Home Order, Full Access has temporarily closed the office to the public. The health and safety of our staff, clients, families, and providers are of the highest priority for our agency and we are doing our due diligence to uphold recommendations for social distancing. Please know our staff are continuing to operate behind the scenes and will be committed to providing the same level of customer service that you are accustomed to. General hours have been reduced, but phone calls will still be answered between the hours of 9:30 am and 5 pm. Personal Agents can be reached on their work cell phones and/or email. Please also consult our facebook page for updates from ODDS regarding agency processes and how we are addressing concerns related to COVID-19.



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To: Rep Nosse; Sen Beyer; Sen Gelser; Sen Hansell; Rep Hayden; Rep Salinas; Rep Schouten; Rep Stark; JWMHS Exhibits; Sen Johnson; Sen

Steiner Hayward; Rep Rayfield

Cc: OregonDDC@gmail.com

Subject: Please do not eliminate the Family to Family Networks and Family Support program funding from the DD Services Budget.

Thursday, July 23, 2020 10:28:47 AM Date:

Attachments: image006.png image007.png

#### To whom it may concern;

We are living in very challenging and uncertain times. The COVID pandemic continues to impact nearly every aspect of our lives at home and in our communities. I understand that adjustments need to be made to the budget, but please do not eliminate the Family to Family Networks and Family Support program funding from the DD Services Budget. Families need continual access to systems of support during this pandemic and this is not the time to eliminate these programs.

#### The Value of Family to Family Networks:

- Reach more than 12,250 families throughout Oregon
- Provides an immediate safety net for children who fall through the cracks of formal service systems
- Families are connected with other families with shared experiences which alleviates isolation, averts crisis, builds resiliency and a positive trajectory for the child's future
- Offers an array of supports to families not available in any other part of the DD Services System
- Flexible and responsive to families, especially as many families continue to quarantine due to their children's health conditions

This is not the time to eliminate funding for Family to Family Networks when it is vital for families to stay connected to systems of support during this pandemic when they are experiencing higher degrees of isolation, fear and stress. Please keep \$665,000 in the DD Services Budget for the remainder of biennium to protect Family to Family Networks.

#### The Value of Family Support:

- Allows DD Services to provide a small amount of annual flexible funding for purchases of goods and/or services that benefit children with Intellectual or Developmental Disabilities who are not enrolled in Medicaid-funded DD services.
- General funds allow flexibility as has been especially helpful since COVID when the State was able to offer Expanded Family Support Funds to purchase items for the child related to their disability and the state of emergency.

This is not the time to eliminate Family Support Funding when alternate types of support are needed when especially as families are faced with additional challenges imposed by COVID. Please keep \$540,000 in the DD Services Budget for the remainder of biennium to preserve the Family Support program.

Eliminating the second year of funding for these two programs would eliminate them completely which is not in alignment with Guiding Principles outlined in the 2020 Ways & Means Co-Chair Rebalance Plan. These General Fund programs are critical to supporting families of children experiencing disability and must be preserved so that Oregon continues to be a place where families are supported to raise their children in their home.

Alicia Johnson Personal Agent Pronouns: her/she D: (503) 935-5253













Assisting people with disabilities to live empowered, self-determined lives through community connections.

Click here for CPI's COVID-19 updates and resources. We're in this together.

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To: Rep Nosse; Sen Beyer; Sen Gelser; Sen Hansell; Rep Hayden; Rep Salinas; Rep Schouten; Rep Stark; JWMHS

Exhibits; Sen Johnson; Sen Steiner Hayward; Rep Rayfield; OregonDDC@gmail.com

Subject: Please do not eliminate the Family to Family Networks and Family Support Program funding from the DD Services

Budget

**Date:** Wednesday, July 22, 2020 11:16:05 PM

Hello, my name is Michael, and I live in Medford, OR. I am writing to you today to express concern for the future of my Family Network. These networks provided such a huge array of information and support that was unavailable to our family before we met them. We don't have family or relatives that are close enough, trustworthy enough, or knowledgable enough to give us even a small portion of the support we have received and still receive today to provide our son an amazing opportunity at a successful life. Without these networks, we would still be figuring out how to teach our child how to speak at age 4 because we wouldn't have found out where to look for speech therapy or even who to ask. We would have been intimidated by the mounds of paperwork and the many programs that we could have access to if our family network didn't show us how to navigate them, narrow down the ones we needed, and guide us thru the sign-up processes to take advantage of them. Our Family Network has provided my family the opportunity to find and navigate needed resources, develop friendships and support systems, and keep from feeling isolated – especially during this time of Covid-19.

Please do not eliminate the Family to Family Networks and Family Support Program funding from the DD Services Budget. Families need continual access to systems of support during this pandemic, and this is not the time to eliminate these programs. I am available to speak to you, should you have any questions.

Thank you for your time and consideration, Michael Rowbotham Medford, OR 541-326-6545

To: Rep Nosse; Sen Beyer; Sen Gelser; sen.billhansel@oregonlegislature.gov;

rep.cedrichhayden@oregonlegislature.gov; Rep Salinas; Rep Schouten; Rep Stark; JWMHS Exhibits; Sen

Johnson; sen.elizabethsteinerhayword@oregonlegislature.gov; Rep Rayfield

 Cc:
 oregonDDC@gmail.com

 Subject:
 Please don"t cut their budget!

 Date:
 Wednesday, July 22, 2020 4:38:44 PM

----- Forwarded Message -----

From: Carol Hansen <carog424@yahoo.com>

To: CAROL <carog424@yahoo.com>

Sent: Wednesday, July 22, 2020, 04:10:10 PM PDT

Subject:

My Name is Carol Hansen. My family lives in Lane County, OR. I am the legal Guardian of 2 boys that are a product of the The foster care system. We receive support from Families Connected through the ARC of Lane County.

Families Connected has been a Godsend for families

during the pandemic. They have provided so many activities for the kids, online support groups for parents

and caregivers and information for services to keep us all as connected as possible.

Families Connected has been an invaluable resource for us during this challenging time and been a huge help to guide and support us through it.

Please do not eliminate the Family to Family Networks and Family Support program funding from the DD Services Budget. Families need continual access to systems of support during this pandemic and this is not the time to eliminate these programs..

#### Carol Hansen

#### Sent from Yahoo Mail for iPhone

---- Forwarded Message -----

From: Carol Hansen <carog424@yahoo.com>

To: CAROL <carog424@yahoo.com>

Sent: Wednesday, July 22, 2020, 04:10:10 PM PDT

Subject:

My Name is Carol Hansen. My family lives in Lane County, OR. I am the legal Guardian of 2 boys that are a product of the The foster care system. We receive support from Families Connected through the ARC of Lane County.

Families Connected has been a Godsend for families

during the pandemic. They have provided so many activities for the kids, online support groups for parents

and caregivers and information for services to keep us all as connected as possible.

Families Connected has been an invaluable resource for us during this challenging time and been a huge help to guide and support us through it.

Please do not eliminate the Family to Family Networks and Family Support program funding from the DD Services Budget. Families need continual access to systems of support during this pandemic and this is not the time to eliminate these programs..

Carol Hansen

Sent from Yahoo Mail for iPhone

To: Rep Nosse; Sen Beyer; Sen Gelser; Sen Hansell; Rep Hayden; Rep Salinas; Rep Schouten; Rep Stark; JWMHS

Exhibits; Sen Johnson; Sen Steiner Hayward; Rep Rayfield

Subject: Please don"t eliminate funding for CODSN Date: Wednesday, August 5, 2020 6:26:34 PM

Hello, my name is Nicole Pierce, and I live in Bend, Oregon. I am writing to you today to express concern for the future of my Family to Family Network, Central Oregon Disability Support Network in Central Oregon. I have three kids, ages 9, 7, and 4. My daughter Natalie is 7 and was born with a rare genetic syndrome called CHARGE. I currently stay home with my kids and depend on unique resources through many organizations. The Family to Family network has been one of the most influential and essential support systems available in the area. The network has given my family opportunities to be involved within the community. Not only does it improve the well being for Natalie, but her siblings get the opportunity to learn about other disabilities and serve within the special needs community.

One of the most difficult aspects of families with a special needs child is experiencing unexpected stress, such as Covid-19. Families that have a child that experiences a disability experience a higher level of isolation – especially during this time of Covid-19. Family to Family Networks decrease this sense of isolation.

Now is not the time to eliminate Family to Family Networks which serves as a vital lifeline for thousands of families across the State, including many whose children with disabilities cannot access formal services. Please maintain current service level funding in the DD Services Budget for Family to Family Networks to help ensure equitable access for children with disabilities and their families that are vulnerable to isolation and systemic discrimination, especially during this ongoing pandemic.

Thank you for your time and consideration,

Sincerely,

Nicole Pierce

314-445-8823

Rep Nosse; Sen Beyer; Sen Gelser; Sen Hansell; Rep Hayden; Rep Salinas; Rep Schouten; Rep Stark; JWMHS To:

Exhibits; Sen Johnson; Sen Steiner Hayward; Rep Rayfield

Cc: OregonDDC@gmail.com

Please keep the FAMILY SUPPORT PROGRAM Subject: Thursday, July 23, 2020 10:20:11 AM Date:

image006.png Attachments:

image007.png

## To whom it may concern;

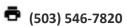
My name is Sarah Ehret and I am a case manager for adults with Developmental Disabilities I live in Portland, Or.

We are living in very challenging and uncertain times. The COVID pandemic continues to impact nearly every aspect of our lives at home and in our communities. I understand that adjustments need to be made to the budget, but please do not eliminate the Family to Family Networks and Family Support program funding from the DD Services Budget. Families need continual access to systems of support during this pandemic and this is not the time to eliminate these programs.

Sarah Ehret Personal Agent Pronouns: she/her

Call/text: 503-545-4924













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To: Rep Nosse; Sen Beyer; Sen Gelser; Sen Hansell; Rep Hayden; Rep Salinas; Rep Schouten; Rep Stark; JWMHS

Exhibits; Sen Steiner Hayward; Rep Rayfield

Cc: oregonDDC@gmail.com; Laura Dahill; Ben Hurlimann; Dylan Hurlimann; wyatthur720@gmail.com

Subject: Please keep the Funding for DD Services

Date: Thursday, July 23, 2020 9:48:28 AM

## Good morning, Everyone,

My name is Lisa Hurlimann. Together with my husband, Ben Hurlimann, we'd like to make an important plea. We live in Eugene, Oregon and I'll get right to the point of my message. Please do not eliminate the Family to Family Networks and Family Support Program funding from the Developmental Disabilities Services Budget. Families need continual access to systems of support during this pandemic and this is not the time to eliminate these programs.

For our family, here's why: we have three beautiful children, two sons ages 17 and 14. Our youngest child - our daughter, age 10, was born with Down Syndrome. The journey of life with her has been a blessing because we all love her so much and she shines her bright light wherever she goes. However, living with her developmental disabilities has had its fair share of hard knocks. The services we have received for her speech therapy, occupational therapy, special education and emotional support have been invaluable to us. Now the school districts all over the nation have shuttered their doors for the health and safety of our children, the alternative (distance-learning) for Special Education and support is **completely non-existent**. No one knows, especially us as parents, what the long-term effect will be, but rest assured it will not be positive. Vallory's growth and development will suffer a great deal. Eliminating the funds to DD Family Services and Support would be detrimental to all of us.

Please don't sweep disabled children and adults under the rug. We respectfully request you all consider carefully keeping these funds reserved for what they were originally intended. Thank you for your time.

Sincerely,

The Hurlimann Family Ben, Lisa, Dylan, Wyatt & Vallory 3976 Century Dr Eugene, OR 97402

<u>Lhurlimann31@gmail.com</u> (206) 504-0426 mobile #

JWMHS Exhibits; Rep Nosse; Sen Beyer; Sen Gelser; Sen Hansell; Rep Hayden; Rep Salinas; Rep Schouten; Rep To:

Stark; Sen Johnson; Sen Steiner Hayward; Rep Rayfield

Subject: Please read ASAP: Family to Family Networks - DD Services Budget

Thursday, July 23, 2020 10:18:58 AM Date:

#### Greetings,

My name is Janelle Sutter. I live in Dallas, Oregon.

This is not the time to eliminate the funding for Family to Family Networks from the DD Services Budget. It is so vital for families to stay connected to systems of support during this pandemic.

I work for Developmental Disabilities Services and I am a proud parent of a boy that experiences Cerebral Palsy and Autism.

I hear on a consistent basis from parents that they appreciate the support that Creating Opportunities Family Network provides to their families.

I too have experienced the support and training opportunities provided by Creating Opportunities Family Network.

Having a child with significant disabilities can be an isolating experience. Creating Opportunities Family Network gives me a resource that lessens this feeling and empowers me to act in ways that promote the best possible life for my son.

I am confident that the decisions made by you will not be without careful consideration and care. Thank you!

Janelle M. Sutter, M.S. **DD Foster Home Licensing Specialist Designated Referral Contact** Polk County Developmental Disabilities

Ph: 503-831-5969 Ext. 2349

Fax: 503-623-1874

"Oh how cleverly we defend ourselves against all that might do us good!" - C.S. Lewis

To: Rep Nosse; Sen Beyer; Sen Gelser; Sen Hansell; Rep Hayden; Rep Salinas; Rep Schouten; Rep Stark; JWMHS

Exhibits; Sen Johnson; Sen Steiner Hayward; Rep Rayfield

Cc: <u>Cheryl Cisneros</u>

Subject: Please Save Family Networks DD Services Budget!!

**Date:** Thursday, July 23, 2020 12:05:48 PM

#### Good afternoon,

My name is Rebecca Hill. I live in Salem with my husband, David, and two children, Noah and Hannah. I am gravely concerned about the funding for our Family to Family Networks from the DD Services Budget. This is not the time to eliminate the funding when it is so vital for families to stay connected to systems of support during this pandemic.

I want to take a moment to share with you the impact that my local Family to Family Support Network, Creating Opportunities, has had on my family. During a time in my family's lives, when we were on a downward trajectory, living in destitute due to the isolation we were experiencing, I was introduced to our local Family to Family Support Network and that is when things began to change. My family and I were welcomed and introduced to other families living with similar experiences. We were no longer alone. We were given a new outlook on life and the life of our children who experience a developmental disability. We were given information and learned about available resources. My family gathered with other families during events hosted by our Family to Family Support Network and we began to flourish! We have been an active part of our community ever since. Through their support my Family and I have changed our trajectory in an upwards swing to where our life will go. Because of their support, my family is no longer in isolation!

During the recent pandemic, our Family to Family Support Network has not stopped! They did not shut down. They have made personal phone calls to my family and others to check in on how we are doing. Even during this time, they have been working to keep families connected, offering activity kits for our family and opportunities for us to connect with other families virtually. They continue to share information and resources as they become available. The support in keeping connected with other families has been overwhelmingly influential in my families well being during a time when we are now isolating again to remain safe during the pandemic.

I am writing to ask you to not eliminate Family Support Funding when alternate types of support are needed. Especially as families are faced with additional challenges imposed by COVID. Family to Family Support Networks reach more than 12,250 families throughout Oregon. Please keep \$540,000 in the DD Services Budget for the remainder of biennium to preserve the Family Support program. A program that I attribute to saving my family and put us back on an upwards trajectory and part of our community.

I am happy to engage in any further discussion or to answer any questions you may have.

Thank you,

Rebecca Hill

To: JWMHS Exhibits; Rep Nosse; Sen Beyer; Sen Gelser; Sen Hansell; Rep Hayden; Rep Salinas; Rep Schouten; Rep

Stark; Sen Johnson; Sen Steiner Hayward; Rep Rayfield

**Subject:** Please save my Family to Family network in the DD budget

**Date:** Thursday, July 23, 2020 8:58:01 AM

Hello, my name is Dianna, and I live in Central Oregon. I am writing to you today to express concern for the future of my Family Network. Our Family Network has provided my family with so many opportunities such as; trainings, resources, support and connection especially during this time of Covid-19 when resources and connections are hard to come by.

As a family, the network has given us the tools to help our daughter (age 16) navigate the DD system, education system, learn how to advocate for her when she was little and is now providing the tools for her to learn to advocate for herself. Through the Family to Family network we have been able to have the mindset that she can work, and given the tools for her to actually work in a fully paid, integrated job at a restaurant doing what she loves. She has plans to move out after high school graduation and attend the culinary program at our community college. She will be a contributing member of our state and I give lots of that credit to the Family to Family network for helping our family see the possibilities and achieve these goals.

Please do not eliminate the Family to Family Networks and Family Support Program funding from the DD Services Budget. Families need continual access to systems of support during this pandemic, and this is not the time to eliminate these programs. I am available to speak to you, should you have any questions.

Thank you for your time and consideration,

Dianna Hansen Tumalo, Oregon (541) 280-4878



To: <u>JWMHS Exhibits</u>
Cc: <u>Rep Nosse; Sen Beyer</u>

Subject: SAVE Family to Family Networks & Family Support Funding in DD Services Budget

**Date:** Thursday, July 23, 2020 3:24:57 PM

Dear Ways & Means Human Services Sub Committee,

My name is Amber Ruedi and I live in Bend, Oregon.

The purpose of this email is to provide advocacy in support of a local human services program. Please do not eliminate the Family to Family Networks and Family Support program funding from the DD Services Budget. Families need continual access to systems of support during the pandemic and this is not the time to eliminate these programs.

I am a mom to my son who has developmental disabilities, Autism with behavioral and emotional challenges. Without the support of our local DD non-profit agency, many of our families will suffer the consequences, especially our children who have disabilities. The Family to Family Networks help in so many ways. They provide support, connections to other families experiencing similar situations, build community connections, help to match services for our children, education, advocacy and other resources from birth through adulthood.

With an open heart, open mind and compassion for our children, who struggle with various disabilities, please take into consideration the importance of supporting the Family to Family Networks budget and how it can help support them, and us as parents. We struggle daily to ensure the safety, health and well-being of our children. Please do not let them fall through the cracks.

Sincerely,

Amber

To: <u>JWMHS Exhibits</u>
Cc: <u>Rep Nosse; Sen Beyer</u>

Subject: SAVE Family to Family Networks & Family Supports Funding in DD Services Budget

**Date:** Wednesday, July 22, 2020 4:38:46 PM

## To Whom It May Concern,

My name is Greg Copley and I live in Bend, Oregon.

I'm writing to urge you to maintain (or increase!) funding for the Family to Family Networks and Family Support program within the DD Services Budget. Now more than ever, families need continual access to these systems of support.

As a parent of a child with intellectual and physical disabilities, the services I've received through these systems have supported my family with the additional burdens we carry in raising kids like this. Where government implemented services continually fall short, these systems pick up the slack and provide families with more clarity on their options with much better perspective. It's a lonely experience raising a child with special needs and these systems make it less so.

Thank you for your support in maintaining this critical funding,

\_-

Greg

To: Rep Nosse; Sen Beyer; Sen Gelser; Sen Hansell; Rep Hayden; Rep Salinas; Rep Schouten; Rep Stark; JWMHS

Exhibits; Sen Johnson; Sen Steiner Hayward; Rep Rayfield

Subject: Save Family to Family Networks & Family Supports Funding in DD Services Budge

**Date:** Thursday, July 23, 2020 9:20:00 AM

## Hello all,

My name is Kory Aschoff and I live in Portland. I am writing this morning to kindly ask that you do not eliminate the Family to Family Networks and Family Support program funding from the DD Services Budget. Families need continual access to systems of support during this pandemic and this is not the time to eliminate these programs. These programs are extremely important and offer a great amount of support for families and children with intellectual and developmental disabilities. The loss of these programs would be absolutely devastating to those who need them, especially during this time.

--

Thank you for your time and take care,

# **Kory Aschoff**

(Say: Ash-off)

**Advocacy Coordinator** 

She/her

Phone: 504-484-9875 Cell: 971-544-9006

kory.aschoff@askosac.org



To: <u>JWMHS Exhibits</u>
Cc: <u>Rep Nosse; Sen Beyer</u>

Subject: SAVE Family to Family Networks & Family Supports Funding in DD Services Budget

**Date:** Thursday, July 23, 2020 11:20:40 AM

#### Hello,

My name is Yecenia Rodriguez; I live in rural Klamath Falls. I am a mother of two wonderful children. My son who is 9 was born with Cerebral Palsy. I have been part of the Family Network for a few years now.

First, I would like to say to please do not eliminate the Family to Family Networks and Family Support program funding from the DD Services Budget. Families need continual access to systems of support during this pandemic and this is not the time to eliminate these programs.

Secondly, the family to family network has been such a help for our family. We have been able to connect to so many people who are experiencing the same barriers as us. *The family network has brought my community together. The network has given us an opportunity to enjoy the same things that are offered in the community with keeping disabilities in mind and making sure our children's needs are met.* My son has been able to make friends where he wasn't able to before. We feel accepted now.

We used to frequently meet for a support group and be able to network and pass ideas with other parents. There were many times when I had an emergency and I was about to go to the ER, but remembered a parent saying they experienced the same thing and called them instead.

As COVID 19 hit us it reminded me again of how isolated I was before the family network. The feeling of being depressed, not being able to talk to anyone, and especially looking at my son and seeing how sad he is that he doesn't get to enjoy the events that our family network did.

Please don't take this away from me and my children. This is what we look forward to. I wish I could say my son's quality of life would be the same without the family network but it will not. We need this for the community, us parents, and especially for children experiencing disabilities.

--

Yecenia Rodriguez

Program Coordinator
Family Advocacy & Support Network
Cell (541)591-5507
FASNFamilynetwork.org

Facebook: Family Advocacy & Support Network

Any information provided by CODSN, its staff, and/or its volunteers is intended for informational and educational purposes only. Any information expressed or implied is not intended nor should be construed as legal, medical, or other professional advice. This email may contain information that is confidential. If you are not the addressee, or if it appears that you have received this email in error, please advise me immediately by reply email, keep the contents confidential, and immediately delete the message and any attachments from your system.

To: Rep Nosse; Sen Beyer; JWMHS Exhibits

Subject: SAVE Family to Family Networks & Family Supports Funding in DD Services Budget

**Date:** Thursday, July 23, 2020 11:52:50 AM

My name is Diane Cole and I'm the mom of a disabled daughter in Bend, OR. Please do not eliminate the Family to Family Networks and Family Support program funding from the DD Services Budget. Families need continual access to systems of support during this pandemic and this is not the time to eliminate these programs.

Central Oregon Disability Support Network here in Bend has been extremely helpful to let us know what services are available for my daughter. We rely on them so much and would be at a loss if they are not funded appropriately. Please vote to save these services!!

Sincerely, Diane Cole Bend, OR

From: To:	JWMHS Exhibits
Cc: Subject: Date:	Rep Nosse; Sen Beyer SAVE Family to Family Networks & Family Supports Funding in DD Services Budget Thursday, July 23, 2020 12:21:12 PM
Hello	
My name is Yes Falls.	sica Morales; I am a 11th grader at Klamath Union High School in Klamath
program fundir	please do not eliminate the Family to Family Networks and Family Supporting from the DD Services Budget. Families need continual access to systems ng this pandemic and this is not the time to eliminate these programs.
	t with Family Advocacy & Support Network. I have so many families and they ach FASN has helped them. I learned alot about disabilities and how they are
Please don't eli	minate this program.

To: <u>JWMHS Exhibits</u>
Cc: <u>Rep Nosse; Sen Beyer</u>

Subject: SAVE Family to Family Networks & Family Supports Funding in DD Services Budget

**Date:** Thursday, July 23, 2020 12:29:49 PM

#### Hello

My name is Martha Farias, I live in Klamath Falls OR.

Please do not eliminate the Family to Family Networks and Family Support program funding from the DD Services Budget. Families need continual access to systems of support during this pandemic and this is not the time to eliminate these programs.

My grandson has Cerebral Palsy. He had always been stuck at home because of his disabilities. My daughter felt isolated and alone and since she didn't see other kids with disabilities she would rather stay home so people didn't look at her or her son differently.

I would see my daughter so depressed and alone. After the family network she slowly started going out to events and support groups. We were very surprised to see so many children with special needs. Slowly my daughter and grandson started blooming and eventually volunteering more and going to more events. She is now so happy and so is my grandson.

During this Covid pandemic I have seen her slowly going back to depression. She lives for the family network, we are going through a hard time as a nation. Please, don't take this away from my children.



Virus-free. www.avg.com

To: <u>JWMHS Exhibits; Rep Nosse; Sen Beyer</u>

Subject: SAVE Family to Family Networks & Family Supports Funding in DD Services Budget

**Date:** Thursday, July 23, 2020 12:56:21 PM

My name is Shantra Reese and I live in Springfield in an apartment with my husband, an essential home health worker for adults with disabilities, my 6 year old daughter and my 8 year old son with dual diagnosis ASD/ADHD and mental health diagnosis.

Please do not eliminate the Family to Family Networks and Family Support program funding from the DD Services Budget!

Our family has lost so much over these past months and each day has been a struggle. What has impacted us the most was the loss of services for my son provided by the school district as well as specialized child care programs, and the mental health services he received which dissapeared almost overnight due to furloughs and budget cuts.

I have been unable to return to my job in order to stay home with my son and daughter. I haven't received unemployment in months due to some unknown error and the possibility of becoming homeless has become very real. Our families have isolated themselves from us out of fear that my husband will aquire covid-19 at his job. Since March 17th it's just been my two children and I at home each day feeling the effects isolation. Most heartbreaking is the despair, anger, confusion, fear, and grief my son has been experiencing each day.

Families Connected has been a lifeline for us during this extremely difficult time. They provided us with free crafts we otherwise couldn't afford to buy so my children had something to do to keep their minds off of everything. They provided a parenting resource book that gave me much needed parenting tips to use, they have kept us in the loop with community available webinars directing us to MUCH needed programs, online support groups, and much more. Just the idea that there are other families out there like us to connect with on their Facebook group has provided so much comfort. I don't know how I would have gotten by each day without the hope they have provided.

Please do not take this program away from our family and our community when we have already lost so much.

Thank you for you time, Shantra Reese

To: <u>JWMHS Exhibits</u>
Cc: <u>Rep Nosse; Sen Beyer</u>

Subject: SAVE Family to Family Networks & Family Supports Funding in DD Services Budget

**Date:** Thursday, July 23, 2020 8:19:01 PM

To whom it May Concern,

My name is Mandy Wallace, and I live in Bend Oregon. I am a speech language pathologist who works in the school setting.

Please do not eliminate the Family to Family Networks and Family Support program funding from the DD Services Budget. Families need continual access to systems of support during this pandemic and this is not the time to eliminate these programs.

I work with many families in Central OR who access supports provided by Family to Family Networks. Cutting funds would further the inequities that many of these families already face.

Thank you.

Amanda Wallace MS, CCC-SLP

To: <u>JWMHS Exhibits; Rep Nosse; Sen Beyer</u>

Subject: SAVE Family to Family Networks & Family Supports Funding in DD Services Budget

**Date:** Friday, July 24, 2020 10:30:27 AM

Hi,

My name is Alli Faucher and I live in Bend, Oregon. I am a board member of Central Oregon Disability Support Network and a mental health therapist for Deschutes County. I specialize in working with families with intellectual/developmental disabilities.

Please do not eliminate the Family to Family Networks and Family Support program funding from the DD Services Budget. Families need continual access to systems of support during this pandemic and this is not the time to eliminate these programs.

There is already a lack of resources and support for these families within so many systems. We need family to family networks to help families get the support they need for mental health, medical help, advocacy, assistive technology, peer support, and education support.

Thank you, Alli Faucher From: To:

Subject: SAVE Family to Family Networks & Family Supports Funding in DD Services Budget

**Date:** Monday, July 27, 2020 12:12:49 PM

Hello,

My name is Onalee Roe, and I am a pediatric occupational therapist in Bend, Oregon. I am writing in support of the Family to Family Networks and Family Support Program. Please do not eliminate the Family to Family Networks and Family Support program funding from the DD Services Budget. Families need continual access to systems of support during this pandemic and this is not the time to eliminate these programs. I have seen firsthand how these programs help the families in our community, including many of the children and families I work with. Programs like Central Oregon Disability Support Network are crucial resources for families of children with disabilities, who tend to be underserved and who face extremely difficult situations.

For more information, please see the GO Bulletin: <a href="https://conta.cc/2ZRWNbY">https://conta.cc/2ZRWNbY</a>

Thank you for your time and consideration!

Sincerely, Onalee Roe, MOTR/L

--

**Treehouse Therapies Associates** 

Office: 541-389-1848 Fax: 541-550-7956

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To: <u>JWMHS Exhibits</u>
Cc: <u>Rep Nosse; Sen Beyer</u>

Subject: SAVE Family to Family Networks & Family Supports Funding in DD Services Budget

**Date:** Tuesday, July 28, 2020 10:26:46 AM

# Hello Ways & Means Human Services Subcommittee:

The purpose of this email is to ask that you please do not eliminate the Family to Family Networks and Family Support program funding from the DD Services Budget. Families need continual access to systems of support during this pandemic and this is not the time to eliminate these programs.

My name is Kelsey Carr. I live in Bend, Oregon with my family. I am a stay at home mom to three wonderful children. My oldest suffers from multiple disabilities including seizures, developmental delays, ADHD and more. We have worked with multiple agencies over the years to get him the best possible help for a successful life; without these different people on our team, I cannot tell you where we would be today. We originally didn't even know what was going on, or where to start. We just knew something was wrong/off, and the pediatrician can only do so much. Without experiencing it for yourself, it would be will difficult to comprehend the struggles, joys, ups and downs that come with being the parent of a child with a disability. It adds additional layers of questions unanswered, frustrations, battles to the standard challenge/joy that is found in raising kids. When they aren't meeting milestones, aren't making friends, are having difficulty in multiple areas and you don't know how to help your child, you NEED these groups to point you in the right direction, to give you emotional support, to give your child support. He is a very happy child and making progress each year, but we wouldn't be where we are without CODSN and too many more to list. Especially with Covid-19 shutdowns, this has only made daily life and education more challenging for families. Please don't take away our support systems. Thank you for your consideration!

Sincerely, Kelsey Carr Bend, Oregon

To: <u>JWMHS Exhibits</u>

Cc: Rep Nosse; Sen Beyer; Dianna Hansen

Subject: SAVE Family to Family Networks & Family Supports Funding in DD Services Budget

**Date:** Wednesday, July 22, 2020 3:43:51 PM

Attachments: <u>image001.png</u>

Hello my name is Cecilia Silcox I am a Personal Agent/ Program Coordinator, family member and community member in Klamath Falls Oregon.

Please do not eliminate the Family to Family Networks and Family Support program funding from the DD Services Budget. Families need continual access to systems of support during this pandemic and this is not the time to eliminate these programs.

These services are essential to families especially of school age children, parents have to put up fights in the school system on a constant basis and fight to access the services they are entitled to for there children. Without the advocacy and support of Family Networks families have no one to turn to that will help them fight for service equity in a bureaucratic system and families become overwhelmed and just give up. I would hate to see the support for families go away and children not getting to live a sweet life because of the complicated systems.

In my work as a case manager and program coordinator there was a time we did not have a Family Network in our local area during this time families where failed in our local area especially those with children between birth and 18 years. I was in a community meeting and the stories we heard from families about there services made me cry. There was almost no dry eyes in the room. Since Family Network has started in Klamath families have support I have personally attended trainings offered and partnered with Family Network to bring the SPROUT Film Festival to Klamath Falls to try and repair the community to gain trust of families and bring a sense of comfort.

Thank you for your time and consideration

Sincerely,

# Cecilia Silcox

**Program Coordinator** 

Ph: 541.672.9140 ext. 225 Direct: 541.851.7056 Fax: 541.882.4496

www.connectionscm.org



(Formerly Southern Oregon Regional Brokerage)

NOTICE: Our name has changed to Connections Case Management, please update your email and all records accordingly.

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To: <u>JWMHS Exhibits</u>
Cc: <u>Rep Nosse; Sen Beyer</u>

Subject: SAVE Family to Family Networks & Family Supports Funding in DD Services Budget

**Date:** Wednesday, July 22, 2020 3:26:54 PM

Hi,

My name is Katie Dasher and I live in Klamath Falls Oregon.

Please do not eliminate the Family to Family Networks and Family Support program funding from the DD Services Budget. Families need continual access to systems of support during this pandemic and this is not the time to eliminate these programs.

My son and really our whole family has greatly benefited from the programs and other events held by F2F. There is nothing else in town like this program for special needs people. The social aspect of these events is just priceless for children and those of all ages who really need the help and support of others to grow socially and become productive members of our community. There is nowhere else to feel as welcome and comfortable for many of these people and to cut funding will be extremely detrimental to all of us. On the other hand for the families of special needs individuals it gives a support group and provides an outlet for Q&A of others going through similar issues. The information and techniques learned through this group is extremely helpful and much needed. Thank you so much for your time and consideration.

Katie Dasher

Subject: SAVE Family to Family Networks & Family Supports Funding in DD Services Budget

**Date:** Wednesday, July 22, 2020 2:23:01 PM

I'm Jocelyn Day from Wilsonville, Oregon. I work for an organization for teens and young adults with disabilities called Capernaum.

Please do not eliminate the Family to Family Networks and Family Support program funding from the DD Services Budget. Families need continual access to systems of support during this pandemic and this is not the time to eliminate these programs.

I've seen friends directly impacted by this wonderful program, and watched as families have found support and encouragement during the most trying days of their lives. This program means the world to so many.

Thank you for your consideration and all you do!

Best, Jocelyn Day

To: <u>JWMHS Exhibits</u>

Cc: Rep.RobNosse@oregonlegislature.gov Sen.LeeBeyer@oregonlegislature.gov

Subject: SAVE Family to Family Networks & Family Supports Funding in DD Services Budget

**Date:** Wednesday, July 22, 2020 4:28:22 PM

My name is Rita F. Hernandez. I live in Portland, OR. I work with individuals and their families in Multnomah, Clackamas, Washington, Hood River and Wasco counties.

Please do not eliminate the Family to Family Networks and Family Support program funding from the DD Services Budget. Families need continual access to systems of support during this pandemic and this is not the time to eliminate these programs.

As a Behavior Consultant, I work with families who have the most intense needs. Having access to this extra funding can mean the difference between having a child placed out of the home (at great trauma to the child and family and astronomical expense to the state) and being able to keep these kiddos in their own homes with their families. Especially during the pandemic, we were able to provide some extra supports during the unprecedented time when kids couldn't go to school nor access familiar recreation activities in the community. The extra funding has been a godsend!! Please continue to fund these programs!!

Thank you!

Rita F. Hernandez, MSCCC-SLP Behavior Consultant/Licensed Autism Specialist Speech Associates LLC Cell: 503 329-1405

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To: Rep Nosse; Sen Beyer; Sen Gelser; Sen Hansell; Rep Hayden; Rep Salinas; Rep Schouten; Rep Stark; JWMHS

Exhibits; Sen Johnson; Sen Steiner Hayward; Rep Rayfield

Subject: SAVE Family to Family Networks and Family Support program funding

**Date:** Wednesday, July 22, 2020 3:49:17 PM

To to Ways and Means Human Services Subcommittee -

My name is Kristine Ulit, a Central Oregon resident living in Bend.

Please do not eliminate the Family to Family Networks and Family Support program funding from the DD Services Budget. Families need continual access to systems of support during this pandemic and this is not the time to eliminate these programs.

We are thankful for the services that our local family support network, Central Oregon Disability Support Network (CODSN), has provided to our family over the past two years since we moved to Central Oregon with our 4 children, including one 5-year old son who experiences significant delays from Autism Spectrum Disorder. Being new to the area, CODSN was a key partner and resource to help us immediately identify and connect with financial and social services. They provide meaningful times to connect with other families, as well as answer questions about special needs education, financial planning, and practical helps for activities of daily living. These services have profoundly and positively impacted our well-being as a special needs family who daily navigates the changing tides of having a child on the spectrum. The need for the services they provide is growing! We continually refer other families experiencing disability to CODSN for support, especially those struggling to find connection. We are ever grateful for CODSN and its partners in our local community, and cannot imagine not having their partnership in the years to come.

Once more, please do not eliminate the Family to Family Networks and Family Support program funding from the DD Services Budget!

Thank you, Kristine Ulit

To: <u>JWMHS Exhibits</u>
Cc: <u>Rep Nosse</u>

Subject: SAVE FAMILY TO FAMILY NETWORKS AND FAMILY SUPPORTS FUNDING IN DD SERVICE BUDGET.!!!!

**Date:** Thursday, July 23, 2020 12:17:57 PM

I am writing desperately pleading with you not to cut these programs! These networks have been amazing and continue to help my little girl. If it were not for family to family support networks, we wouldn't have known about an amazing family camp we are going to in 3 weeks. This camp is the most magically place, and we would not have known. This is only a very small glimpse of the importance to these programs. Respectfully, if you do not have a child with special needs, you could never understand the importance of connecting with other familys in what seems like a lonely special needs world.

Thank you

To: Rep Nosse; Sen Beyer; Sen Gelser; Sen Hansell; Rep Hayden; Rep Salinas; Rep Schouten; Rep Stark; JWMHS

Exhibits; Sen Johnson; Sen Steiner Hayward; Rep Rayfield

Subject: RE: Save the Family Networks and the Family Support Program in the DD Services Budget

**Date:** Thursday, July 23, 2020 11:35:04 AM

Dear Members of the Ways and Means Committee.

May name is Pam Ring, and I live in Eugene, Oregon. I am the executive director of The Arc of Lane County and have an adult son who experience developmental disabilities. I am extremely concerned about the proposal to eliminate Family Networks and Family Support Program in Oregon. I am proud of how Oregon policy makers have been responding the Covid-19 pandemic and how responsive they have been to keeping Oregonians safe. I cannot stress enough how essential the Family-to-Family Networks and Family Support Program are to families who have children with disabilities during this pandemic.

I have experienced firsthand and have heard directly from families how Families Connected, Lane County's family network, has made such a huge difference to their family. Many of the families involved in the network are single parent families with limited income and resources, and whose children have significant support needs. Many children fall through the cracks in the formal service system. The Networks provide a safety net for these children and their families, especially during this time of higher degree of isolation, fear and stress. Families Connected has allowed families to stay connected with other parents through zoom game nights, providing information about resources that are available in our community, providing craft kits to help entertain their children while sheltering in place, and provided parents a forum to share resources around virtual learning.

I urge you to continue the funding for Family to Family Networks. This is not the time to eliminate funding for Family to Family Networks when it is vital for families to stay connected to systems of support during this extreme of uncertainty.

Thank you for your consideration and the important work you do.

Sincerely,

Pamela S. Ring | Executive Director The Arc of Lane County

To: Rep Nosse; Sen Beyer; Sen Gelser; Sen Hansell; Rep Hayden; Rep Salinas; Rep Schouten; Rep Stark; JWMHS

Exhibits; Sen Johnson; Sen Steiner Hayward; Rep Rayfield

Cc: <u>OregonDDC@gmail.com</u>

Subject: Save the Family Networks and the Family Support Program in the DD Services Budget

**Date:** Wednesday, July 22, 2020 4:06:45 PM

#### Dear Members of the Ways & Means Committee:

My name is Laura Dahill, and I live in Eugene, Oregon. I am the proud parent of twin boys, one of whom experiences a disability. I am writing to express my trepidation about the proposed cuts that will eliminate the Family to Family Networks and Family Support Program funding from the DD Services budget. Families need continual access to systems of support during this unprecedented time, not less.

My family has benefited greatly from our local family network, which is part of the developmental disability services budget. Through the family network, I have been able to connect with other families traveling a similar journey, which has made an incredible difference in my life and the life of my child. When my child was first diagnosed with an autism spectrum disorder, I felt isolated and overwhelmed. I distinctly remember wanting to move to a deserted island so I could protect my son. Thanks to the family network, I no longer feel the need to self-isolate. I have found other parents with whom I can share in my child's success and trials and tribulations.

My son has benefited greatly from the team of professionals supporting him, including his pediatric development specialist, speech and language pathologist, occupational therapist, and teachers. While he has benefited greatly from professionals, I have benefited the most from the connection with other parents walking a similar path - parents whom I can call for support and camaraderie when I need to refill my cup.

My son has many wonderful strengths and gifts. Just like his peers, my son wants to graduate from high school, attend college, have a career and be a valued and respected member of his community. Thanks to the family network, I have learned how to advocate and empower my son to reach his dreams. I have no doubt my son will make his mark in this world – and it will be to the betterment of others in our community.

Please do not eliminate the Family to Family Networks or the Family Support Program from the developmental disability services budget. Please understand that cutting the second year of funding will eliminate the family networks entirely. Children continue to be diagnosed with disabilities, and the need for family support continues to grow during the pandemic. Without the family networks, families will feel isolated, alone and in crisis. We need to move forward - not backwards - in supporting people who experience disabilities & their families at this time.

Thank you for your consideration.

Sincerely, Laura D. Dahill

To: <u>JWMHS Exhibits; Rep Nosse; Sen Beyer</u>

Subject: SAVE Family to Family Networks Funding in DD Services Budget

**Date:** Thursday, July 23, 2020 6:45:49 AM

#### Hello,

My name is Stephanie Widler and my family and I live in Redmond, Oregon. My older son is 15 years old and experiences a developmental disability. We've been involved with the local Family to Family Network since he was 6 or 7 years old.

The Family Networks support more than 12,250 families in Oregon: Families like mine. Through Family Networks, families with shared experiences can connect which alleviates isolation; averts crisis; and builds resiliency and a positive trajectory for the child's future. During this pandemic crisis, the Family Networks have been able to pivot their supports to meet families where they are, and to do so safely. Even as the state begins to reopen, many of us have children who are at high risk and have to continue to isolate at home.

This is not the time to eliminate funding for Family to Family Networks when it is vital for families to stay connected to systems of support during this pandemic when they are experiencing higher degrees of isolation, fear and stress. Please keep \$665,000 in the DD Services Budget for the remainder of biennium to protect Family to Family Networks.

Thank you, Stephanie Widler

To: Rep Nosse; Sen Beyer; Sen Gelser; Sen Hansell; Rep Hayden; Rep Salinas; Rep Schouten; Rep Stark; JWMHS

Exhibits; Sen Johnson; Sen Steiner Hayward; Rep Rayfield

Cc: <u>OregonDDC@gmail.com</u>

**Subject:** Proposed Cuts

**Date:** Thursday, July 23, 2020 9:54:38 AM

Attachments: image006.png image007.png

## To whom it may concern;

We are living in very challenging and uncertain times. The COVID pandemic continues to impact nearly every aspect of our lives at home and in our communities. I understand that adjustments need to be made to the budget, but please do not eliminate the Family to Family Networks and Family Support program funding from the DD Services Budget. Families need continual access to systems of support during this pandemic and this is not the time to eliminate these programs.

# Family to Family Networks

The Value of Family to Family Networks:

- Reach more than 12,250 families throughout Oregon
- Provides an immediate safety net for children who fall through the cracks of formal service systems
- Families are connected with other families with shared experiences which alleviates isolation, averts crisis, builds resiliency and a positive trajectory for the child's future
- Offers an array of supports to families not available in any other part of the DD Services System
- Flexible and responsive to families, especially as many families continue to quarantine due to their children's health conditions
- See the Oregon Consortium of Family Networks Video | Fact Sheet

This is not the time to eliminate funding for Family to Family Networks when it is vital for families to stay connected to systems of support during this pandemic when they are experiencing higher degrees of isolation, fear and stress. Please keep \$665,000 in the DD Services Budget for the remainder of biennium to protect Family to Family Networks.

# Family Support Program

The Value of Family Support:

- Allows DD Services to provide a small amount of annual flexible funding for purchases of goods and/or services that benefit children with Intellectual or Developmental Disabilities who are not enrolled in Medicaid-funded DD services.
- General funds allow flexibility as has been especially helpful since COVID when the State was able to offer Expanded Family Support Funds

to purchase items for the child related to their disability and the state of emergency.

This is not the time to eliminate Family Support Funding when alternate types of support are needed when especially as families are faced with additional challenges imposed by COVID. Please keep \$540,000 in the DD Services Budget for the remainder of biennium to preserve the Family Support program.

Eliminating the second year of funding for these two programs would eliminate them completely which is not in alignment with Guiding Principles outlined in the 2020 Ways & Means Co-Chair Rebalance Plan. These General Fund programs are critical to supporting families of children experiencing disability and must be preserved so that Oregon continues to be a place where families are supported to raise their children in their home.

Respectfully,

Linda Peck Athens Personal Agent Pronouns: she/her/hers

D: 503-935-5250 C: 503-545-4141











Facebook



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Click here for CPI's COVID-19 updates and resources. We're in this together.

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To: Rep Nosse; Sen Beyer; Sen Gelser; Sen Hansell; Rep Hayden; Rep Salinas; Rep Schouten; Rep Stark; JWMHS

Exhibits; Sen Johnson; Sen Steiner Hayward; Rep Rayfield

Cc: <u>OregonDDC@gmail.com</u>

**Subject:** Proposed reductions to programs, including DD services.

**Date:** Wednesday, July 22, 2020 10:45:30 PM

My Name is Liz Killam and I live in Eugene Oregon. I am the mother of a child on the Autism Spectrum.

I am writing to ask, practically beg, that you not eliminate the Family to Family Networks, and Family Support Program funding from the DD Services Budget. Families need continual access to systems of support during this pandemic – they needed daily support even before the pandemic!

I am the parent of a child that is hyper-sensitive to his surroundings, and is easily overwhelmed and frustrated. He had no skills yet to regulate his emotions (but was in therapy to learn), and his only way to show stress, anxiety or displeasure was to explode emotionally by screaming and throwing things. As a parent you are frustrated, trying to give your child time interacting with peers, happy experiences at the park, the theatre, the petting zoo etc.... But, each of those experiences ends with you carrying your child away in your arms kicking and screaming when he gets overwhelmed or misunderstands his peers while playing. You just want to cry, and now all the other parents are looking at you like you are the worst parent in the world, they don't understand because your son's disability is not visible. You feel embarrassed, alienated, alone, scared, frustrated and eventually angry......"why me!" This is where a parent without support can find themselves in despair, and this can lead to both parent and child suffering – possibly entering the social services system because they have become dysfunctional – even violent.

But one day you find out about The Family Support Network. You get the resources you need, you find parents going through the same challenges, they have kids who have similar behaviors. These children get along with each other, and now your child is getting critical time with his peers. You're not afraid to go out on outings with these parents, where you all understand, you are accepted, you share together the challenges of taking your kids into public.

What is the alternative? Families in crisis, not families finding support in each other, getting the resources they need. What is the cost? That is your question. That is the choice you are making. Please think about that. These resources saved my family.

To: Rep Nosse; Sen Beyer; Sen Gelser; Sen Hansell; Rep Hayden; Rep Salinas; Rep Schouten; Rep Stark; JWMHS

Exhibits; Sen Johnson; Sen Steiner Hayward; Rep Rayfield; OregonDDC@gmail.com

**Subject:** Regarding Budget Hearing tomorrow of my Family Network

**Date:** Wednesday, July 22, 2020 3:54:13 PM

Hello, my name is Sara, and I live in White City, OR. I am writing to you today to express concern for the future of my Family Network. Our daughter is 9 years old and has Autism Spectrum Disorder, Sensory Processing Disorder, ADHD, and Anxiety. Our Family Network has provided me much needed help and opportunity to find and navigate needed resources, develop friendships and support systems, and keep from feeling isolated – especially during this time of Covid-19. Prior to finding this network I was struggling with my daughter and not having any friends or family that could support and understand our situation. As each child is different it is still extremely difficult to find friendships and have people who do not judge you especially when you have a child with special needs.

Please do not eliminate the Family to Family Networks and Family Support Program funding from the DD Services Budget. Families need continual access to systems of support during this pandemic, and this is not the time to eliminate these programs. I am available to speak to you, should you have any questions.

Thank you for your time and consideration,

Sara Pine

White City, OR

541-499-7045

To: JWMHS Exhibits; Rep Nosse; Sen Beyer; Sen Gelser; Sen Hansell; Rep Hayden; Rep Salinas; Rep Schouten; Rep

Stark; Sen Johnson; Sen Steiner Hayward; Rep Rayfield

**Subject:** Regional Family to Family Networks - Please keep them funded

**Date:** Wednesday, July 22, 2020 10:34:06 PM

#### Hello,

My name is Carla Cudmore and I am from Dallas. With all that is happening and impacting our lives, programs such as the Family to Family Network are even more important. Special education in schools will be stretched to the breaking point as will the families that have relied on the support of Family Networks. Taking care of a child in normal times is difficult but trying to take care of a child with disabilities in the time of COVID can be unbearable. Please protect the Family Network from being eliminated in the DD Services Budget.

Thank you for your time and consideration.

Carla Cudmore

Dallas, OR

JWMHS Exhibits; Rep Nosse; Sen Beyer; Sen Gelser; Sen Hansell; Rep Hayden; Rep Salinas; Rep Schouten; Rep To:

Stark; Sen Johnson; Sen Steiner Hayward; Rep Rayfield

Subject: Save Family Network Funding Thursday, July 23, 2020 8:06:22 AM Date:

image003.png Attachments:

image006.png

#### To Whom It May Concern:

My name is Rondi Delos Reyes and I live in Keizer, Oregon. It is not the time to eliminate funding for Family to Family Networks from the DD Services Budget. It is vital for families to have support and feel connected to systems of support during this pandemic. I have reached out to Creating Opportunities Family Network multiple times over the past two years. We received guidance after our son was diagnosed with ASD. Creating Opportunities was our lifeline to learning about available services, our child's rights as a citizen, and his rights as a student in the public school system. The services these networks provide are vital to local families.

Thank you,

## **Rondi Delos Reyes**

Human Resources Specialist **Options Counseling and Family Services** 

Cell: 503-910-6199 http://options.org







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To: <u>JWMHS Exhibits</u>
Cc: <u>OregonDDC@gmail.com</u>

Subject: Save Family Supports and Family to Family Networks

**Date:** Thursday, July 23, 2020 11:06:52 AM

# Good morning,

I am Chrystal Burns, Program Director for Full Access. Full Access is a case management entity in Eugene, OR that serves adults with Intellectual and Developmental Disabilities. I am writing today to urge you, please, do not eliminate the Family to Family Networks and Family Support program funding from the DD Services Budget. Families need continual access to systems of support during this pandemic and this is not the time to eliminate these programs.

Although we work with adults, many of the families we work with have utilized Family Supports and/or Family to Family Networks in before coming to us. This support was invaluable to these families who are often struggling to find someone who understands the struggles they face and can help problem solve at a peer level. We also have clients who have children of their own with disabilities and could really use these services.

Thank you for your consideration,

Chrystal Burns
Program Director
Full Access

p 541.284.5070 ext. 107 | f 541.284.5067



In an effort to be compliant with Governor Kate Brown's Stay at Home Order, Full Access has temporarily closed the office to the public. The health and safety of our staff, clients, families, and providers are of the highest priority for our agency and we are doing our due diligence to uphold recommendations for social distancing. Please know our staff are continuing to operate behind the scenes and will be committed to providing the same level of customer service that you are accustomed to. General hours have been reduced, but phone calls will still be answered between the hours of 9:30 am and 5 pm. Personal Agents can be reached on their work cell phones and/or email. Please also consult our facebook page for updates from ODDS regarding agency processes and how we are addressing concerns related to COVID-19.

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To: <u>JWMHS Exhibits</u>
Cc: <u>Rep Nosse; Sen Beyer</u>

Subject: SAVE Family to Family Networks & Family Supports Funding in DD Services Budget

**Date:** Wednesday, July 22, 2020 3:17:00 PM

Hi.

My name is Michaela Lukens and I live in Bend, Oregon. I have utilitized CODSN's resources and advice/help multiple times for various reasons for my 6 year old autistic son, Matthew. When we first moved to Oregon the CODSN helped us navigate services in the community that helped Matthew benefit and work towards his personal goals. They guided us with meetings for IEPs for kindergarten. We have attended their support meetings to meet other parents experiencing the same things with their children who have disabilities as well. Please do not eliminate the Family to Family Networks and Family Support program funding from the DD Services Budget. Families need continual access to systems of support during this pandemic and this is not the time to eliminate these programs. Eliminating this budget for DD services will hurt SO MANY families. Please make the right decision!!!

Sincerely,
Michaela lukens
Sent from Yahoo Mail on Android

To: <u>JWMHS Exhibits</u>
Cc: <u>Sen Beyer</u>

Subject: Save our CODSN and our DD services

Date: Thursday, July 23, 2020 7:16:39 AM

My name is Larry Armitage, I live outside of Madras Oregon. Even though i live very far away from Bend oregon where the hub is for CODSN IT IS VITAL for our family. We are a family with a child with serve disabilities. This is our community our contact to other families for help. We live on a farm out in Central Oregon and have very little services if any in some areas. Without this resource and community we would be alone, struggling lost and forgotten. This network is our family our life line. They have helped us find other people, to share resources, help our child be a child an not just a disability. Please save this life saving organization, i don't know what we would have done without it. Thank you.

Larry Armitage

Sent from my T-Mobile 4G LTE Device

To: Rep Nosse; Sen Beyer; Sen Gelser; Sen Hansell; Rep Hayden; Rep Salinas; Rep Schouten; Rep Stark; JWMHS

Exhibits; Sen Johnson; Sen Steiner Hayward; Rep Rayfield

Subject: Supporting Oregon"s Family to Family Networks

Date: Wednesday, July 22, 2020 4:23:51 PM

**Date:** wednesday, July 22, 2020 4:23:51 PM

## To Whom It May Concern,

My name is Heidi Robinson and I live in Hillsboro with my husband and our 3 children. Our daughter, Isabelle, was diagnosed with Kabuki Syndrome at birth and experiences intellectual and developmental disabilities. She is now 10. We moved to Oregon 5 years ago from Arizona and the first thing I did when we moved was look up Oregon's Family to Family Networks. We'd been involved in Arizona's Family to Family Network since Izzy was born and I knew they were invaluable. I was new to the state and applying for and navigating new programs and resources for Isabelle and our Family to Family Networks is where I gained valuable information and learned more about what programs and resources we had access to. As our daughter prepared to enter Kindergarten, we attended trainings through our Family to Family Networks that gave us more information on preparing for her IEP and knowing our parental rights as she entered the school system. We've used our Family to Family Networks to learn how to set up Izzy's ABLE fund, participated in activities they have put on in the community all over Portland, made friendships with other families experiencing disability and I've learned how to be a better advocate for Izzy at the community and state level.

Please do not eliminate the Family to Family Networks and Family Support program funding from the DD Services Budget. Families need continual access to systems of support during this pandemic and this is not the time to eliminate these programs.

Now is not the time to take away valuable resources from our most vulnerable community. Our Family to Family networks make our communities stronger, provide support to families who feel isolated and alone and empower families who experience disability.

Our daughter's diagnosis left us feeling alone. We had to navigate a new future for her one filled with doctor appointments, therapy visits and many unknowns, but we have been continually strengthened and supported by our Family to Family Network on our journey. Our family hopes that the members of the Human Services Ways and Means Subcommittee and the Chair of the Joint Ways and Means Committee recognize the importance of the Family to Family Networks in our communities in Oregon and continue to support them and to prioritize the support of people experiencing disabilities in our state.

Thank you for your time,

Heidi Robinson

Hillsboro, Oregon

Hello, my name is Tara Stoll, and I live in Talent, Oregon. I am writing to you today to express concern for the future of my Family Network. My husband and I have three young daughters, one of whom experiences disability. Our Family Network has provided us the opportunity to find and navigate needed resources, develop friendships and support systems, and keep us from feeling isolated – especially during this time of Covid-19. With Family Networks, many families, including my own, would withdraw from our communities.

Please do not eliminate the Family to Family Networks and Family Support Program funding from the DD Services Budget. Families need continual access to systems of support during this pandemic, and this is not the time to eliminate these programs. I am available to speak to you, should you have any questions.

Thank you for your time and consideration,

Tara Stoll

Talent, OR

From: To: Subject: Date:



### Ways & Means Committee:

Just as any individual going through life's challenges relies on someone with experience and wisdom, families experiencing disability rely on other families experiencing disability. Families are the lifeblood of a precious network offering advice, resources, support, and experience. Nothing can ever replace this network.

Two years ago, our family relocated to Talent, Oregon. Coming from the Midwest, we knew no one. The Family Network, Bridging Communities, reached out immediately to offer support, advice, and friendship...all things we so desperately needed. These connections allowed us to choose the proper school district for our situation, a welcoming dance studio, and a welcoming children's theater group -- all extremely important to our family.

Our child, Olivia (11), experiences disability in the form of Down syndrome. Liv is a 5th Grader, a dancer, an actress, and a friend. Without the Family Network, we would simply be: a family navigating a new world full of uncertainty, relying on formal systems for experience they simply cannot give. I will say it again: Formal systems simply cannot replace the work Family Networks do.

As a Mom, as well as someone tightly involved with our Family Network, I ask you to consider the implications of cutting Family Network funding from the DD Services Budget. Cutting them now would eliminate them entirely. This small investment NOW undoubtedly financially relieves formal supports/systems in the long term. The cost/benefit ratio is in everyone's favor - families AND formalized systems.

Please support Family Networks. We are relying on you to think of vulnerable families, especially during this uncertain time.

Thank you for your time and consideration, Tara Stoll

Ways & Means Committee.

Unto a sary mid-finded gring through life's challenges relies on someone with experience and window, families experiencing disability, rely on other families experiencing disability. Families are the lifeblood of a precison network offering arbier, resources, support, and experience. Nothing can ever replace this notes

Fey come any any containst Palend on The London To Bank Copyrs. Consiste from the Modern Version were seen. The Family Network, Beinging Communication, readed ori membration by older approx, about, and instantiated, these was expectable from the content of above as to charge for pure who did did for our attained, and the content of above as to charge for pure who did did for our attained, and the content of above as to charge for pure who did did for for our attained, and the content of above as to charge for pure who did did for for our attained and the content of above as to charge for pure who did did for for the content of above as to charge for pure who did did for for our attained and the content of above as to charge for the pure who did not the pure who did not for the pure who did not for the pure who did not the pure who did not



To: JWMHS Exhibits; Rep Nosse; Sen Beyer; Sen Gelser; Sen Hansell; Rep Hayden; Rep Salinas; Rep Schouten; Rep

Stark; Sen Johnson; Sen Steiner Hayward; Rep Rayfield

Subject: The importance of family to family networks

Date: Thursday, July 23, 2020 9:22:47 AM

#### Dear Legislators,

My name is Jessica Brosius and I live in Turner Oregon, In Marion County. Please do not make budget cuts to areas of DD Services at this time, specifically in the areas of family networks.

COVID-19 proposes unique to challenges to individuals and families experiencing disability. People experiencing disability already have to work extra hard to fight isolation in every area of their lives, COVID-19 makes this exponentially harder.

My daughter experiences Down Syndrome. I have advocated for her to be fully included in the General Ed Classroom where she is a full contributing member of her community. Due to COVID-19, she has no inclusive education and is instead isolated at home. All this to say, with all these extra challenges, please do not remove additional supports that are available to families and individuals to connect. Networks like Creating Opportunities are vital - especially during these isolating times.

Specifically, our family has received valuable information and support from Creating Opportunities, that was not available elsewhere. I have received help with employing Personal Support Workers, help with advocacy training, and community events and connections.

Thank you for your time, please advocate for those who do not have a voice, and for those experiencing disability. Please do not remove funding for these family to family networks that are so needed.

Jessica Brosius

Greetings Ways & Means Human Services Subcommittee,

My name is Heather Hopkins-Slechta (Slek-ta). I am the Executive Director of Full Access High Desert, a support services brokerage serving 400 individuals with intellectual and developmental disabilities (I/DD) in Deschutes, Crook, Jefferson, and Lake counties.

Please do not eliminate the Family to Family Networks and Family Support program funding from the DD Services Budget. Families need continual access to systems of support during this pandemic and this is not the time to eliminate these programs.

Family Support Networks provide critical services for parents, individuals with intellectual and developmental disabilities, and their community partners. They help bridge the gaps and provide guidance for families who are already facing complex and challenging needs navigate through a complex system.

Family Support program funding has allowed families to acquire good and services to meet needs that have arisen due to the pandemic. With families quarantining to protect the health of their child with I/DD, these funds have help create safe spaces that are more enriching.

Especially during this time of the pandemic, families of children with I/DD need all the support they can get. It is exceptionally difficult for those with I/DD and their families to address the anxiety, fear, stress, and isolation that come from quarantine. Family Networks offer support in connecting families to vital services and provide a safety net to avert crisis. The Family Support funding allows for goods and services to address disability related supports that would otherwise be unavailable. These programs address the health and safety all Oregonian's deserve.

Please keep the \$665,000 to protect Family to Family Networks and the \$540,000 to preserve the Family Support program in the DD Services Budget for the remainder of biennium.

Sincerely,

Heather Hopkins-Slechta Executive Director

Full Access High Desert

From: To:

Subject: Ways and means human services sub committee

**Date:** Thursday, July 23, 2020 2:17:36 PM

## Hello,

Please remove these programs from the list of budget cuts.

# Family support funds

# Family to family networks

This directly affects my 3 year-old girl who gets a tiny \$30 per month in disability and does not qualify for Developmental Disability and K plan despite being disabled. We struggle to purchase food, pay our bills and of course, pay for much needed care and medical supplies not covered by medicaid.

Dear Members of the Ways and Means Human Services Subcommittee,

My name is Stephanie Hunter and I live in Redmond. I am writing to ask that you do not eliminate the Family to Family Networks and Family Support program funding from the DD services budget. I am writing from the perspective of a parent that has a daughter with autism, a foster parent for a young man with autism and intellectual disability, and as an Oregon Behavior Professional that works directly with families in Central Oregon. I am also a board member for the Central Oregon Disability Support Network.

My daughter is 17 and she was diagnosed with autism when she was 3 years old. I started down the road of "therapy parent" and listening to professionals about all of the ways she needed to be "fixed". Thankfully, her early intervention program connected me with the local family networks in Portland where we lived at the time. I went to a free workshop hosted by this group and it was about a strength-based approach to raising our kids with disabilities called *person-centered planning*. Talking to other parents was transformative. Learning to focus on my daughter's strengths vs. fixing her challenges has had everything to do with her success. All along the way, the family network has been there on our path. When we moved to Central Oregon I did not worry because I knew there was a family network there waiting for us. My daughter has grown up only seeing her disability as an attribute and not a deficit. She is a confident and brilliant young person that I do not doubt will be leading our state and country in the near future. The values of the family network that were there for us 14 years ago have been a part of shaping her success.

My foster son did not come to our home raised with the same values. Due to lack of services in his home county they could not manage his challenging behavior at home. They chose to have him go into a children's residential group home where he lived for 3 years before we took him in as foster parents. He was on a path to live the "service system life" of receiving services but was not challenged to do more. After 2 years in our home with the same values we learned from the family network he is talking about his future apartment vs. group home. He is thinking about the different types of jobs he wants in the future. Thanks to these values my kids will require less services and live their best lives.

I see the positive impact of family support funding directly in my work as a behavior professional. When these supports are limited or not available it increases the likelihood that a child will end up in residential services. These services cost the state much more money. The use of hospitals and police to mitigate crisis situations is another expense. I have worked directly with families for over 14 years, trust me when I say that families are most often frugal. They believe that using family support services takes away from someone that needs it more. I have seen the equipment, services, and supports have an immediate positive effect on crisis situations.

Thank you for the work you are doing in these difficult times in our state and nation. I am hopeful that Oregon will continue to care for our citizens that experience disability, their families, and support providers. It is not only a decision of integrity but it is also more cost effective than funding a service system life or frequent use of crisis services.

Sincerely,

Stephanie Hunter Stephanie.c.hunter@gmail.com Hello name is Lucia Mendoza,

I am a Marion county resident. I am writing this letter because I would like to ask that you not eliminate funds from family to family networks from DD Service Budget especially during these difficult times with COVID19. It is important for families to be able to stay connected to supports during this difficult time of uncertainty. These services support families through many challenges in raising children with disabilities. Creating Opportunities is a great resource for our families because they are strengthening families through support, information, advocacy, leadership activities and family events. They also strengthen communities through awareness and collaboration. They provide free trainings to the community as well. I hope you can take some time to see all the good they do for your constituents.

#### Co-Chair and Members of the Committee:

Good afternoon Co-Chairs Nosse and Beyer and Members of the committee, my name is Emilie Wylde Turner and I am from Medford, Oregon. My youngest son Parker is 15 years old, experiences autism and I share this story today with you with his permission. Last summer he began to seriously struggle with Obsessive Compulsive Disorder. OCD is something that many people throw explain their desire for order in their refrigerator or cleanliness in their car, but what my son experienced was much different. It was the inability to leave the bathroom for HOURS in the middle of the night because he was has to go through certain patterns before he could open the door. It was having to open and close drawers and kitchen cabinets in the same order DOZENS of times in a specific routine as he went through certain thoughts in his head and if something new crept in, he would have to start the whole thing over. We went through bottles of hand soap a week and even the seemingly simplest of tasks became monumental. He cried and begged for me to help him and I had no idea how. It escalated to a crisis situation overnight. We weren't sleeping. We were barely eating. I called his pediatrician and he was able to get onto medication but it would take weeks to build up in his blood stream. I called to get him into counseling but that was a lengthy process as well. I read books. I googled everything I could online because I was desperate to help my son— but all that did was terrify me more.

If you have ever been in a world altering situation or place in your life, what you need is someone who has been in that experience before. Someone who can reach back a hand and take yours and tell you to "keep breathing, it's going to be ok." This is when I needed the family network. I was able to connect with another parent whose child has also has significant OCD experiences and their recommendations and understanding is what kept my head above water for several weeks. COVID 19 has brought on a lot of anxiety in my son, as it has for many people and as such his OCD has escalated once again. Again, we are seeking the medical and more formalized helps, but the most critical support that I need is that beautiful work that is outside of the scope of work of a services coordinator. It is the work that for years the family networks do to support hundreds of families across the state like mine. Often times, this level of support is what keeps us out of costly crisis services.

The Family to Family Networks are the formal structure that connects families to other families—without it, families cannot find each other. These networks are supporting over 12,000 families and 1800 community partners for an investment of \$665,000 for the remainder of this biennium. Eliminating the 2<sup>nd</sup> year of this funding is elimination of this program. This program has ENORMOUS impact for a small financial investment.

Do not make cuts here that will impact families like mine in this way when we are already physically isolated during this COVID crisis. Thank you.

Together with you,

Emilie Wylde Turner, Medford OR

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July 23, 2020

TO: Ways and Means Human Services Subcommittee

FROM: Dr. Audrey Cramer Eugene, Oregon

Dear committee members.

I am writing with sincerity and urgency as you begin to make decisions about the upcoming budget. I am the mother of a 14 yr. old son who experiences autism and other disabilities.

Some of the decisions you are in the process of making include the funding for DD Services. Part of this funding supports the Family to Family Networks and Family Support programs. One of these programs, the ARC of Lane County's Families Connected Program has been a lifeline for my family and many others. Let me explain.

I moved to Eugene in January, 2009, with my (then) 2 yr. old twins. One twin, my son Adam, has profound developmental disabilities and had been receiving help form UCLA's early childhood support programs. When I moved to Eugene, I knew no one and had no idea where to turn. Once I learned about the Families Connected program, our lives begin to change substantially.

These are some of the ways my son (and me, his mom) have benefitted from Families Connected:

- 1. Learning about community resources and assistance
- 2. Meeting other parents who are raising children with special challenges
- 3. Attending meetings and workshops on a variety of topics
- 4. Learning to become advocates for children in the school system
- 5. Joining other parents to share ideas and resources
- 6. Having access to school year and summer activities for children with challenges (when regular camps and programs cannot admit and/or support our children). Examples include field trips, crafting, holiday celebrations, fishing, hiking, etc.
- 7. Allowing my son to meet peers and engage with other children in a caring, supportive, non-judgemental way, that allowed him to develop the critical social skills he needs.

My son, Adam did not begin to talk until he was six years old. Because of Families Connected, I was able to ensure that he received the occupational and speech therapy he needed. Throughout all his school years, up until now (my twins start high school this fall), Families Connected has given me the support, the community, and the optimism I needed to guide my son to success. Today, although Adam will always have some special differences, he speaks with fluency, is a positive self-advocate, AND, most importantly, is completely on track academically as his classmates!!! None of these things could have happened without the support of Families Connected.

Young children with special challenges, and their families, must continue to have access to the support systems that make a fulfilling life possible.

Investing in Oregon's family networks, funded through DD Services, is a wise decision that will have positive repercussions for all Oregonians.