Allow Oregon's Disabled Kids to Keep Parent-Caregivers

A proposal to widen and continue a pandemic-era policy that kept families together and vulnerable children safe and healthy.

Compiled by Advocates for Disability Supports

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…and hundreds more supporters

Parent Caregivers for Children

Proposal

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Introduction

The problem

With the 2014 adoption of the K-plan, Oregon made huge strides for children with intellectual and developmental disabilities. But unfortunately for many, the Medicaid program was barely more than a mirage of services.

For years, parents struggled to find adequate in-home caregivers for their children. A review of 5,646 individuals showed that in 2018, only 59% of the combined allotted attendant care hours were utilized. As community members, we know that many of those hours were filled by non-parent relatives due to the difficulty of finding other qualified applicants and the childrens' need for consistent, stable, loving caregivers.

With the post-COVID-era labor shortages and nursing crisis, this problem has only gotten worse.

The solution

During the pandemic, Oregon inadvertently entered into a “pilot program” of allowing some parent-caregivers to be paid. The results were stunning. Families escaped homelessness, children avoided institutionalization, clients were happier, healthier and more included in the community.

We are a broad coalition of parent advocates, disability justice self-advocates, I/DD service leaders, and medical providers from a variety of socioeconomic, ethnic, geographic and political perspectives with one goal — to save and improve the lives of Oregon's disabled children by working collaboratively to ensure **all children with in-home caregiver hours have the freedom to choose their parent as a provider.**

Children with disabilities rely on their caregivers who know them on an intimate level. Parents are able to recognize when their child is experiencing an absence seizure or respond to respiratory concerns prior to having a life-threatening medical emergency. Parents are able to comprehend the needs of their child’s subtle communications, to know their sensory triggers, and how to create important safety plans.

Disabled children deserve to be cared for by the most loving, knowledgeable, and consistent caregivers. Their physical, mental, and emotional wellbeing is directly tied to their environment, which was proven to be vastly improved by this temporary program.

Legal Arguments

In our appendices you can read many searing and emotional arguments for why minor children who qualify for in-home caregiver supports should be allowed to choose their biological or adopted parent as their provider. Our movement is supported by Oregonians of all backgrounds, including thousands who have signed our first and second petitions, the more than 200 I/DD community leaders who signed our letter to policymakers, the entire Medicaid Advisory Committee and the Oregon Disabilities Commission.

In this introduction we have compiled many legal arguments for continuing Oregon's enormously successful program of paying parent-caregivers of minor children. This has been temporarily allowed during the federal COVID-19 public health emergency and has shown dramatic effects to participant families. As far as we can tell, this temporary program is only prevented from continuing by a bizarre and discriminatory carve-out in OAR 411-375-0020 2(b)(A):

> (b)An independent provider may not be authorized to deliver services to an individual in any of the following circumstances:
>
> (A) The individual is a child and the independent provider is the parent of the child unless, for the duration of the COVID-19 public health emergency, the parent meets the qualifications in section (1) of this rule, resides with the child, and the child:
>
> **(i)**
>
> Meets the enrollment criteria for any of the Children's Intensive In-Home Services programs; or
>
> **(ii)**
>
> Has a service level of at least 240 hours per month.

In fact, Oregon itself made fabulous arguments for why this program should be allowed in its temporary filing. These arguments will still be true after the federal COVID-19 public health emergency expires.

> Failure to act promptly and immediately amend OAR 411-375-0020 will result in serious prejudice to children receiving developmental disabilities services and their parents.
>
> Failure to act promptly and immediately amend OAR 411-375-0020 will prevent ODDS from allowing the parent of a child meeting certain enrollment or service level criteria to deliver services as the child's independent provider for the duration of the COVID-19 public health emergency.

The families with lived experience say the freedom to employ parents of client children *is* the support they need. We have potential plaintiffs who say barring them from these jobs will directly result in the institutionalization of their child. These restrictions and their outcomes are completely contrary to the spirit of Oregon's moral and ethical obligations to the families of its most vulnerable children and are also in direct violation of ORS 427.007 1(c):

> Support for families with children who have developmental disabilities must be based upon principles of choice and self-determination, with families receiving the support they need to support their children at home.

Strategic plan alignment:

This program also directly aligns with the core values in Oregon's I/DD strategic plan:

- Choice, self-determination and person-centered practices
- Children and families together
- Health, safety, and respect.
- Community inclusion and community living
- Strong relationships
- Service equity and access

The strategic plan goes on to list goals that people with lived experience say directly point to a program like this.

> Goal # 2: "Honor and support people to make their own choices about who they want to be and what they want to do in their life."

ODDS says it will do this by following National Core Indicators (NCI). These are not enumerated in the Oregon report and there is little general data on the minor child population's wishes. However, a 2015 NCI slideshow here details the results of adult choice. Of note, 77 percent of adults with I/DD who use a self-directed care model choose their parents as caregivers, compared to 32 percent of members who are not in self-directed care models. They also report higher autonomy and more ability to go shopping and on vacation. (Also of note, self-advocates quoted in that report noticed that: "Agencies say they believe in self-determination but then don't want to give up the money (or the power).")

Explicit in the strategic plan is also that families are given the supports they need. Families will readily tell you that being paid for their labor is the support they need.

> Goal #4: "Provide families the amount and type of supports they need to raise their children at home, or when necessary, in another family home within their community."
>
> **Our "North Star:"** Children live in their family home, or a family-like environment, have typical childhood experiences and are supported along a trajectory toward full lives where integrated supports help them be independent, active members of their community.

Impact of “pilot” program:

Advocates for Disability Supports conducted a survey that captured 94 families who said they were among the few hundred who qualified for limited and temporary paid parent-caregiver program during the pandemic. Their responses are stunning in illustrating the success of this program. It has transformed the lives of these children — 13.8 percent of the families were saved from the brink of homelessness, half of families reduced their need for other public assistance programs, hospitalizations dropped dramatically and the vast majority of families reported their disabled children were happier, healthier and more included in their communities. Many other families of children requiring services who were NOT eligible for this program also explained in survey responses how an expanded and permanent program would dramatically improve their lives. The results were reported here.

- 90.3 percent of respondents said their child’s physical health improved
- 89.2 percent of respondents said their child’s mental health improved
- Before the program, many of these children spent days and days in the hospital. Seventy-two families said their children were hospitalized one or more days every year on average before the program, 15 of those for 10 days or longer. After the program? The number of children who did not need to visit the hospital at all nearly doubled. Only 32 needed hospitalization, and only four of those were for 10 days or more.
- 69.9 percent said their child was more included in the community after the program and 28 percent said it was about the same.
- Families were on a wide range of public assistance programs prior to this income — more than half said they were able to reduce their reliance on those.
- What about the narrative of greedy parents taking up all the hours? Most (58.5 percent) continued to hire outside providers and those who didn’t mostly said it was because they couldn’t find anyone or they were too worried about infections.
- All families reported improvement in financial freedom. Before the program, 13 said they were practically homeless and another 38 said they were only a step away.

Federal law:

This policy is not prohibited by federal law. The National Academy for State Health Policy put together a report showing several ways that states are doing programs like this and Arizona recently passed another one. Colorado’s permanent paid parent caregiver plan has shown a six-fold reduction in hospitalizations. Indeed, even Oregon’s 1915(k) waiver as written does not prohibit parents of minor children being paid as caregivers.

> "Natural supports are identified during the person centered service planning process and utilized when available to the individual. Natural Supports are defined as resources available to an individual from their relatives, friends, significant others, neighbors, roommates and the community. Natural supports are determined to be available when an individual listed above is willing to voluntarily provide the identified services and the service recipient is willing to accept services from the natural support. If the natural support is unwilling or unable to provide the identified services, paid supports will be provided. **Nothing in the natural support determination prevents the Department from paying qualified family members who**

> **are performing paid work.** The state will not provide services or supports that are within the range of activities that a parent/legally responsible individual would ordinarily perform on behalf of a child without a disability or chronic illness of the same age."

Oregon conducts a meticulous annual assessment (the Oregon Needs Assessment) of the needs of client children and how many hours of work per month their needs constitute above those of a neurotypical child their age. When hired caregivers are absent or unable to be found, that work does not disappear. It is the right thing to do to pay whomever is performing that labor, regardless of genetic proximity to the child client. Oregon needs to pay parents who are tube feeding, diaper changing or managing their children's behaviors in ways that are not "within the range of activities" they would "ordinarily perform."

Workforce issues:

In a recent webinar on family caregivers, Connecticut noted a six-fold increase in the caregiver workforce when they allowed family caregivers to work these jobs, from 2,477 to 14,680 workers. Connecticut Co-Leader of the Community Options Unit Dawn Lambert said Connecticut never would have reached their workforce goals without that allowance.
"There is nothing to me like a family member, who wants to be there through that journey, to be paid to be there, if the member wants it... to me there can be nothing more dignifying than that," she said. Lambert also said institutionalization of disabled people decreased with improved use of paid caregivers, including family.

Oregon's current flawed plan:

Instead, as the Oregon DD Coalition has stated (whose opposition is cited by the Office of Developmental Disabilities Services as their reason for not going forward with this plan without legislative input), the state would rather:

> "[Invest] millions in new rate models, increased wages, collective bargaining and more to build the personal support worker and direct support professional workforce to meet the demands. Much of this has happened in the last few years. As wages increase and career ladders strengthen, so will this workforce." [DD Coalition, April 14, 2022]

These methods have been tried and found wanting. In 2018, state data showed that only 59 percent of hours were utilized, many due to families with non-parent relatives available to work those hours. Children do not want a parade of unfamiliar adults performing intimate tasks on them, which is what Activities of Daily Living are. Children with medical complexity and significant mental health conditions — the children who qualify for in-home caregiver hours —

require stability and safety. The childhood envisioned by the state is not healthy, realistic or appropriate.

Budget implications:

Paying parents is revenue-neutral and would likely actually save the state money. The hours are allocated and the state says it is committed to filling the hours. The children's needs do not disappear when hired workers are absent or unable to be found. Unless the state is relying on exploiting the free labor of parents, the budget for this program is already part of the in-home caregiver program as it exists.

Additionally, the program is shown to save taxpayer dollars. Families have gotten off other public assistance programs; avoided costly medical foster, group home or care facility placements; and have improved the health and wellbeing of these children — all of whom are on public health insurance.

Conclusion:

We have a program that is proven to dramatically improve the health and wellbeing of children and families, both here in Oregon and in states across the nation. The time has come to implement it widely and permanently.

Survey Results

Keep the anxiety knots in my stomach at a mild level. Before being a paid caregiver, my knots were keeping me awake at night.

We could save for our daughter's future (fund her ABLE savings acct), modify our home or build an accessible one, buy a new van to be converted to a wheelchair van.

I can continue to teach my kiddo life skills to navigate the world around him. Haven't been able to find a caregiver that will take my kiddo in public.

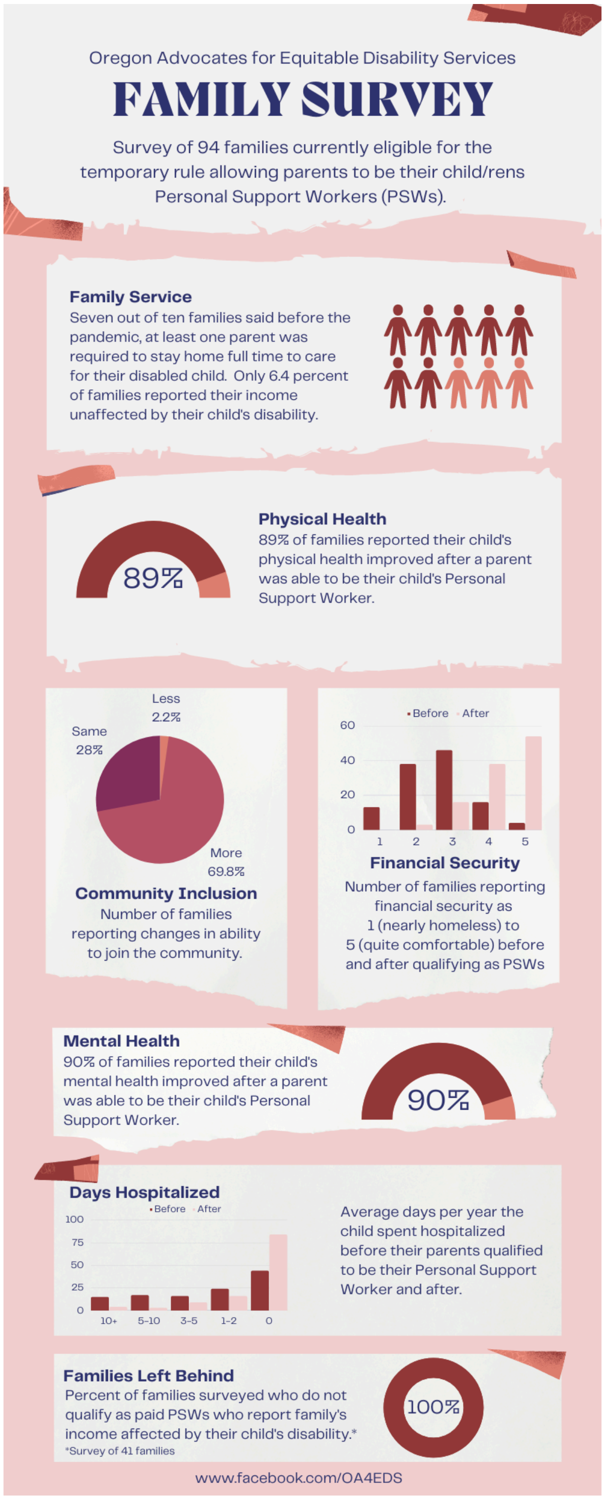
What one thing would change for your family if you were able to be paid for the attendant care hours you provide your disabled child?

Be able to afford to take my kid out to community activities and work in his community goals. Not have to stress that a caregiver won't show up when they say they will. Won't have to stress they won't properly manage his diabetic needs.

I'd be able to keep my child at home and not have to institutionalize her to keep a roof over my head.

I could afford fun gym classes to improve physical therapy for my daughter.

It would dramatically decrease my stress and anxiety over how to hold a job and earn a salary to support my family while making sure my son is taken care of. We could save for the purchase of an accessible van.



Oregon Advocates for Equitable Disability Services

FAMILY SURVEY

Survey of 94 families currently eligible for the temporary rule allowing parents to be their child/rens Personal Support Workers (PSWs).

Family Service
Seven out of ten families said before the pandemic, at least one parent was required to stay home full time to care for their disabled child. Only 6.4 percent of families reported their income unaffected by their child's disability.

Physical Health
89% of families reported their child's physical health improved after a parent was able to be their child's Personal Support Worker.

Community Inclusion
Number of families reporting changes in ability to join the community.

Financial Security
Number of families reporting financial security as 1 (nearly homeless) to 5 (quite comfortable) before and after qualifying as PSWs

Mental Health
90% of families reported their child's mental health improved after a parent was able to be their child's Personal Support Worker.

Days Hospitalized

Average days per year the child spent hospitalized before their parents qualified to be their Personal Support Worker and after.

Families Left Behind
Percent of families surveyed who do not qualify as paid PSWs who report family's income affected by their child's disability.*

*Survey of 41 families

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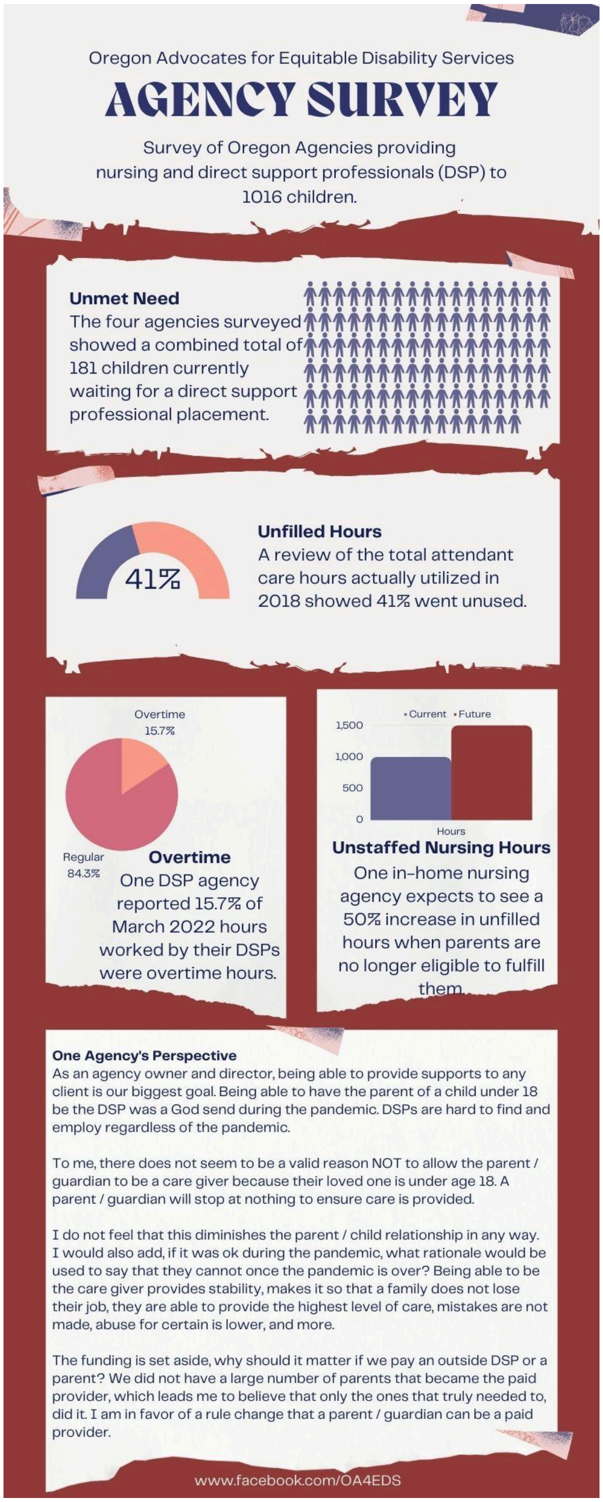

Oregon Advocates for Equitable Disability Services

AGENCY SURVEY

Survey of Oregon Agencies providing nursing and direct support professionals (DSP) to 1016 children.

Unmet Need
The four agencies surveyed showed a combined total of 181 children currently waiting for a direct support professional placement.

Unfilled Hours
A review of the total attendant care hours actually utilized in 2018 showed 41% went unused.

Overtime
One DSP agency reported 15.7% of March 2022 hours worked by their DSPs were overtime hours.

Unstaffed Nursing Hours
One in-home nursing agency expects to see a 50% increase in unfilled hours when parents are no longer eligible to fulfill them.

One Agency's Perspective
As an agency owner and director, being able to provide supports to any client is our biggest goal. Being able to have the parent of a child under 18 be the DSP was a God send during the pandemic. DSPs are hard to find and employ regardless of the pandemic.

To me, there does not seem to be a valid reason NOT to allow the parent / guardian to be a care giver because their loved one is under age 18. A parent / guardian will stop at nothing to ensure care is provided.

I do not feel that this diminishes the parent / child relationship in any way. I would also add, if it was ok during the pandemic, what rationale would be used to say that they cannot once the pandemic is over? Being able to be the care giver provides stability, makes it so that a family does not lose their job, they are able to provide the highest level of care, mistakes are not made, abuse for certain is lower, and more.

The funding is set aside, why should it matter if we pay an outside DSP or a parent? We did not have a large number of parents that became the paid provider, which leads me to believe that only the ones that truly needed to, did it. I am in favor of a rule change that a parent / guardian can be a paid provider.

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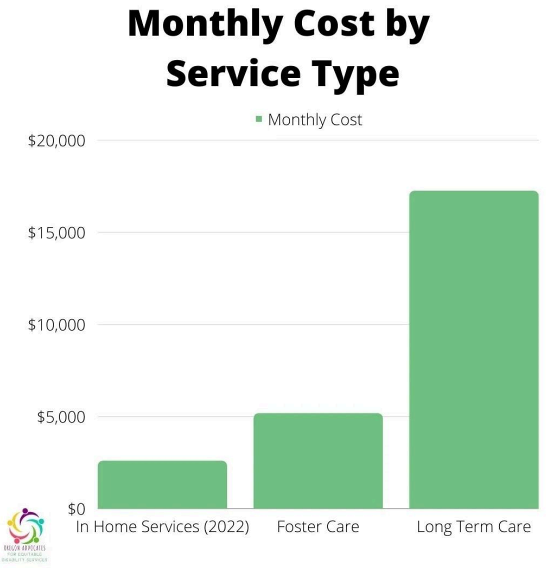
ODDS Data

Through consistent advocacy, we have received long awaited data from ODDS. This data confirms in-home services are fiscally sound, highlights the unmet need of the 0.6% of Oregon's most vulnerable children, and shows the long waitlists children face for the most in depth services. Allowing Oregon's 5,300 most vulnerable children to choose a parent as their caregiver ensures children remain in their homes receiving the support they need now.


Monthly Cost by Service Type

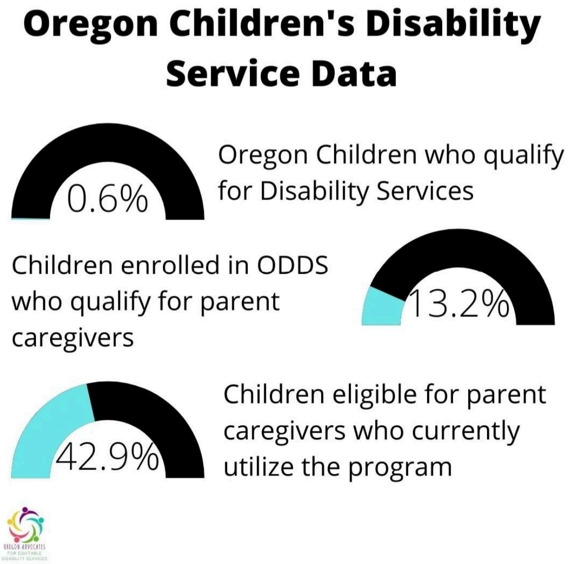

Oregon's Children's Intensive In-home Services

Children currently pending referral for Behavior Model Waiver

Children currently pending referral for Medically Involved Model Waiver

200

Children allowed on each of the three CIIS waivers


Oregon Children's Disability Service Data

0.6% Oregon Children who qualify for Disability Services

Children enrolled in ODDS who qualify for parent caregivers 13.2%

42.9% Children eligible for parent caregivers who currently utilize the program

Press Coverage

THE LUND REPORT

Oregon's most vital source of health news

Oregon Parents Fight To Keep Care Payments As Pandemic Winds Down

PREMIUM

By: Christian Wihtol

Mick Stevens of Tigard put his paralegal career on hold to take care of his daughter, Jillian, during the pandemic./Courtesy of Mick Stevens.

Tigard resident Mick Stevens never had an easy time finding trained caregivers to look after his daughter Jillian.

Jillian, 11, is quadriplegic with cerebral palsy, and is also autistic. With Medicaid paying her caregivers only $16-$19 an hour, money was not a big draw. And besides, most caregivers were scared away by the complexities of her medical and physical needs, Stevens said.

- Oregon parents of disabled kids seek reimbursements from the Portland Tribune.
- We Are All In This Together on KBOO
- "Oregon Parents Fight To Keep Care Payments As Pandemic Winds Down" on The Lund Report
- KBOO interview with Parent Advocate Gabriel Triplett
- KGW story Parents with disabled children risk losing caregiver funding with nowhere else to turn
- My view: Disabled children, families hurt by unfair Oregon rule
- Mindful Inspiration Champion Podcast: Labor of Love - Ep. 73
- Medical Motherhood: The case for paying parents of disabled children
- Medical Motherhood: Mother fears being forced to choose between her daughter and homelessness
- Medical Motherhood: Oregon families of disabled kids rally to demand parent pay
- Business Insider: A mom of a disabled child receives $5,000 a month through an Oregon paid caregiver program — but she's scared of what will happen when the payments stop this year
- Statesman Journal: Parents paid as caregivers for kids with disabilities may lose funds

Other States' Plans

NASHP
NATIONAL ACADEMY
FOR STATE HEALTH POLICY

State Approaches to Reimbursing Family Caregivers of Children and Youth with Special Health Care Needs through Medicaid

January 15, 2021 / by Olivia Randi, Eskedar Girmash and Kate Honsberger

State Medicaid agencies have developed unique approaches to finance family caregivers who provide home health services to children and youth with special health care needs (CYSHCN). As states face home health service workforce shortages, COVID-19 restrictions, and rising costs of care, policies that allow reimbursement of family caregivers can alleviate these challenges and provide essential support for families. This report explores how states have used a variety of waiver authorities to promote reimbursement of family caregivers and their CYSHCN.

- National Academy for State Health Policy report: State Approaches to Reimbursing Family Caregivers of Children and Youth with Special Health Care Needs through Medicaid
- Arizona
- Colorado
- California
- Connecticut (limited)
- Minnesota

Appendix A: Sign-on letters

Feb. 24, 2022

Subject: Letter regarding paid parent caregiving to minor disabled children under Medicaid Home & Community Based Services

To the policymakers of Oregon,

We the undersigned feel that it is time for Oregon parents of disabled children to have direct access to the money taxpayers have dedicated to their children.

Oregon Medicaid has an expensive and dysfunctional program for in-home caregiver supports of disabled children broadly known as K-plan. Since 2014, Oregon parents have tried to make this program work for their minor children — but for most it has been a mirage of support, wasting time and energy they could have been spending on their children's care.

In 2021, through the temporary federal public health emergency, parents were suddenly allowed access to these caregiver dollars. The changes have been stunning. Families who were reduced to single-income households due to the birth or adoption of a child with significant disabilities were suddenly able to pay their bills. Mothers who hadn't been able to earn a paycheck for years due to the extraordinary care needs of their children suddenly had economic capital and freedom.

But, most importantly, the love, care and stability that Oregon's disabled children received grew immeasurably. Families could afford to buy specialized toys, clothes, equipment or fund needed therapies or ABLE accounts. Some children were likely even saved from medical foster care and homelessness.

We refuse to go backwards. No more mirages of support. No more hoops to jump through. No more discrimination against parents.

We call on Oregon policymakers to adopt a Medicaid program that includes biological and adoptive parents as candidates for in-home caregivers — "Personal Support Workers" or "Direct Support Professionals" — to their minor disabled children. Whether this is a program like Colorado's or

California's or Oregon's own innovation, it is past time for policymakers to do what is best for the state's most vulnerable families.

Sincerely,

Elected Officials

Sen. Lew Frederick, Senate Majority Whip
Sen. Chris Gorsek, Full Joint Committee on Ways and Means
Sen. Tim Knopp, Senate Minority Leader
Sen. Deb Patterson, Chair, Senate Committee on Health Care
Sen. Kim Thatcher, Senate Interim Committee on Judiciary and Ballot Measure 110
Sen. Lee Beyer, Senate Interim Committee on Finance and Revenue
Sen. Rachel Armitage, Senate Interim Committee on Finance and Revenue
Sen. Bill Hansell, Co-chair, Senate Committee on Conduct
Sen. Bill Kennemer, PhD, retired clinical psychologist, Senate Interim Committee on Human Services, Mental Health Recovery
Sen. Brian Boquist, Vice Chair, Senate Interim Committee On Finance and Revenue
Sen. Akasha Lawrence Spence, Co-chair, Joint Interim Committee On Ways and Means Interim Subcommittee on Transportation and Economic Development
Sen. Dennis Linthicum, Senate Interim Committee On Health Care
Rep. Sheri Schouten, House Interim Committee on Human Services
Rep. Christine Goodwin, House Interim Committee on Health Care, House Interim Committee on Behavioral Health
Rep. Duane Stark, Joint Interim Committee on Ways and Means, Subcommittee on Human Services
Rep. Barbera Smith Warner, House Interim Committee on Education
Rep. Susan McLain, Joint Interim Committee on Ways and Means
Rep. Dr. Cedric Hayden, Vice-Chair, Oregon House Committee on Health Care
Rep. Jessica George, House Interim Committee on Education
Rep. David Gomberg, Co-Vice-Chair Joint Interim Committee on Ways and Means
Rep. Courtney Neron, Vice-Chair, Oregon House Committee on Education
Rep. Rachel Prusak, Chair, Oregon House Interim Committee on Health Care
Rep. Dacia Grayber, Oregon State Representative
Rep. Anna Williams, Chair, Oregon House Interim Committee on Human Services
Rep. Greg Smith, Joint Interim Committee on Ways and Means
Rep. Travis Nelson, House Interim Committee on Behavioral Health, House Interim Committee on Human Services
Rep. Jack Zika, House Interim Committee on Early Childhood, House Interim Committee on Housing
Rep. Paul Evans, Co-Chair, Joint Interim Committee on Ways and Means, Interim Subcommittee on Public Safety.

Rep. Ron Noble, House Interim Committee on Health Care, House Interim Committee on Human Services
Rep. Mark Owens, House Interim Committee on Human Services
Rep. Raquel Moore-Green, Vice Chair, House Interim Committee on Behavioral Health
Rep. John Lively, House Interim Committee on Behavioral Health
Rep. WInsvey Campos, Joint Emergency Board Subcommittee On Human Services
Rep. Boomer Wright, House Interim Committee On Behavioral Health, House Interim Committee On Early Childhood, House Interim Committee On Education
Christine Drazan, Gubernatorial Candidate, Former Minority Leader for the Oregon House of Representatives
Betsy Johnson, former Oregon State Senator, Gubernatorial Candidate
Mayor Rick Hobart, Vernonia, OR
Julie Parrish, former Oregon State Representative
Chloe Eudaly, former Portland City Commissioner
Paul Anthony, former Portland Public Schools board member
Mike Rosen, former Portland Public Schools board member
Christy Thompson, school board member

Community Leaders/Disability advocates

Laddie Reed, Oregon Disability Justice Advocate
Joe Wykowski, founder of Community Vision
Jill Escher, President, National Council on Severe Autism
Katherine Ball, Family Services Director, UCP Oregon
Jess Lindley, self-advocate
Allen Hines, Director of Real Choice Initiatives
Nico Serra, Disability Justice Organizer
Cheryl Green, Media Accessibility Advocate
Jake French, Professional Speaker and Disabilities Advocate
Nicolas Brown, Self Advocate & Board Member of YASA (Young Self Advocates of America)
Ian Jaquiss, ADA Coordinator, OHSU
Shasta Kearns Moore, Medical Motherhood, Clackamas DD Council, parent
Emily Fern Dayton, MS, parent
Lisa R Ledson, RN, BSN, SERV-OR, Clackamas DD Council, parent
Gabriel Triplett, Spiritual Director, Community Advocate
Jenny Hoyt, UCP Oregon Board of Directors
Romi Ross, M.S., Board Certified Behavior Analyst
Kårun Virtue, Chair of Advancing Consumer Experience (ACE) - Voices of Consumers Advocating for Life (VOCAL), Medicaid Advisory Committee member
Cameron Herrington, Living Cully (affiliation for identification purposes only)

Penny FitzMaurice, Former Oregon State Ambassador, Rare Action Network
Kelsey Smith, foster parent/advocate
Hayley Palmer, parent advocate
Lenore Eklund, parent advocate
Sylvia Triplett, parent advocate
Tina Stracener, parent advocate
Calli Ross, parent advocate
Jennifer Murphy, parent advocate
Michael Paruch, parent advocate
Mellani Calvin, ASSIST Program Founder/Director
Tamara Bakewell, Former Medicaid Advisory Member, advocate for Children and Youth with Special Health Needs
Elaine Piper Vardas, parent and disability advocate
Matt Faler, parent and podcast host Mindful Inspiration Champion
G Cody QJ Goldberg, parent and Co-Founder of Harper's Playground
Kristina Gollier, parent & advocate

Medical Professionals

Kurt Freeman, PhD, ABPP, Director of the OHSU Institute on Development and Disability, Professor of Pediatrics, OHSU Doernbecher Children's Hospital.
Dr. Benjamin Hoffman, M.D., FAAP, FCCM, Professor of Pediatrics, OHSU Doernbecher Children's Hospital, Director Oregon Center for Children and Youth with Special Health Needs
Dr. Dana A. Braner, M.D., FAAP, FCCM, Credit Unions for Kids Chair, Professor and Chair, Department of Pediatrics, Physician-in-Chief, OHSU Doernbecher Children's Hospital
Stephanie Hunter, Behavior Professional and Child Foster Provider
Raelynne Virshup, RN, BSN, nurse manager, EQC Home Care Agency
Dr. Adebimpe Adewusi, pediatrician and parent
Debra Kannan, parent, Licensed Mental Health Therapist Intern, DSW.
Kimie A Frakes Mental Health Therapist MSW, LCSW
Dr. Pari Faraji, Assistant Professor, OHSU Child and Adolescent Psychiatry
Dr. Cedar Levine, DPT, early intervention specialist/physical therapist
Christy Fawcett, MSN, RN, complex needs nurse
Richard Keuneke, RN, retired
Gerald Keuneke, RN, Retired
Carl Edward Stracener Jr., MA/QMHP
Pamela Keuneke, RN, retired
Karen Keuneke, MSN, RN, CIC
Dr. Gail Watnick, DPT, early intervention specialist/physical therapist
Dr. Aishwarya Deenadayalu, MD, pediatrician

Erin Cochran, MA, OTR/L, occupational therapist
Katherine L. Criswell, MSN, RN
Bethany M. Sloane, PT, DPT, physical therapist
Dr. Felicity Case, PT, DPT, PCS, pediatric physical therapist
Dr. Britta Gurgel, PT, DPT, PCS, pediatric physical therapist
Dr. Heather Higashi, PT, DPT, pediatric physical therapist
Julia Waschow, RN, BSN pediatric complex care manager
Courtney Lackey, speech language pathologist and parent
Sheila Stahl Butler, physical therapist
Jennifer Siegel, Teacher of the Deaf
Alicia O'Leary, Teacher of the Deaf
Julie Hargreaves, Licensed Clinical Social Worker
Karma Clarke-Jung, Autism consultant
Michael Millard, BPharm, MS, Pharmacist and Professor Emeritus, Pacific University
Marissa Nicole Merrill, X-ray technologist, B.S., R.T. (R)(ARRT)
Candice Elliott, M.S., Licensed Professional Counselor
Leslie B. Andrews Licensed Child Protection M.S.W
Sarah Sahl, Registered Dietician
Diane Robinson, RN, FNP Family Nurse Practitioner/Community nurse
Capt. Chad Ledson, Tualatin Valley Fire & Rescue

Medical and Disability Organizations

Oregon Pediatric Society
Oregon Family Support Network (OFSN)
Oregon Family to Family Health Information Center
Jill Brown, executive director, NW Kidney Kids
Julie Hutchinson, President/Co-Founder, Chelsea Hutchinson Foundation
Mike Graglia, MBA, MA, Co-Founder & Managing Director, Syngap Research Fund
Shawn Satterfield, CEO/Founder, Shine Music Festival
Jill Foster, Development Director, Wheel to Walk Foundation
Seth Kannor, CEO and President, Enabling Devices
Jill Escher, President, National Council on Severe Autism
Tobi Rates, Executive Director, Autism Society of Oregon

Advocacy Organizations

Family Forward Action

Organized Labor

Oregon AFSCME Local 328

Service Providers and Professionals

Jill Chuculate-Welch, Owner/Founder Joieful Connections (provider agency)
Tara Dupuis, Owner, It Takes a Village (provider agency)
Jason Kinsey, Owner, A Helping Hand Support Service (provider agency)
Liberty Wecker, Director, Out of the Box Solutions (provider agency)
Trina Hart, Executive Director DSP Connections (provider agency)
Timber Swindell, Director, T&T Cares LLC, (provider agency)
Kathy Legmeyer, CEO/founder, KIDS NW (provider agency)
Kim Elliott, Director of Programs & Services, Community Vision
Stephanie Cammack, Benefit Coordinator Manager, OSH, Parent
Alicia Ratto, Supported Living Director, Community Vision
Mike Bates, regional director, NuMotion (durable medical equipment)
Angela Fleming, Owner, Fleming Foster Care (adult IDD)
Daniel Fleming, Owner, Fleming Foster Care (adult IDD)
Alisha Langford, parent and Special Needs Planner at Abeona Group
Jennifer Sackey, case manager, Multnomah County
Katheryn Barnett, early childhood special education specialist
Ashley Hrouda, social service specialist
Sherri Vogt, Early Intervention Specialist
Brenda Cox, personal support worker, foster care
Toni Zimmer, Licensed Clinical Social Worker
Amber Wilkinson-Polomsky, LCSW
Nichole Matz, QMHP, PSS

Faith Leaders

Shaun Konopaski, executive pastor Garden Valley Church
Rick McKinley, Lead Pastor Imago Dei Community (Portland, Oregon)
The Rev. Cecil Charles Prescod, Ainsworth United Church of Christ
Jeanne McKinley, Spiritual Director and Personal Support Worker

Others

Carrick Flynn, Congressional Candidate, District 6

In addition to the above community, political, medical, faith and organizational leaders, please note that more than 3,800 people have also signed our petition asking for this change.

Please contact Gabriel Triplett to discuss further: 541-680-6509.

Response to Oregon DD Coalition Arguments

Subject: Response Requested: DD Coalition stance on parent caregivers
To: *[sent to DD Coalition member organizations individually on April 29]*

Please distribute this letter to your board of directors.

I am concerned by this letter from the Oregon DD Coalition of which you are a member. The letter indicated that its members don't support the life-changing funding that allowed parents of minor children to be paid for the incredible work they were already doing. The views represented in this letter don't represent my lived experience nor that of others I know in my community. **I am requesting your organization issue a letter declaring your stance on this issue or announce a meeting on this issue so I can understand why your organization would support this letter from the DD Coalition.**

Oregon's in-home caregiver program through Medicaid's Home and Community Based Services, known as K-plan, has never worked well for children. That is, until the federal public health emergency allowed for special funding and flexibilities that allowed for parent pay. The benefits were direct, immediate and massive. Parents reported their children were much healthier and happier with fewer hospitalizations and more inclusion in the community. You can see results from a survey of parents impacted by the program here.

Unfortunately, this special allowance is ending when the public health emergency is set to end, July 15. Though there are several pathways to do so, ODDS is not expanding and making this program permanent, citing opposition in the DD community.

The Oregon DD Coalition's April 14 letter conflates the experience and needs of adults with the experience and needs of children and families. Do you endorse the Oregon DD Coalition letter?

Please note:

1. Children do not like and should not be expected to have intimate tasks performed on them by a long list of adults. Activities of Daily Living are by definition intimate tasks.

2. Paying parents for the services they are performing above and beyond what a typical child would require gives them value, dignity and economic freedom. The benefits to

children in higher-income households are clear and proven. Almost all families of children with significant-enough needs to qualify for K-plan have taken a hit to their ability to work, some to the point of homelessness. These are also “unsafe” and “inequitable” situations, to borrow phrases from the DD Coalition letter.

3. Self-determination for children must be defined differently than it is for adults, as is age-appropriate. All children have limits. Children with these in-home support workers cannot go to the store by themselves or do anything else counter to the decision of their guardian. But if our concern is giving children more freedom, we are taking away their choice of their own parents providing their care and taking away the many freedoms that parents can offer when they have the income to do so.

4. The DD letter argues — without supporting data — that paying a parent can harm the relationship between parent and child. Parents in the limited and temporary program have overwhelmingly reported positive changes in the last 14 months — including improved ability to achieve respite, afford mental health care and afford the expensive toys, therapeutic equipment and personal items their children require. For just one example, two families reported their previously nonverbal child learned to talk when they were able to have daily stable parent support.

5. ODDS puts families through a meticulous and exhausting process to determine the number of hours of work their child requires above what a typical child their age would. That work does not go away when caregivers are absent or cannot be found, as is pervasive during the current labor shortage. Someone is doing that labor and that person should be paid from already-allocated funds, no matter their identity.

Oregon law states that: "Support for families with children who have developmental disabilities must be based upon principles of choice and self-determination, with families receiving the support they need to support their children at home.”

Those with lived experience say that is what a parent-pay option does.

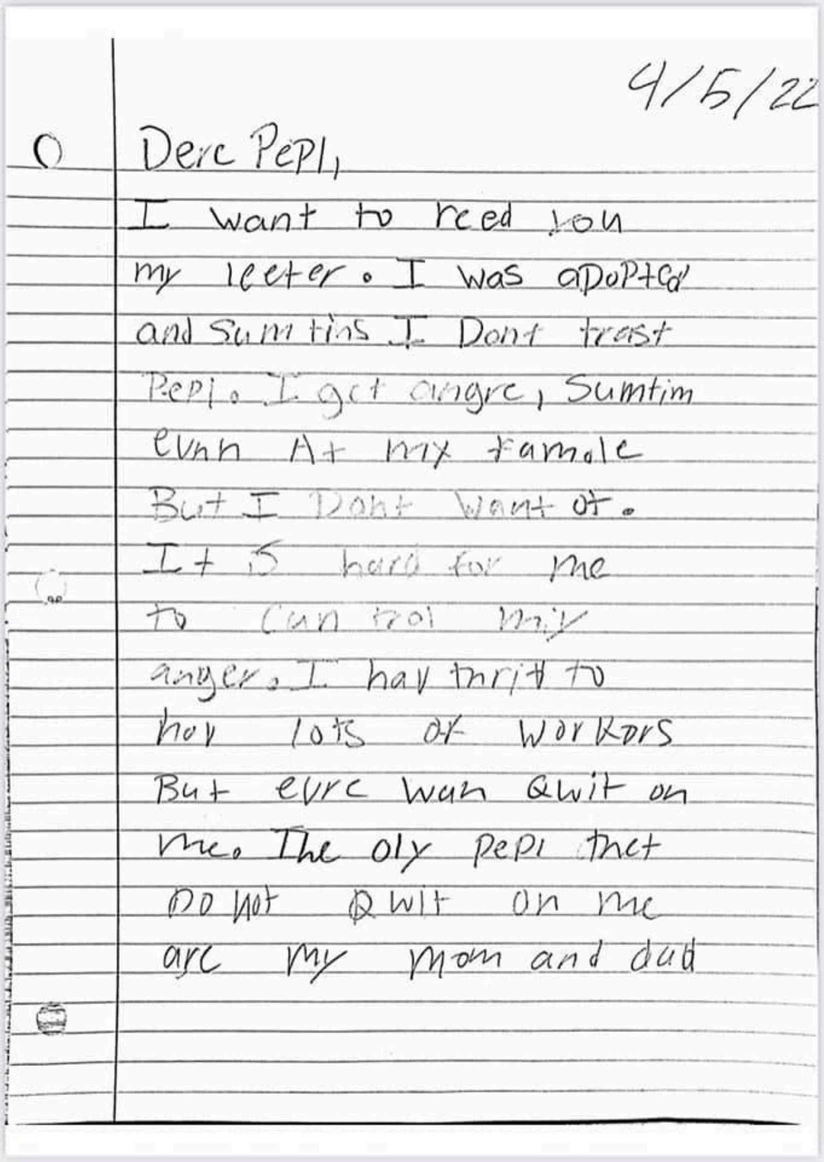
Thank you,

Amanda Padilla
Amy Haigh
Amy Jackson
Amy Wilkerson
Angela Beltran
Antonio Dominguez-Silva
April Harrah
Ashley Wells
Audra Marsh
Belen Molina
Beverly Silbernagel

Brandi Laubscher
Brianna L Robbins
Calli Ross
Candice Elliott
Carie Pagan
Carly S. Anastasion
Celia Vander Velden
Chanti Cavett
Chad Ledson
Courtney Coleman
Crystal Watson
Dawn Schoppe
Elaina Johnson
Emilee Sellers
Emily Sisk
Emilyfern Dayton
Gabriel Triplett
Hubert George
Jacob & Ainslee Pressly
Jennifer Murphy
Jenny Hoyt
Jil Dominguez-Moreau
Jill Johnson
Joshua Widmer
Julia Corson
Julie Hargraves
Karen Krieger
Kari Kaiser
Kari Lorz
Karun Virtue
Kate Widmer
Kathy Lehmeyer
Kathy Shean-Jones
Katie Reding
Kaytlin PineTree
Kellie Hayes
Kellie McClelland
Kelsey Smith
Kimberly Seigal
Krystal matthews
Kyla Bly
Lauren Ferber
Liana Fatani
Lillieth Grand
Lindsay Freedman
Lisa Fugere
Lisa Ledson
Lisa Tschudi
Loreena Menzel
Lucia Vander Velden
Lynne Mason
Margaret Maes
Maria Jolley
Mariah Coggins
Matt Faler
Meghan Newstone
Melisa Jordens
Michael Paruch
Michael Tennison
Oriana Horneck
Patrick Murphy
Patrick Ross
Priscila Gomora
Rosie amrani
Sarah Ellett
Sarah Holgate
Shasta Kearns Moore
Sheril Butdine
Sylvia Triplett
Tami Wood
Tanya McNeill
Theresa Jahangir
Tina Stracener
Tynan Mara
Vanessa Rentschler

Appendix B: Support letters

Self-advocates



4/5/22

Derc Pepl,

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and Sum tins I Dont trast
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But I Dont want of.
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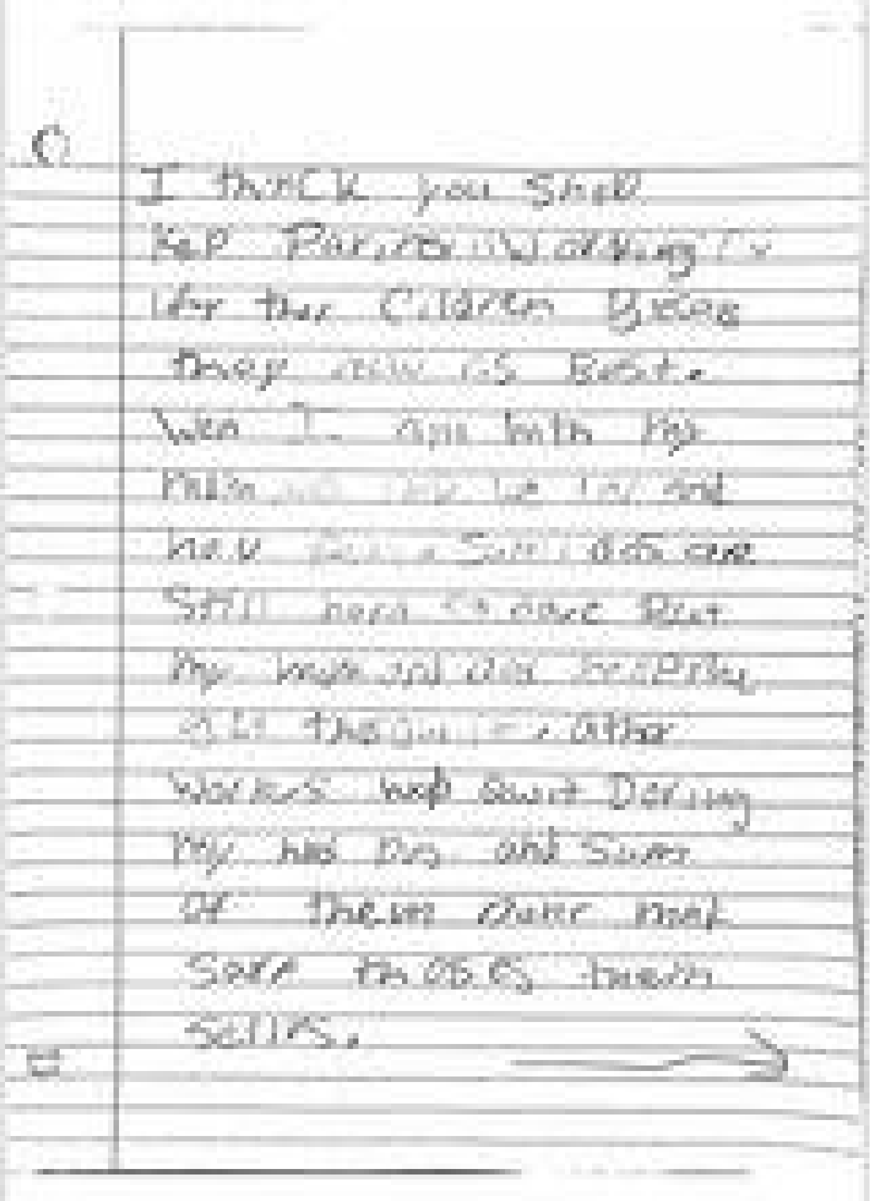
to Cun trol my
anger. I hav thrit to
hov lots of workors
But evrc wun Qwit on
me. The oly pepl thet
Do not Qwit on me
arc my mom and dad



I think you shold
keep Parents working [illegible]
for the Children [illegible]
they now is best.
Wen I was with my
mom [illegible] [illegible] and
knew [illegible] Sum [illegible]
Still need to come Back
my mom and dad keeping
[illegible] the [illegible] other
works [illegible] about Doing
my home [illegible] and Some
of them [illegible] [illegible]
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So [illegible] [illegible] to [illegible]
[illegible] [illegible] [illegible].

Thank you,
Rhea (19)

Parents Being Paid Position

My name is Nic Brown. I am 22 years old and was born with myotubular myopathy. This is a muscle disease. The mitochondria in my skeletal muscle cells doesn't function right. I have low tone (floppy) muscles and I cannot bear weight. I have never walked and have used a power wheelchair since I was 5 years old.

I have always been raised by a single mom. I have also required nurse/caregiver hours since I was 5 years old. We were able to find two good caregivers in Atlanta but they had to be paid out of pocket. My mom owned a housecleaning business and worked while I was at school.

When I was 7, we moved to San Diego. Hoping that the weather would be better for my respiratory health. I had been hospitalized over 30 times with pneumonia. At this point, I had a g-tube and fundoplication. I did nebulizer treatments several times a day with a humidifier. I required oxygen when I wasn't feeling well. I needed assistance with all of my daily living activities. I can move all of my muscles, just not very well. I have been in physical therapy, occupational therapy, speech therapy, hippotherapy and swim therapy. I have had over 8 major surgeries.

A few months after moving to San Diego, I got the flu and ended up in the hospital. While in the hospital I had respiratory failure. This is when I got a tracheostomy and became ventilator dependent. I was in the hospital for 16 months. It was my longest stay ever. Once I came home, I required 24/7 nursing care. Whatever hours weren't covered, my mom had to cover them. We found out about IHSS when we went to the county offices to apply for benefits. My mom was approved for 4 hours of caregiving per day, no matter how many hours she was caring for me. Because of the vent, I had to take care overnight: suctioning, repositioning, kangaroo pump feeds, oxygen requirements, pulse sox, etc. My mom would go for days without sleeping more than 2 hours when there were no other nurses available. When I had a full staff of nurses, my mom worked full-time outside of the home to support us. As I got older, IHSS allowed my mom more paid caregiver hours. By the time I was 17, she was paid for up to 8 hours a day to care for me even though she was covering 12 hours a day, seven days a week. Because of this, we were able to pay our rent and basic bills. We got food stamps and went to food banks when our food stamps ran out. My mom would drive for Uber and Lyft at 7pm when the night nurse arrived and work until midnight. She would sleep until 7am and take care of me until 7pm. This schedule continued for 13 months without her having one day off. The nursing shortage in California was very hard on both of us.

Having strangers come into your home to care for you is weird. You hope it all fits and you can trust them to care for you. But you never know. I've had wonderful nurses/caregivers and I have had really terrible nurses/caregivers. You hope for the best and try to work with what you get. Emotionally unstable and physically unhealthy nurses get into home health care a lot. That can be taxing on your nerves and draining to your emotional health. I have had a caregiver that fell asleep in my bathroom and woke up in panic looking for her water bottle. She was waving the air looking for it. I'm pretty sure she was on drugs. Thank goodness my mom was working from home that day and was able to send her home and take over. I was in my bed without my phone or any way to call for help. I also get scared that someone will have a health scare on the job and leave me to fend for myself. I'm also sad when the best ones leave to go to the hospital for higher pay and so they can use the skills they went to school to learn. I've had to sort through a lot of abandonment issues with so many people coming through my life. I'm grateful for the nurses that I still have relationships with long after they have left my home.

The only time during my 22 years that I felt I did not have self-determination was in the Bernardy Center in San Diego, a medical facility for respite. I had no choice about what and when I ate, took a shower, got up in my chair from the bed, who i was able to visit with and when, ability to go outside, my cell phone and ways to speak to the outside world were taken from me. There was one nurse who did not like me and would get me in trouble everytime she worked. She would say things like; he is going too fast, his goal is to run over the patients. By the end of six months I was not even allowed out of my room. This place turned me into a sad, very depressed human being. Things that I am still dealing with to this day. My mom and I always seem to be in survival mode, looking over our shoulder for the next caregiver to quit, the next shoe to drop, the next bad news to deal with. It's hard to be happy and find daily joy when you are in fight/flight mode.

I had many nurses and caregivers who treated me like they were my nanny, intimidated me to make different choices in their favor, told me not to tell them what to do when it came to my care, treated me like I was intellectually delayed and could not make informed choices on my own. There were nurses who abused me emotionally, threatened me with religion, came to work drunk and passed out and so many terrible stories that I should write a book about so people can be clear about what we have to go through. I think because my mom was a single parent and very vulnerable, the nursing agencies sometimes sent us the worst nurses because my mom didn't have a partner or family to stand up for us. It was just my mom doing everything. I cannot tell you how many times my mom was defamed and slandered by nurses at the agency because she caught them sleeping on the job, destroying medical equipment and taking no accountability for things that happened.

My mom has always said if I don't give up, she won't give up. There were a few times when she didn't think I was going to make it and she always talked about my choices and that she would support whatever I choose, even if she disagreed. Our biggest disagreements come at the same time a parent butts heads with a typical kid: the transitions during puberty and adulthood. It can be a challenge to separate parenting from care-giviing but they are two different things. Neither my mom nor myself want her as my full-time caregiver. She's been doing it on her own with no partner or family for 22 years. She deserves to have a career doing what she loves and I deserve to live my own life, being supported by caregivers. I have no desire to leave my family home. I do not believe that the things in my life that I need to thrive would run well if I didn't live with my mom. But again, I believe paying parents is a very good thing. I think it helps the relationship between the parent and child because the parent can focus on parenting and caregiving without the constant stress and worry of how to pay the bills while caring for their child who experiences disabilities.

Sometimes I feel like a burden to the world, especially to my mom. I've seen her burnt out, depressed, exhausted, stressed, scared and worried about life, about me, about paying bills, keeping me at home, being able to give us a good life, trying to maintain friendships, keeping up a home, van, garden, etc. It feels like we have to fight for so much, to be seen, to be heard, to be supported. It's a strange system to navigate and my mom makes it look easy. But it's not. She makes a lot of sacrifices to make sure I have a happy, healthy life. It’s exhausting to have to fight so much for help, support, resources, caregivers, nurses and trying to inform a system about what we need and just not being heard. I’m still surprised by all that we’ve been through and have survived. I wish it was easier. I wish we were supported by the system and by the community that we live in. When you are so isolated, it’s difficult to find, create and sustain a tribe. It’s hard to watch people who make the rules for people with disabilities who don’t have the same lived experience and don’t seem to want to hear from people with different experiences. It’s like “if your life isn’t like mine, it’s not real or it doesn’t exist.” So much judgment, like I choose to be disabled. I didn’t. I wish I wasn’t. I wish I didn’t need all of the help that I do.

I completely agree with parents being paid to care for their minor children. If my mom had not been paid to be my caregiver during the times that there were no caregivers or nurses available, I don’t know what would have happened to me. I would probably be living in a facility and I feel like I would have just given up. The six months I did have to spend in a facility broke me as a human being. I still experience PTSD because of the time I spend there. My mom being paid as my caregiver never took away my ability to make my own decisions. Her being paid actually made our lives easier. Wondering how you will pay the rent and buy groceries while caring for your child is stress on top of stress. No family should have to go through that because their child is born with a disability. There were so many times my mom had to put her ego aside to sit all day in the social security office, the county offices, etc. trying to get support for us. You have to dig deep to find the resources that you need. It should be easier for all of us.

Nic Brown
Member: Young Self-Advocates of America

I am a single mom to Gavin, a 17 year old boy with Down Syndrome. I want to tell you how we have been using the COVID Parent Providers funding, and the profound impact this has made on my son's life and mine.

Gavin has had 300 hours per month of community based in-home care available to him for several years now because of challenging behavior; unfortunately the behavior itself has also made it difficult for us to find and keep support workers, so this has been a Catch 22.

It also meant that, without support workers, I had to fill in the gaps in order for my son to get the care he needed; so in addition to my role as his mom, and my role as our family breadwinner, I also had to do the work of two nearly full-time support workers. I did this for many years without compensation, because Oregon state rules do not allow parents of children under 18 to be paid as their own child's caregiver, even if there are no other caregivers available.

A few years ago I was diagnosed with autism. Although I had been functioning well enough for my neurodivergence to go undetected my whole life, the strain of trying to care for my son without adequate support was taking its toll.

My son is not verbal. Over the years, many of us on his IEP team have felt that his lack of communication skill may be actually causing his challenging behaviors, but although we obtained a communication device and software several years ago from a private foundation, and he carried it to school every day, he never made much progress with using it consistently. I was trained in using the communication software when we got the device, but his teachers and aides were not; and, though well-intentioned, they did not have time to focus on communication in the fast paced school environment.

As the years passed, his challenging behavior continued and got worse, which interfered with his educational progress and made it difficult for both of us to maintain relationships. He's had times when it was very difficult for him to be in school because of behaviors. Because of this, and because care was all but impossible to find for a behavioral kid, I had to abandon my online business to take care of him, and we had been subsisting on Social Security.

Last year, I learned that we were eligible for this parent provider program.

I thought, what if I signed up for the program and used the hours to teach him how to use his communication device? And we just used it all day long, intensively, in all settings?

So that's what we did.

It started with me asking him questions, yes/no. Then, multiple choice: do you want chicken strips? Do you want cheeseburger? You can choose.

He began to respond. He started expecting to be included in decision making and planning, and expecting to be consulted on what HE would like to do, how HE would like to approach daily tasks, what HE would like to eat today (rather than us guessing at what he usually liked). The behaviors reduced dramatically as he gained control over aspects of his life.

The program was also a great help to me, because I had been living for many years in a state called "autistic burnout", caused by having too much to do and also being faced with constant economic hardship. If you've got enough money to live, you can choose conveniences like grocery delivery, which relieves some of the pressure. Having financial stability from the program has helped relieve the constant anxiety that goes along with poverty. This allowed me to get better sleep, and I began to heal.

Thanks to the program, I didn’t have to worry about trying to make ends meet at the same time. I could focus on teaching him. He caught on quickly to the communication when it was presented all day long, everywhere, with the expectation that he would participate fully in the community.

After a few months, he stabilized into a new way of life. His communication skills have steadily expanded. The behaviors have all but vanished. His confidence has grown, and it has now been many months since a meltdown. He learned to navigate challenging environments with trust in his caregivers. His speech therapists, behavior specialist, and service coordinator cannot believe the transformation!

In retrospect, I think my neurodivergence helped me to understand his neurodivergence. I can't say for sure, but I think I could understand what was blocking his language from emerging because my brain was also different. Little did I know, I was the best person for the job!

****

Thank you for the opportunity to share our story!

Lynne

To Whom it May Concern,

As a resident of Beaverton, Oregon, I wanted to reach out and make sure you're aware of an urgent issue regarding parents of medically complex/disabled children. Currently, parents are under a special Covid exemption through July 15th that allows them to be paid caregivers for their child, but there is a looming crisis coming that can be prevented. If we could get your support to turn the public health emergency (PHE) extension into a permanent policy, it would provide stability for these fragile children, relieve the financial strain from the parents, and reduce the burden on our hospitals.

Although I'm not a parent, I am a disabled adult who requires a caregiver every day. For the past 13 years I've experienced both having my parents as caregivers, as well as hiring outside help. By far the times I have received the highest quality and most consistent care has been when my parents were able to act as paid caregivers. You would not believe the unnecessary stress it introduces into a family when you have to coordinate care with outside providers. As a quadriplegic, I'm totally at their mercy for when or if they show up, whether they are careful with my delicate body, and I spend hours a week coordinating their schedules. When my parents can be my caregivers, life is so much easier! They know exactly how to work with my body, what my medical needs are, where my vulnerabilities exist, and I don't have to waste so much time making schedules.

Life is exponentially more difficult for families that have a medically complex child, and the last thing they need to do is stress about coordinating care. Could you even imagine entrusting your extremely fragile child to a stranger? Having lived as both an able bodied and now a disabled person, the biggest surprise was how much longer it takes to recover from any type of medical issue. If these parents lose the ability to get paid as caregivers, they will invariably end up at the hospital because someone who was not familiar with their child's unique needs will cause an issue that requires expensive medical attention.

This is not an issue we can afford to just consider, it's important enough that you take immediate action. It's an easy ask too because the state is already giving these children funding to help with their needs, we just need to approve the option to have the money go to their parents for care. Here is a chance to make a decision that can benefit everybody. Will you help?

Sincerely,

Jake French

May 5, 2022

To Whom It May Concern:

I am writing to you today to encourage the Oregon Self Advocacy Coalition (OSAC) to support changes to Oregon Administrative Rule (OAR) 411-37-0020 2(b)(A). Specifically, I encourage OSAC to support changes in that rule that would allow parents of children with disabilities to have direct access to the money taxpayers have dedicated to their children. Currently, parents are able to access those funds to care for their children, but that is due to a temporary change in the rule. The change is set to expire July 15, 2022.

Since the temporary change went into effect many positive changes have happened to the children and to families of those children:

- Better, more stable environment through consistent care from parental caregivers;
- Better physical and mental health of the children;
- A significant reduction in the number of children who need to either visit or stay at a hospital;
- A much greater participation in community programs by the children;
- Improved financial freedom for many of the families, some of who would have faced dire consequences without the ability to access the taxpayer money.

Some states, including California, allowed parents to access the money prior to the Pandemic. Other states, too, have made changes, allowing parents this access. It is time Oregon joined that group.

Additionally, by supporting the change in rule, OSAC will be living up to its Mission to: Engage individuals and communities in advocating for the rights of people with intellectual/developmental disabilities. Further, this support reflects OSAC’s vision, specifically to: develop programs to help further the advancement of people with disabilities.

Thank you for the work you have done and are doing. I believe supporting this rule change will help OSAC help people with disabilities immediately and long into the future.

Sincerely,

Ian Jaquiss
A person with a disability since 1969

Hello Sen Gelser,

My name is Jessica Lindley and I live in Corvallis, OR. I’m writing on behalf of families of disabled children in Oregon who will have their paid parent program cut off come July 15th if actions are not taken immediately.

I don’t have a child with disabilities, rather I bring to the table a unique voice. I am both an adult with disabilities and my mother is my paid caregiver. Without my mother there are many things I would not be able to do. The pool of people that are available to hired are often not trained and do not know how to care for a disabled individual. The disabled individuals' parents or guardians will be the ones who know the most about the care and what is needed for the individual. Often the things that need to be done are very personal or need someone who is trained to do those things. Paying a parent as a caregiver for a child or adult disabled person makes a big difference and often parents of disabled children are unable to work due to the child being a full time job needed with care.

I support this cause because I am a physically disabled adult and to this day need my mother to help me with many things. I need her there for me for procedures and after when my care needs often change. As one of your constituents and someone with lived experience I beg you to take my voice into consideration. And -since not all of these children have the same option, in lieu of their voices- those of their parents must be heard.

Thank you,

Jessica Lindley

Self-advocate

Professional Support Letters

4/20/2022

Lilia Teninty
Developmental Disabilities Services Director
Oregon Department of Human Services
500 Summer Street NE
Salem, OR 97301

Dear Director Teninty:

My name is Stephanie Hunter, and I am a proud parent of a young adult that experiences disability and also an IDD foster provider for transition age adults. As a parent, I have been involved with Oregon's family networks and public education advocacy for over 15 years, and am a 2008 graduate of Partners in Policymaking. I have been on state committees, commissions, and workgroups supporting adults, children, and families in the Oregon IDD system. I have worked for residential agencies and I provided statewide technical assistance to families, training, and mentorship for behavior professionals with Oregon Training and Consultation (OTAC) for seven years. In response to the DD Coalition's letter, and my extensive history both personally and professionally navigating Oregon's DD system, I would like to share my considerations and recommendations.

I am writing in support of allowing parents and guardians to use caregiver hours under K-Plan permanently. I recommend continuing to pay parents/guardians equitably and in a manner that supports the self-determined, envisioned futures of people with IDD, self-advocates, and their families. There is a significant workforce shortage of available in-home supporters, which has been further impacted by the pandemic. Continuing to pay parents/guardians will work proactively to combat this ongoing crisis.

I wholeheartedly believe in and advocate for inclusion and self-determination. I raised my daughter with these values, and I support foster youth in the same way. I understand how powerful it is to flip the narrative using person-centered values to help empower people with disabilities. I am concerned that these principles are driving the recommendation that the state should place the burden of fixing our broken social services and declining workforce on the backs of struggling families. The families that are the most impacted when systems fail are historically excluded groups such as people living in poverty, Black, Native and Indigenous, people of color, disabled, immigrants and refugees, grandparents raising grandchildren, single parents, families whose first language is not English, families caring for aging parents, and those also managing co-occurring mental health needs. Oregon has a real opportunity here to reduce the cost to the state and reflect our values of supporting children and families by easing systemic barriers that currently prevent families from staying home, caring for their child, and receiving a living wage to do so.

As a behavior professional I see people at their most vulnerable. I provided behavior consultation through the counties and regions back before K-Plan came into existence. At that time, the way to get behavior support for your child was to tell your services coordinator you wanted out of home placement. Families that would never place their child in residential care had to "say the words" so they could receive help. When I started with OTAC it was refreshing to learn there was a state-funded program that provided free family training, training for DD agency employees, and behavior support services that did not require a focus on the negative to receive help. When K-Plan started there was hope that it would open up more access for children and families. Unfortunately, the state felt K-Plan replaced the OTAC Community Supports and Crisis contract. Technical assistance and free training for families, DD providers, and mentorship for behavior professionals went away. I strongly feel that losing this resource has left a gap, particularly in rural areas with fewer resources. This is where we were even before the pandemic started.

When I tell people that do not have knowledge of the IDD system that I am a foster provider they assume the children I support were removed from their family home. I then explain that in our state if a child is eligible for services and their parent/guardian cannot care for their basic needs due to medical, behavioral, or other circumstances the state will pay someone else to care for that child. People are appropriately shocked upon hearing this. I do not disagree with those advocating to fund DD agencies to strengthen their workforce. I do not understand how funding agencies versus continuing to pay parents is an either/or situation. I would love to see the math on how much it costs to pay a parent versus traumatizing a child in a well-meaning but high turnover residential group home. It should be a last resort to place a child, due to an immediate threat to safety. With rising income inequality, shortened school days for children with complex needs, lack of childcare, programs that cannot or will not serve youth with high medical or behavioral needs, and additional barriers in rural areas, the last resort has become the rule rather than the exception. Families can be helped now, as we wait for the investments in the workforce to show progress. Money being used in unhelpful ways could be identified, programs that are supposed to be helping could be improved. There are people on the ground all over the state–beyond the usual suspects–with valuable information and ideas to share. There are families with lived experience of how being paid is making a difference. Please seek out the perspectives of families that have had their quality of life transformed by this opportunity.

A significant concern I am witnessing as a behavior professional is the ***current increase in institutionalization of children*** because families cannot meet their basic needs due to systemic issues, long wait lists, and limited access to services outside of the Valley. I was a DSP when Fairview was still open and I have heard the stories from self-advocates placed there against their will as children. We cannot repeat history. Children are often placed hours and many miles away from their families. We have to do what other states are already doing to address this and improve the lives of their most vulnerable citizens.

I am offering the following as possible solutions. Please consider my suggestions and explore any alternatives that will allow family members to be paid as caregivers for their child.

- I suggest rolling out the continued payment of parents/guardians in this manner:
    - Continue to pay those currently receiving pay.
    - Next, look at every child on the residential wait list and determine whether those

    families have chosen this option because of basic need barriers due to systemic issues and can become caregivers for their child, thus effectively removing them from the list.
    - Then, work with children's residential providers to identify which families would be able to bring their child home if they could be paid. Fund that agency, foster provider, or local family network to help develop a transition plan back home versus moving the child without any medical, educational, and/or behavioral support in place.
    - Start a gradual process of moving tiers of parents/guardians into the plan so eventually any family member that can be paid has the option.
    - Ask that the family networks, as part of their funding, provide training for families on how to balance being a paid caregiver with being a parent. Continue to keep the values of self-determination and identify what a future of NOT being a caregiver would look like.

- If parents/guardians will not continue to be paid then provide families the same rate a residential provider would be paid to care for their child. Perhaps the family must keep that rate in a separate account and show that it is used for meeting the caregiving and staffing/respite needs of the child and family.
- Resume the Community Supports and Crisis contract that provided free statewide training and consultation to families and providers, autism-specific training led by self-advocates, and behavior professional mentorship.
- Provide Oregon's family networks with funding to provide stipends and basic need resources to pull together focus groups that are more representative of the families and individuals left out of the conversation. Seek input from different voices in Central, Southern, Eastern, and Coastal parts of the state. Work with nonprofits with access to families from historically excluded groups. Understand it takes time to build trust with populations that have been left out.
- Create a pathway for attendant care agencies to request additional funding for complex situations that require further medical and/or behavioral training.
- Explore how the Oregon Home Care Commission can strengthen the workforce. Work with local residential providers that could provide parents/guardians with the onboarding training and then utilize those parents as part-time or on-call employees for their programs and resolve shortages in that part of the workforce.
- Convene a workgroup or task force that looks at how the social services systems overlap and impact each other. Ensure that the entire state is included in this work. Audit these systems and how they spend their money. The people that rely on these services can tell you how it can be improved in a less costly manner, trust me!

Speaking personally as a behavior professional I would like to be able to serve more families by ONLY providing what they need. Often, what they need is not a full functional behavioral assessment and positive behavior support plan; the K-Plan requirement to develop these documents hinders my ability to efficiently and effectively support them with any relevancy and contributes to mounting crises as people needing support must wait for services.

In closing, please use your influence to ensure parents/guardians continue to be paid as caregivers, and expand this over time to be available to all families with K-Plan hours. If paying families is not an ongoing option, then provide the monthly rate a residential provider would be given. Empower, expand, and fund the family networks to be a resource and share successes and concerns about parents as paid caregivers. ***Recognize that Oregon is returning to institutionalization of children and in particular children from historically excluded populations by waiting for other systems that are failing children right now to be fixed.*** Learn from what has been effective in the past with programs like statewide training, technical assistance, and behavior mentorship. Remember that Oregon extends beyond the Valley and intentionally reaches out to hear from new faces and voices in all parts of the state.
Thank you for reading my letter. I would be happy to provide further perspective on this important decision. I welcome you to contact me to discuss this matter.

Sincerely,
Stephanie Hunter
Stephanie.c.hunter@gmail.com

Metropolitan
Pediatrics, L.L.C.

September 8, 2022

Resa Bradeen MD
Chief Medical Officer
Metropolitan Pediatrics LLC

To Whom it May Concern:

I am writing today on behalf of Metropolitan Pediatrics in strong support of continuing caregiver payment for Oregon parents of disabled children that has been allowed during the temporary federal public health emergency.

With over 40 pediatricians and nurse practitioners and 10 behavioral health clinicians, we are the largest private Pediatric group in the state of Oregon and are the medical home for many children with complex medical needs. We work closely with parents to develop care plans for their disabled child(ren) and to access the many critical services that these children need to be able to develop to their full capacity.

It is not uncommon for us to see parents have to miss work, quit their jobs, or work 24-hour shifts with their disabled child because they cannot find qualified staff to fill the hours they have been allotted towards in-home caregivers. In addition, these parents know their child the best and understand the complexities involved in carrying out their child's care plan. Certainly, there are times where parents are able to find highly qualified and committed caregivers for their child; but, there are many times where that is not the case. There are even times when the parents must stay in the home with their child even if a caregiver is present.

It is beneficial for the child, the parents, and other family members for the parent to receive the money allotted to caregivers when they are performing that work. We are asking you to support changing our state program to allow biological and adoptive parents as candidates for in-home caregivers ("Personal Support Workers" or "Direct Support Professionals") to their minor disabled children that require significant amounts of in-home monitoring and care.

Sincerely,

Resa Bradeen MD

Chief Medical Officer
Metropolitan Pediatrics LLC

To Whom It May Concern,

I am writing to express my support for the permanent continuation of the Paid Parent Caregiver Policy for Oregon parents of children with severe medical disabilities and terminal diagnoses.

My name is Leslie Andrews. I am a retired Master's level clinical social worker. For 20 years I worked with young people involved in the criminal justice system. Additionally, I worked for 10 years as a Child Protection investigator. In total I have served hundreds of families experiencing extreme stress from various causes. There were, of course, multiple causes of stress, resulting in the breakdown of the functional family system.

The purpose of this letter is to address the impact significant long-term financial strain usually has on families already dealing with literal life and death issues on a daily basis. In most cases severely disabled children require 24 hour care, 7 days a week. That type of care isn't merely "supervising" or "baby-sitting" the child. It involves a complex set of skills and tasks such as:

- Maintaining ventilator and/or trach care
- Feeding tube needs
- Wound care
- Administration of medications and injections multiple times during the day and night
- Being confident in the skill of initiating life-saving measures in emergencies
- Providing daily physical and occupational therapy (beyond the bi-monthly or weekly visits of specialized providers)
- Educational needs (beyond the minimal support provided by public school)
- Providing stimulating, fun and joyful experiences
- Ordering medical supplies
- Lifting and moving the child and heavy medical equipment
- Diaper changes
- Bathing
- Scheduling and attending multiple medical appointments
- Monitoring and maintaining medical machinery

There are no breaks, no vacations from necessary life-maintaining and life-saving responsibility. Home care of loved and cherished medically fragile children is unrelenting and exhausting, but it is also deeply loving and satisfying to both the parents and the child. Parents providing full-time home care (even when partial home nursing is occasionally available) develop an intuitive sense of their special needs child's life-rhythm. They "know" before the mechanical alarms go off. They "sense" their child's needs and respond appropriately. They are the "voice" of their child.

Most families of medically fragile children are burdened by frequent unexpected costs not covered by insurance or Medicaid. Some necessary medications are not covered, or are only partially covered, transportation to multiple appointments and hospitals is not covered, special-needs clothing and equipment may or may not be covered. In the majority of cases only one parent is able to maintain a full-time job outside the home, and even that can be disrupted by emergency medical situations.

It is literally impossible for most sets of parents to maintain 2 full-time, out-of-the-home jobs. With a medically fragile child, even an in-home, part-time job is realistically impossible due to the number of daily care tasks an in-home parent must provide.

Of course, families of severely disabled children may have other, non-special needs children in the home. Those, equally cherished and loved family members also need and deserve the level of care we assume most “normal” children require.

In today’s world, most two-parent families require two incomes to meet their basic needs, to be able to save for the future and to provide a reasonable sense of safety and security and happiness for their children. When the strain of financial insecurity is added to an already living-on-the-edge family, it is impossible to maintain a healthy family system. The result can range from mild depression and anxiety to severe depression and anxiety, suicide ideation, coping methods of substance abuse, verbal and physical abuse, poor job performance for parents who work out of the home and poor school performance by children in the family attending school. Of course non-disabled children who grow up in dysfunctional homes have an increased risk of aberrant social behavior, criminal behavior, mental health issues and substance abuse.

In conclusion, I reiterate my strong support of the permanent continuation of the Paid Parent Caregiver Policy.

Sincerely,

Leslie B. Andrews,
M.S.W.

Julie Hargraves LCSW

444 Masyn Ct Roseburg, OR 97471

May 11, 2022

RE: Paid Parent Caregiver Policy
To Whom this May concern
I am a Licensed Clinical Social Worker and I would like to take this time to express my support of the "Paid Parent Caregiver Policy." Paid Family Caregivers Policy provides the needed assistance to help families so they may remain in the home caring for their disabled children versus the parent working outside the home. In my practice, I work with both children and adults with emotional and behavioral problems. I am a witness to the difference it has made in several children's life when a parent is able to stay home and provide the care for their child. When parents are given this opportunity to stay home versus working outside the home, they not only are providing quality care to their children, but also meeting that child's emotional needs. Who better to provide for the needs of a disabled child than their parents? When a child's emotional needs are met, I see thriving children. When parents are given the opportunity to stay home and provided with the monetary support of being their child's caregiver, I see thriving parents. A child's healthy development depends on their parents. Paid Parent Caregiver Policy can give families the opportunity to stay connected and they can give that child a better quality of life because the mental health of children relates to their connection with their parents. The benefits are endless in my personal and professional opinion. Not only does Paid Parent Caregiver Policy support quality care, mental health, and family values, but it also can significantly reduce costs to Medicare, Medicaid, and private insurance, Paid Parent Caregiver Policy can be known as the foundation of the nation's long-term care system resolution by providing parents the opportunity to provide the many long-term care services and supports received by persons with disabilities of all ages. Parents providing these services will lessen the burden on the State's financial system, lessen family's burdens, and improve quality of life for these families. It is my hope that policy makers will view the Paid Parent Caregiver Policy as being an effective policy that should be continued because well-adjusted families create healthy strong communities.
Sincerely,
Julie Hargraves
LCSW Mental Health Therapist

FROM THE DESK OF

Frank Andrews, Ph.D

This is a response to my daughter's request for a letter supporting extending financial assistance to parent care providers of severely disabled children. She is the mother of a seven year old child (Tennyson() who was born with multiple chromosomal abnormalities. He is approved for 24 hour nursing care. This is unavailable in the Portland area. Tennyson is a 33 pound, three foot tall bundle of joy. He holds the record for number of times he has watched the Greatest Show On Earth. Hugh Jackson made him a personal video. Tens has a crush on the bearded lady.

May 2, 2022

You asked for a letter supporting continuing paid parent caregiving to minor disabled children under Medicaid Home and Community Based Services. I am happy to do so. As I understand it, parents of severely disabled children in Oregon recently tapped into funding which allows them financial support to provide medically necessary care for their own child(ren). In many instances, including yours, this has financially allowed a parent to remain at home providing care for their child. This has decreased reliance upon the increasingly scarce services of a home health agency or non-family care provider (when they were available). For a child like Tennyson approved for constant 24 hour nursing, he has never been able to receive it because pediatric home nursing sources in the Portland area are stretched. This assistance has been a Godsend. Monitoring medication, adjusting home life support equipment, providing physical therapy, applying ventilation, and monitoring vitals twenty four hours a day leaves no alternative other than hospitalization or the parent to provide the level of care he requires.

As the grandparent of a medically fragile child under the K-plan adopted by Oregon, I've experienced strengths and weaknesses of the former program. I very much appreciate that despite the decrease in nursing care, Ten's continued cognitive and physical improvement has not regressed. In some respects it has accelerated. With direct parent funding, Tennyson and his family remain in their home. Tennyson's dad works two jobs now rather than three and is able to assist with night respiratory schedules and daily care routines within his work schedule. Tennyson's mom continues the skilled nursing and medical coordination roles that were formerly provided through the local nursing agencies. The time she formerly spent arranging nursing schedules and communicating Ten's schedules and status, she now spends helping Tens with his communication and physical therapy homework. Moreover, the financial support has had a holistic consequence, affecting not only Tennyson but those who love him. The level of financial distress is considerably lower, the family works as a team meeting his needs, communication is clearer, and there are small periods of respite when extended family members can assist without getting in the way of medical personnel. I hope these specific changes will be addressed more fully in others' letters of support.

I will focus on your other concern; the issues underpinning why I believe as a psychologist that direct compensation payments to parents of vulnerable children makes imminent practical and psychological sense. I'm not an expert in this area. I was trained as a neuropsychologist, child development psychologist, and later as a forensic psychologist. I understand public policy, competition for funding, philosophically different medical and family concerns, diversity, and limited resources add layers of complexity to this issue. I will leave to other experts arguments concerning the cost comparisons between traditional provider care vs. parent reimbursement provider care. I will cut to the basics I do understand and note that many similar arguments apply with some modification to family elder care.

My two comments concern CONSISTENCY and INNOVATION. These observations can be addressed both at the macro level toward Government Programming, and on a micro level, toward the quality of the parent-child care provider's relationship meeting the needs of the vulnerable child. CONSISTENCY at the program level addresses the validity and reliability of interventions designed to support the child, including oversight, program planning, and implementation and INNOVATION addresses the creative design and implementation of interventions themselves to most efficiently meet the child's needs within the structural limitations imposed. INNOVATION always meets resistance, and requires an impetus - Covid, a critical shortage of home nursing, or exploding healthcare costs. In Oregon, that time might be now.

CONSISTENCY:

At the program level, the most significant contribution to outcome effectiveness is careful planning and oversight using the input of a needs assessment from the affected population, and applying intervention CONSISTENCY with the planning objectives. Carefully surveying the population of those needing and receiving services functions as an important planning, implementing and monitoring component for measuring CONSISTENCY.

And at the micro level, the child care provider level, CONSISTENCY is particularly important with vulnerable populations. Tennyson frequently takes as many as seven medications, his sleep has to be monitored and alarms set to vital signs are triggered throughout the day and night. We know children generally thrive with CONSISTENCY. Harlow's parenting studies using monkeys are a part of every elementary psychology textbook. We keep regular bedtimes, study times, school rituals, and meal times - we see this kind of consistency as beneficial and efficient for our children. With the multi-need, vulnerable, medically fragile child CONSISTENCY reaches a whole new threshold. The issue is no longer whether this child will thrive with CONSISTENCY, rather, can this child survive without it? Parents of a medically fragile child fear their child 's imminent death. A child dependent on a care provider meeting his every basic function, ventilation, feeding, interventions for basic systems regulation, is significantly dependent upon that caretaker's CONSISTENCY. And whereas the care provider functions for a child in a normal population are often non-critical, the care provider functions for a child in the k-population are often highly critical, and the complex response required from the Care Providers must be CONSISTENT! We know from elder care studies, the support for the Care Provider must also be CONSISTENT. Services which reduce Child Care Provider stress positively impact the quality of services for the child.

There are factors such as degree of medical skill and knowledge, or various parental capacities and competencies that might be viewed as equally important. And in individual cases, they might be. When I was a Forensic Examiner, one of the questions I was asked frequently by judges in custody trials was, "which parent is likely to spend more time with the child, and which will be able to provide them with the most consistent environment." One parent might clearly display superior parenting skills, and a stronger bond with the children, but because of occupation (e.g., a commercial pilot), joint custody was awarded with disproportionate visitation time granted to the non-working adequate parent. In other words in the minds of these decision makers, parenting skills were important, but contact CONSISTENCY was deemed more important. Likewise, in my experience with medically fragile children and their families, highly skilled nursing care, adjunct in-home services, or institutionalization, all of which serve legitimately valued roles, rarely trump adequate parental child provision.

What other factors from the psychology literature suggests the parent, rather than an institution, home health agency, or home health aid might offer the most logical choice for implementing CONSISTENT care and treatment for the medically fragile child?Psychology would suggest the contributions from attachment theorists on how vitally important early uninterrupted attachment is to child's social, personality and brain development. And while bonding has traditionally been applied predominantly to a mother-child bond, increased emphasis now is placed on the many different types of attachments and bonds the child is exposed to. Attachment however addresses another completely different advantage. A multi needs child requires supreme commitments and sacrifices from care providers. These include sleep deprivation, severe adjustments in scheduling, sacrificing family and partner recreations, living with high anxiety and fear, and financial sacrifice and hardship. These demands and stresses can easily defeat a care provider's best efforts to meet the child's needs. Attachment serves as a risk mitigator. What propels a parent to throw themselves in front of a car to save their child is the same engine that sustains a parent under the unrelenting stress of parenting a special needs child when exhausted. Nursing staff catch colds, take vacations, or provide care for their own families. Agencies face cost reductions and staffing challenges. Parents of special needs children have few options. Attachment ensures the child's needs will still be met CONSISTENTLY.

INNOVATION:

Story time. As an undergraduate student many years ago, (yes, after the dinosaurs were extinguished) I served as acting director of volunteer services for the Columbus Ohio Urban League. I coordinated the services of 70 volunteers who were trained to assist parents in reading to their preschool age children. A local publishing company donated several hundred illustrated children's books. Many of the parents were illiterate. The volunteer would read the words while the mother would use the illustrations to act out the story to their child. After a few repetitions, the mothers would have the story memorized, and the children would be turning the pages to see the illustrations. It was a great program. Rewarding to the volunteers, and a source of pride and accomplishment for the mothers, some of whom designed their own t-shirts to identify themselves and their children as participants in the program. The problem was that on any given program night, only half the participants showed up. We started losing volunteers. The program was failing although the comments were universally positive. We went immediately to the people we were trying to serve. We found the average family size was six, and mothers couldn't leave their other children at home. We also found there were few resident fathers. Based on input from the participants, we implemented a series of changes. We used a community center and organized sports activities for older siblings. We opened a supervised homework help room, and we used shared parent babysitting responsibilities. We gave the books to the families as a reward for finishing them. A local pastor asked if he could teach parents how to be bible school assistants and this was a popular program with family members. The program grew in size and we had teachers volunteer to staff the homework room, building the relationship between the community and the school. These innovations were a direct consequence of our using a needs assessment with the input coming directly from our participants.

It was a valuable lesson. Years later, as the director of a three county mental health center, I noticed our no-show numbers fluctuated between 35-40 percent, and were much higher in the winter. We were told these numbers were historic and were a manifestation of the population we served. Surveying our clients, it was apparent that private transportation and finances were problems for many of our clients, especially in inclement weather. We faced opposition installing a coffee machine (viewed as stimulant) - but the hot chocolate counter was a hit. Our local bus service was funded partially on a five year declining federal budget. We used the Board to solicit contributions, and used the contributions to buy discounted bus tokens which we handed out to our clients at the end of the session. Our number of no shows fell by half. The bus company was able to show an increase in ridership meeting their grant goals. Did we attain higher treatment goal outcomes? I'm not sure we measured that, but I know there was a higher rate of treatment completion and clients reporting the reasons they sought treatment were met.

INNOVATION works at both micro and macro levels (it is more difficult to change at the macro level) . I could give many more examples of how the best implementation ideas often come from the served population. Oregon is a progressive state. It is a creative state. I believe it could serve

as a model for its effective use of parent preferred child providers for medically and developmentally needed children. It would certainly be helpful to study similar programs in California and Colorado. I would suggest however you begin by looking within your own state's parenting groups for what needs might better be addressed, and by social networking with the service populations in other states for what they see as the pros and cons of their systems. Once you have that data, and of course the information you are asking for from these letters, it should be possible to go to local media with your success stories and plans. In my experience, legislators are very willing to support stories that draw public interest, and there are few groups of parents more interesting or heroic than those who care for their severely disabled children.

I hope this addresses the areas found in your request. I have included the formal titles you requested in the signature block below.

Your proud father,

Frank M Andrews

Frank M. Andrews, PhD., ABPP, ABFP

Diplomate, American Board of Professional Psychology Fellow, American Board of Forensic Psychology

63O BUCKHORN DRIVE, HAILEY ID, 83333

Prior to starting my agency I worked with Seniors and Disabilities for nearly 20 years. The caregiver shortage and high turnover has been, in my opinion, an ongoing problem in many healthcare fields for many years. This isn't new and shouldn't be a surprise to anyone who has spent 5 minutes working in any healthcare field.

You see, the challenge is more than just finding and retaining a care provider. Sure, at one time you probably could find a warm body to throw into many households but is that the point of what we do? No! Now, even warm bodies are hard to find, and even if you could, who would encourage that? Certainly not someone claiming to advocate for the ID/DD community!

Whether it's my child or your child, the point behind what we do is to create a better quality of life for the individuals we support, provide them with opportunities and choices that will develop and guide this individual into their adult years. Help them make strides towards and achieve goals that will empower them to be involved, successful members of our society as they grow. Without care providers who are truly focused on making a difference and are dedicated to doing more than just checking a box we will continue to find the ID/DD population struggling in growth, development, and progress towards goals.

I can teach anyone to provide caregiving tasks but I can't teach compassion, passion, empathy or how to actually care. Who could possibly be more passionate and driven to provide the needed support then the Parents? Who could possibly be more prepared, equipped and driven to help these individuals achieve their ultimate goals?

Why also is there a separation between a parent of someone who is over 18 can provide care but not parents whose children are under 18? A child's motor (physical), language and communication, cognitive and social/emotional are all being developed at a young age, there is so much that can be accomplished if given the right environment and provider. Do we not think that the role of a parent of a child under the age of 18 is not equally challenging and in some cases harder than the role of a parent of child over the age of 18? There is an obvious disconnect in the rules.

The truth is this. Agencies like Joieful struggle to find good, quality Direct Support Professionals. I had 10 interviews scheduled on Monday, 1 showed. I pay $20 to start, I pay full benefits, offer PTO, Paid Holidays, I pay their birthdays off. I have a turn over conversion of 2% year over year. I am doing all that I can to find and retain Direct Support Professionals but the truth is there is still a massive shortage. I have over 80 families waiting for a DSP. Why on earth would you take away the providers these individuals have in a time where we all know we can't replace them. Does the ODDS actually believe that no care provider is better than having one? Or are they hoping we fill roles with warm bodies who don't truly care and are just there to check a box and get paid?

If ODDS is truly serious about making a difference in the ID/DD world there is no possible way you can look past the advantages a child has when 1. having a care provider and 2. having a care provider that is there to make a difference. We live in a world where no one is going to be more passionate about making a difference in their child's life than the parent. Take away the money element. Would you rather a child be with a parent or a stranger? In any situation. If they are scared, hurt, frustrated, embarrassed, struggling, etc.. Would you rather a child go through that with a parent or with a stranger? How about you? If you were having a difficult time would you rather be supported by a loved

one like a parent or a stranger?
I implore you to reconsider the decision to end the exception and make a new rule allowing parents to be providers. There are hundreds if not thousands of children in the ID/DD community who's future can be positively changed if ODDS would change the rule.

Regards,

Jill Chuculate

Joieful Connections

May 31, 2022

To Oregon's Policy Makers

I am a special educator with over 30 years of experience in the field, currently working as an Autism Consultant for Early Intervention and Early Childhood Special Education in Douglas County. I am writing this letter to encourage the Oregon Self-Advocacy Commission to support changes to the Oregon Administrative Rule OAR 411-37-0020 2(b)(A) that would make it possible for parents of qualifying children to be paid as their child's Personal Support Worker (PSW).

The Covid crisis exacerbated already existing PSW shortages in Oregon. Because of this, Oregon enacted a 'pilot program' that for the first time allowed a parent to be paid as their child's caregiver or PSW. Impacted families report significant improvements in their children's lives because of this, including health benefits, stress reduction in the family, increased participation in community events and more. Unfortunately, the highly successful pilot program is set to expire on July 15th OAR 411-37-0020 2(b) (A) is changed.

I myself am not the parent of a child with disabilities significant enough to qualify for the K Plan, however my work takes me into the homes of many families for whom this is the case. Often parents are struggling to make it all work, trying to make it financially even though taking care of their child is already a full-time job and limits their outside employment options. In my role as the Autism Consultant, I do my best to connect families with community resources that theoretically will lighten their burden. Often I tell them about CLCM (Community Living Case Management) first, knowing that this is how they will be able to eventually access a PSW, someone who can work with their child directly in their home for a significant number of hours. Theoretically, that is. Unfortunately, the reality is that more and more often families I've worked with report back to me that, after jumping through all of the hoops, being assigned a CLCM case manager, having their child evaluated, and finally being allotted a specific number of hours per week for PSW services, **no qualified PSW can actually be found**. This reality is not acceptable. This reality hurts the most vulnerable of children and their families.

The Paid Parent Caregiver pilot project that Oregon enacted because of Covid temporarily fixed this problem. Paying the parents to step into the PSW role has very real and tangible benefits for these children and their families, as I'm sure you can see by reading some of the parent testimonials. Paying a parent to be the child's PSW puts an end to the absurd scenario I encountered in one family, where the mother of a child who is significantly impaired with autism worked as a PSW for a different family, while struggling to find a PSW for her own child at home!

The monies for clearly needed PSW services have already been set aside for children with the most severe of disabilities via the K Plan. If we are serious about making sure these kids actually get the services they need, having the option of paying parents to be PSWs makes sense for everyone.

Karma Clarke-Jung

Autism Consultant

May 8, 2022

RE: Paid Parent Caregiver policy

To Whom It May Concern:

I have spent the past 22 years of my professional career in providing either direct or administrative support in the field of mental health. In both my professional as well as personal life, I often find the personal stories of those I meet interesting and at times, inspiring. While living in our community since 2018, I have had the privilege of getting to know my neighbor who has 2 sons with special needs. I have watched the loving care both my neighbor and her husband provide their sons. The care they provide is "24-7", non-stop. Although my neighbor's husband also works outside the home and my neighbor often serves as the sole caregiver for her sons, I am amazed and inspired by these parents' unwavering devotion to their children. Both sons have medical conditions that are complex. The level of knowledge and skill needed to provide for their care is astonishing, however, both parents have kept their sons happy, as healthy as can be expected, and have provided them with a quality of life that would be impossible to duplicate outside of their home.

Because of my neighbor, as well as other parents experiencing similar challenges in Oregon, I would like to express my support for the "Paid Parent Caregiver Policy" that was enacted by the State of Oregon during COVID. Although the COVID pandemic created numerous challenges, policies enacted by various State governmental agencies also created insights and opportunities regarding how to create more effective policies that should be continued post-COVID. The Paid Parent Caregiver Policy afforded parents of children with special needs and disabilities a financial lifeline. Parents were able to provide the complex level of care these children needed while providing a small financial buffer that enabled these parents to worry less about keeping a roof over their heads and putting food on their table. Although there has been an eager interest for communities to return to pre-COVID conditions, the ability to hire employees in various labor markets remains a well-known challenge. Rural communities such as ours struggled pre-COVID to attract and retain qualified workers. These conditions do not appear to be resolving anytime soon. That is why it is imperative for parents of children with special needs and disabilities, who know the complexities of their children's medical and mental health needs, continue to receive parent caregiver pay. Their knowledge and dedication to their children lessen hospitalizations and institutional care, both of which can create a burden to our State's financial system. Lessening a family's financial worries improves the quality of life for these families who already have challenges providing care for their children. It has been my observation as a mental health professional, that healthy, well-adjusted families create healthy, strong communities.

I am in hopes that policy makers will view the Paid Parent Caregiver Policy as an effective policy that should be continued as it affords parents of children with special needs and disabilities the opportunity to provide quality of life and care to their children.

Sincerely,

Kimie A. Frakes

Kimie A. Frakes, LCSW Mental health therapist

Family Support Letters

May 8, 2022

To Whom It May Concern:

My name is Lauren Perry. I live in Loveland, Colorado. I have two sons. My oldest is 14. I also have a 12 year old son named Will with a rare genetic disease called SYNGAP1. It was around 9 months old that I felt he wasn't developing normally and had not yet met any milestones. The first years of his life he was often sick with various ailments. He suffered greatly from fevers for a year and was finally diagnosed with a rare illness called Periodic Fever, Aphthous Stomatitis, Pharyngitis, Adenitis (PFAPA) syndrome. He had his tonsils and adenoids removed and this seemed to cure this awful cyclical illness. We saw a developmental pediatrician at 18 months and he was diagnosed with global developmental delay. He needed an extreme amount of attention and therapy. He was diagnosed with epilepsy at age 3. The next year he was diagnosed with autism. Also at age 4 he was diagnosed with intractable epilepsy and ended up, after many drug trials and fails, having a vagus nerve stimulator placed. This helped with drop seizures but didn't cure his atypical absence seizures. When Will was 6 he had whole exome sequencing and was finally diagnosed with SYNGAP1.

In my life before Will started getting sick I had a wonderful administrative job at a tech company. I made good money. I was happy. I had two cute boys, both of them able to go to the babysitter for half days while I was at work and I worked the other half of my day when their dad was home in the evenings. I was even able to work from home, which was not that common back in 2010. However, once all of Will's illnesses came up and just the unbelievable amount of therapy he was put into (physical therapy, occupational therapy, speech therapy, ABA therapy), I just knew I couldn't work anymore. There was no way. I was already stretched for time and it felt like I was living in two totally different worlds. I was always tired and gained a ton of weight. Also, there was really no one here who could be with my special needs child on a regular basis. He was so behaviorally aggressive that he was unsafe around other kids and needed to be constantly monitored. He also had such a rigid schedule and way about him that it was hard to constantly be changing his life and day around. It causes so many more behaviors.

It was at age 4 when Will was diagnosed with autism that I was able to get him on a Colorado state waiver called the Children's Extensive Support Waiver (CES). Getting Will on this waiver also meant that he was eligible for Medicaid. Around this same time I was told by a fellow special needs parent that Colorado has a Medicaid program where parents can be paid caregivers for their disabled children. I had never heard of this. I thought, wow, if I could get this it would take such a huge financial burden off my family. My husband at the time was the only financial provider and it frankly wasn't enough. I spent time trying to help out my sister with babysitting her kids for some cash, but the main thing that involved was dragging 3 kids plus my behaviorally and health-challenged child to daily therapy appointments. It was such a hard time. It was hard on everyone and especially the children. It always felt like we were on the go and I was always stressed out. We never had enough money. I hardly had the energy to care for all

of them properly the way I wanted to.
I had Will evaluated by a home health agency in Colorado and was told he would indeed qualify for this parent caregiver program funded by Medicaid. They use a tool provided by the state that calculates the amount of hours he qualifies for. I was thrilled. In Colorado we have to go through Certified Nurse Assistant training in order to get our CNA license and start charting and providing care for our disabled children. I did that. I was also lucky that the home health agency I work for paid for schooling up front, so I didn't have to pay anything out of pocket. The hardest part was finding care for my son while I took the classes, but I had family and friends really step up and help me during that 6 week course. After passing the CNA license state test, I was able
to start charting. I was able to start bringing in a second income.

So many things improved after this. I always felt like I was drowning. Now we could breathe. We could afford our mortgage on time. I wasn't maxing out credit cards to pay for food and gas. The best thing was, though, I knew my son was being cared for very well. We have nursing visits to our home every 6 weeks where I can talk to my manager/Will's nurse and make sure he is getting everything he needs. I can ask for help and advice. Our nurse goes beyond and provides resources and ideas and just about everything else I could ever need support with. I loved re-gaining the feeling like I was a contributing part of society again as I have a taxable income, a real employer with benefits, vacation days, and coworkers. It's just been such a huge blessing.

I really recommend this program in other states. It's actually hard for me to comprehend that all US states don't have this program. I see how much some special needs parents do every day. To me it should be a right as a taxpayer to have a benefit like this. What are we as a society if we can't protect our most vulnerable populations? What would happen to these families and children otherwise? When you are willing to work and want to provide for your family, yet your hands are tied with a child who needs you 24-7, it feels so desperate. The disabled child is at risk, as well as the entire family. What could be greater than helping people who love their children dearly and want to keep them in their home under their care?

Thanks for allowing me to share my story.

Sincerely,

Lauren Perry

Dear Oregon Developmental Disabilities Services,

Please, make permanent the parents as paid caregivers program in the state of Oregon. The impact of this change would be so profound that it is challenging to briefly express it.

I am a parent of four children. One of which experiences intellectual and physical disabilities. The needs of this one remarkable child are such that I have had to sacrifice any career of gainful employment to keep her safely growing.

My child qualifies for the state of Oregon's Children's Intensive In-home Services. Through this she gets 265 hours of attendant care (well over 300 in the summer). At no point have we ever come close to meeting these hours. This is not due to the need of my child but the challenge of finding people willing to do the work. We have rarely had more than one worker at a time. These workers have only ever been part time, 40-60 hours per month. Leaving over 200 hours unpaid most months. Most are students for whom this job is not a career but a means to other things more meaningful in their lives. The level of care required for my child to thrive and defy the odds would in no way be met by the constant turnover of staff, most of whom have no experience with the medical or behavioral challenges my child faces. It is through the consistent high level of personalized care that I have been able to provide her that she has had the opportunity to grow as she has. The challenge of hiring and keeping support staff for my child is constant and always inadequate.

Which brings me to the most dramatic and far reaching aspect of this program, the financial or economic impact on my child's entire family.

This program represents not only an opportunity for me to be validated and recognized for the caregiving specialist I have become but it is the opportunity for my family to achieve a level of financial stability that has been unattainable for us. Families in our position are forced to choose between economic gain (from the income of a parent working) or the care of their child. We chose the care of our child at the cost of financial stability which means: poverty. Present in our lives through less desirable living conditions, more frequent moves, less favorable neighborhoods and schools, less opportunity for siblings, no savings for emergencies, no retirement plan or security for myself including the very basic Social Security which I will not get for my unpaid labor. I fear that due to my financial sacrifices for my child I will become a further burden on my family as I then age and have no savings or retirement to draw on. The far reaching impact of this choice to prioritize one child's needs over our economic opportunities does not begin and end with me. It reaches into the lives of the next generation of my family as the opportunities of my developmentally typical children are limited now which has been statistically shown to impact their success in the future and how well they will be able to provide for themselves and their own families. Poverty quickly becomes systemic and generational.

As there is no means by which my child's needs can be legislated away, please instead take action where you can and give my family the chance at economic stability and my child the best care possible, through the creation of a permanent paid parental caregivers program.

Stacy Stenzel

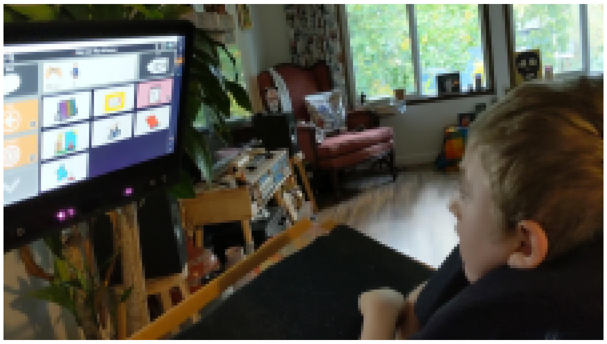
April 4, 2022

Dear Oregon Developmental Disabilities Services,

I am writing to you today about the positive impact that the temporary ruling to allow parents as paid caregivers has had on my son. First, you must understand who my son is and what our life has been like since his birth. Avery Horneck is six years old with a diagnosis of KCNA2 epileptic encephalopathy. This genetic mutation has caused multiple severe disabilities leading to 24/7 care. Not only is it nonstop care, but every day is unpredictable in what it will look like for him. One day he might be having seizures all day and the next he has extremely high tone and is unable to manage his secretions effectively. On a daily basis, we are not only caring for his every need, but also trying to teach him new things and provide him new experiences. He is nonverbal, but working to learn communication strategies with his therapists. All of his therapies should be carried over into the home with our help, but the nonstop health needs combined with trying to live our lives prevents us from doing this and giving Avery what he needs to progress.

Despite his involved care and daily living needs, he is the sweetest boy with the best smile you will ever see. Since his birth, my husband and I have traded off staying at home to care for him, each taking two years at a time. We have PSW hours, but prior to COVID when he had a little more than 200 hours each month, over 140 of those hours were left unfilled. Caregivers were scarce and inconsistent. My husband was filling those hours, unpaid, and then trying to work a part-time job in the evening when I returned home from work. We were exhausted. Neither of us had the energy to be fully present for Avery and his growing needs.

All of that changed with the temporary ruling under the COVID federal health emergency last year. Avery qualified under the ruling and so I was able to pick up a lot of his caregiver hours, providing me a full-time paying job. I was finally able to devote my day to giving Avery the best care because I could also use the hours for some relief from our regular PSW. During the last year of paid work, I have watched Avery improve drastically with his communication. He is nonverbal, but with my support through his online preschool and therapists, I worked diligently and consistently on communication. Prior to last year, Avery was inconsistently using switches to play with a few toys. Now, he is using an eye gaze communication device to communicate WORDS to me! He tells me “Turn the page” when we read a book, and “Finished” when he wants to be done. I have been teaching him the alphabet and he is able to freely “write” using his eyes to choose the letters he wants. It is amazing to see the progress he has made with me in just one year. This never would have happened with an inconsistent PSW, or if I was trying to hold a part-time job alongside caring for Avery.



I strongly urge you to find a way to continue to allow parents of minors to be paid caregivers. It leaves the option open for those parents who want to use some or all of their hours to care for their child. I have seen the overwhelming positive impact on my family and I can only imagine there are countless other similar stories out there. It really has changed our lives for the better.

Sincerely,
Oriana Horneck

TO: Oregon Developmental Disabilities Services
FROM: Dave and Karen DiPietro
DATE: March 29, 2022
RE: Expand Temporary Ruling Allowing Parents as PSW's

We are writing to support expanding the temporary ruling allowing parents to continue as PSW's for children under the age of 18.

This ruling has been a life saver for families experiencing disability. It allows the people who care the most about the children to be the primary caretakers. It also allows the flexibility to hire caregivers outside of parents when a parent is not able to provide these services.

Our daughter experiences multiple disabilities, but she did not have enough PSW hours to qualify as parent caregivers. Even in our case with fewer hours, it would have been a tremendous relief to be able to claim some of the unused hours as we are doing the work anyway.

I, Dave, am employed full-time, but I, Karen, are not able to be employed full-time due to my daughter's disabilities and the difficulty of finding caregivers for her. She is allotted 167 hours a month and yet we only use about 60 hours a month as we cannot find people willing to do the job. We qualify for 14 respite nights a year, yet we have never used any as we cannot find someone who is willing to work at $204 a day. If parents were allowed to collect PSW hours, I, Karen, would be able to provide income to my family that I currently am not able to do due to my daughter's disabilities.

Please continue to allow parents to be paid as caregivers as the children benefit from expert care and the parents can then provide for their families in the same way that parents with non-disabled children do.

Dave and Karen DiPietro
2415 SW Garden View Ave
Portland, OR 97225
503-704-8626

Appendix C: Medicaid Advisory Committee letter

Office of Delivery Systems Innovation
Health Policy and Analytics Division
Kate Brown, Governor

Oregon Health Authority

500 Summer Street
Salem, OR 97306

February 23, 2022

Lilia Teninty, Director
Office of Developmental Disability Services
Dana Hittle, Interim Medicaid Director
Oregon Health Authority
Via email

Dear Ms. Teninty and Ms. Hittle,

During the 1/26/22 Medicaid Advisory Committee (MAC) meeting, MAC members listened to testimony from two families regarding the temporary public health emergency (PHE) policy allowing payment to parents who serve as direct support professionals (DSPs) and personal support workers (PSWs) for their children who require children's intensive in-home services (CIIS). We are aware of similar written and oral testimony from 30 families that was delivered to the Oregon Health Policy Board in December 2021. These families have consistently shared the positive impact of the paid parent caregiver policy, including better care for their children, more reliable coverage, decreased time and anxiety related to the ongoing cycle of finding and training qualified caregivers, better health resulting in decreased emergency department use, and increased financial stability and housing stability for the entire family. These benefits are consistent with the State's health system transformation goal of family-centered, whole person care that supports health-related social needs in addition to treating medical conditions.

Prior to the PHE, families describe an unworkable situation with an inadequate supply of appropriate caregivers willing to serve as PSWs and DSPs. Too often, families are left with an allocation of hours that are not used and therefore have no value in supporting children with developmental disabilities (DD) and their families.

We appreciate the 1/7/22 letter from ODHS and OHA and the 12/14/21 webinar on this topic, both of which describe the complexities and financial trade-offs of Oregon's approach to supporting children with DD. However, the public testimony provides valuable insight into the lived experience of families, and this experience needs to be reflected in Oregon's approach to supporting children with DD.

On behalf of the MAC and families, we respectfully submit this letter in support of a permanent policy allowing parents to serve as paid PSWs and DSPs, and request that as an initial step, OHA and ODHS facilitate a meeting in which families can have a direct dialog with a CMS representative who can share options available to Oregon and details about the policies in place in other states.

Sincerely,

Lavinia Goto, RN, CDE, MPH, MBA, DHA Medicaid Advisory Committee Co-chair	Leslee Huggins, DDS, MS Medicaid Advisory Committee Co-chair

Public testimony submitted to the Medicaid Advisory Committee

Dear Annette and Tara,

I am writing to request consideration of our testimony in support of offering parents the option to be paid caregivers for their medically fragile children.

My husband Neil and I are the parents of a 9 yr old girl called Mattea who was born with a severe medical condition called Clifahdd Syndrome. She is a beautiful child who brings incredible joy to our lives, but she is also medically complex and is 100% dependent on adult caregivers for all activities of daily living. She is non-verbal and uses an AAC device to communicate, she is g-tube fed, and wheelchair bound. She has extremely low tone and needs muti-daily respiratory therapy to keep her airway clear. She cannot sit or stand independently.

Even before the pandemic, we found it extremely difficult to find qualified caregivers to help look after her. We experienced a lot of turnover of PSW/DSPs as the pay is so minimal, it generally only attracts qualified individuals who are in a transition period of their life, such as college or nursing students. This always meant a continual and significant burden on us to try to recruit, extensively train, and retain good PSWs. We were never able to fill all the respite hours Mattea was allotted, simply because we couldn't find enough qualified, consistent help.

When the pandemic hit, it was a gut punch to our family as we had to create a bubble around her to keep her safe. My husband Neil had to quit working in order to look after Mattea full time because we couldn't take the risk of exposing her to COVID-19, and could not have anyone outside our immediate family around her or in our home. When the option to allow paid parent caregivers was finally offered, Neil was able to go to work as her caregiver, and that meant we no longer had to choose between financial hardship and her (literal life and death) safety. This relieved an incredible emotional and financial strain on our family and helped reduce the stress we were all experiencing because of the pandemic.

As we returned to a new post-vax normal, and have had the option to look for new caregivers, the harsh reality is that we are now in an incredibly tight labor market resulting in caregiver shortages and are finding it impossible to attract anyone who is qualified and reliable to help look after Mattea. We have been searching for several months, and keep coming up empty.

The stark facts are that one can work restocking shelves at Walmart ($19.50/hr) or a cashier at Cafe Yumm ($18.45/hr) or McDonalds ($21/hr) for more money and an easier job than being a caregiver for our daughter.

To be a caregiver for our daughter, one must be physically capable of lifting/transferring 50lbs, technically savvy enough to troubleshoot AAC/technology devices, astute and cognizant to recognize seizure patterns and respond, while remaining calm and level headed in stressful situations. This is a physically and mentally demanding job that few are capable of or willing to do for such low wages.

In these continued, unprecedented times, it is incredibly important that parents are given the option to be the paid caregiver for their child. It means financial security for the family and child, consistent levels of care from THE MOST QUALIFIED individuals to do the caring, and the best case scenario for the child from a health and safety aspect.

If the State of Oregon chooses to eliminate this option as we emerge from the pandemic, but still experience labor market shortages, I believe they will find more and more families who are forced to choose between substandard care for their children or surrendering their child to the state, or keeping a roof over their heads and food on the table. I believe the option that is in the best interest of the health and safety of these children like Mattea, and is also the most cost-effective economically for the state, is to adopt changes to the Medicare waiver that will enable parents to be their child's paid caregiver and their best helper and advocate.
Thank you for your consideration,
Amy Haigh
Mother of Mattea Haigh, age 9 in the CIIS program.

Hello Tara and Annette,

I'm writing because I have temporarily been able to work as a parent provider to my thirteen year old son and was told it may help to create a lasting alternative if I shared my experience.

As my son grows, it seems to become more and more difficult to find help and or respite. He is heavier, wants to touch himself and generally isn't an adorable little child anymore even though I think he's adorable of course! He is non verbal and requires a lot of help with toileting (is still in diapers) feeding, mobility ambulation working with a communication system and needs constant supervision for his epilepsy, not to mention he is often up and needing assistance during the night.

Please consider if there is a way to further extend at least some of the parent provider options as it's truly impossible to work and take care of a child with such tremendous needs without additional family and or financial support which many of us are without.

Thank you for your time and consideration!

Andrea

To whom it may concern,

Parents being allowed to be paid care providers allows families access to income to keep their heads above water, not live paycheck to paycheck, and to not have to worry and stress about covering all the bills by going without food or gas. It allows parents the ability to focus attention and care FULLY on the child and the often complex medical conditions that require specific skill and training.

We understand the state of Oregon believes parents of minor children should be charged to care for those minor children just as any other parent. However, we beg you to consider the extenuating circumstances that are our lives. It is VASTLY different than having a typical child. Our children are often sick due to their medical conditions which means we cannot go into work and rack up many sick days and often have to go without pay at a regular job or get disciplined for unauthorized leave. The caregivers that are hired outside the family often call out last minute, no shows, or have a short stay as caregivers-again meaning we call out from our regular jobs and are often penalized for so many call outs- the responsibility ultimately falls on the US every time!

The sheer number of appointments our kids have means we have to use all of our sick and vacation days before we go without pay to get them there – and again we look bad to our employer.

As parents we are unable to just drop our children off at a regular daycare or even with trusted family members to run an errand, have some personal time, or even go out to dinner with our spouse. We rely on paid caregivers as our only source of relief – when they decide to show up. The state of Oregon does not have medically fragile daycares. There is no one but US to rely on. So again, it falls on us and if we are out of work because of it, stress and problems Mount.

The cares of our children are often above and beyond those of typical children. Even bathing can take much more preparation, time, and clean up than a typical child’s bathing routine. For example: Hoyer lifts, specialized chairs, special care around stomas and airways, pin sites, etc. Staff requires very specific and complex training, that we are again responsible to provide. The learning curve is high and many employees do not succeed in training or quit because it’s too hard. This is EXHAUSTING both for the parents and for the Child who has people practicing on them all the time and coming in and out of their lives. Maintaining supplies, scheduling caregivers/nurses, scheduling appointments, and dealing with insurance companies is beyond what a typical parent has to schedule and maintain and takes HOURS each week. This alone is a job.

Our children receive the best care from us when we are paid caregivers because we are not stressed and exhausted from another job just trying to make it all work.

We are able to fully commit to the fulltime job of caring for our children and all that encompasses like: ordering medications and supplies, maintaining equipment, sanitizing their areas, spending countless time on the phone with insurance companies, doctor’s offices and case workers, doing their home physical/occupational/speech therapies, training staff, recruiting and hiring staff, managing staff, maintaining medical documentation, and so, so much more beyond typical parenting! This system is inherently biased against single parents… imagine doing all of this when you get home from your regular job and sleeping for a couple of hours a day for years on end! By staying at home we also reduce the risk of exposure to bacteria, viruses, and other contaminants, reducing expensive hospitalizations.

By paying us to be a caregiver for our child it has also funneled money into our local and surrounding communities. Please improve and update the Kplan to allow even more stability for our children by allowing parents to be paid
caregivers.

As parents, we are the people who know the child best and put the child's best interests first. We should be compensated for the incredible work we do. It is much cheaper to pay the parents than to have to put the child in foster care because the parent is unable to maintain a job and insurance for the child. Let's support parents doing the hard work and prioritizing their children and stop pushing them to the brink of their own mental and physical decline and possibly ultimately turning the child over to foster care.

Currently the only people who can't care for our children outside a state of emergency are biological parents and criminals unable to pass a background check. We would like access to the money that has been allocated to our children based on need for their well-being, that is otherwise inaccessible.

We can do better for our disabled in Oregon and allowing parents to be paid as caregivers is a giant step towards honoring and caring for this population.

Not only is this the RIGHT thing to do, it is ultimately more cost effective.

Thank you for your time.

Sincerely,
Audra

Hello Annette and Tara. My husband and I are writing to share our testimony for why we believe that parents should be allowed to be paid caregivers for their minor children with disabilities. Our son Elliott was born with a rare genetic mutation called DNM1 epileptic encephalopathy. It results in global developmental delays, medication resistant seizures, cortical visual impairment (CVI) and severe hypotonia or low-tone. Elliott is on the extreme side of the mutation resulting in him being non-mobile and non-verbal. He is completely G/J tube dependent for feeding and medication and requires Bi-Pap therapy and a pulse oximeter at night to monitor his oxygen levels. He also requires a suction machine to help him clear his airway throughout the day due to his severe reflux. Due to his significant needs, Elliott requires around the clock care. As a result of Elliott's needs, I (Elliott's mom) have had to quit my job in order to care for him. We are a single income family and struggle to provide for our 2 boys. By allowing parents to become paid caregivers for their minor children, my husband and I would have peace of mind that we can still provide the best care for Elliott and be able to better financially provide for our family. We ask that you sincerely consider allowing this to become a reality, as it would enhance the quality of life for so many families in Oregon. Thank you for your time.
Sincerely,
Christopher and Emily Wagner

To whom this will concern,

We are Dawn and Jason Schoppe, parents to two boys, Juno and Jupiter. Juno is almost 7 years old and has quadriplegic cerebral palsy.

We have had a few PSWs/DSPs over the years, with varying degrees of quality, so we were elated to be able to have Jason be paid for this work during the emergency order through the pandemic. In addition to the fact that he was already performing this work, and we have not been able to secure a reliable DSP willing to be fully vaccinated and work around a school schedule, it has let our family feel safer knowing we don't necessarily have to have strangers in the home at this time.

More than this, though, allowing Jason to be a paid parent caregiver for Juno has provided us a sense of autonomy and choice. This has been an incredible relief to our family. It has provided income to avoid living from check-to-check and having to figure out whether we can pay the electric bill OR the medical bills. It has allowed us to focus our attention and cares FULLY on our son and his disability

Our disabled kids receive the best care when we are paid caregivers because we are not stressed about another job and our performance or attendance there. We are able to fully commit to the full time job of caring for our kids and all that encompasses like: ordering medications and supplies, maintaining equipment, sanitizing, spending countless time on the phone with insurance companies, doing their home physical/occupational/speech therapies, and so much more.

It is immensely important to us that you understand the benefit of simplifying services for families of children with disabilities; specifically, allowing the OPTION of paying parents directly for care. Covid-19 has put families who are in the Special Needs Community at a particularly high risk. Juno is now fully vaccinated against Covid, but the caregiver/nurse shortage is severely acute for families like ours.

This is Oregon’s time to build on the idea that has shaped the original foundation of the K plan: that we are a “Community First” state, and that institutionalizing individuals has a human and financial cost not worth it to our most vulnerable residents. The K-plan has been a great step toward that mission, but needs to be updated with language to allow even more stability for our families. Parents should be allowed to be their children’s PSW or DSP, and be compensated for the work they are doing.

If my son was 18, I could be his paid caregiver. If I was his sister, aunt, or grandmother, I could be his paid caregiver. The only people who can’t be paid caregivers to minor children in Oregon are biological parents and people who can’t pass a criminal background check. Please improve and update K-plan to allow even more stability for our disabled children by allowing paid parent caregivers as a permanent option. We would like access to the Attendant Care funds that have been budgeted and earmarked for our children that is otherwise inaccessible by having the choice.

Thanks so much for your time,

Dawn and Jason Schoppe

I am a father to a medically fragile 16 year old daughter who is a qualified participant in the CIIS program through the State of Oregon. This huge journey began with our daughter’s seizures at 3 months and became disabling quickly as her “catastrophic” grade epilepsy robbed of health and development.

Those seizures began at the end of my parental leave from work and I returned to my employment as a mental health specialist for the local county. At that same time, my wife began a different job with no pay and huge responsibilities—becoming our daughter’s full time care coordinator, case manager, nurse and advocate in multiple systems. Our decision was clearly to not relinquish her custody into medical foster care or residential custody.

We are grateful for the successful support through secondary OHP coverage for her medical bills. But we are seeking the right to be eligible as personal support workers the way California, Colorado, and our own state have done during this current and continuing pandemic. We are hoping the administrators will agree.

Respectfully Submitted
Ed Stracener, QMHP

Dear Tara and Annette and OHA committee members,

I am writing to you today to ask that an exemption be placed within the Medicaid 1115 Waiver to allow biological and adoptive parents to be paid caregivers to their children who have disabilities and chronic, complex medical conditions. I am requesting that parents be paid the same hourly rate as DSP/PSW's.

The state of California pays parents of children who have disabilities and are medically fragile. We have had members in our support group who have been forced to relocate to California in order to be able to successfully support their child's medical needs and alleviate the ongoing financial strain.

As a parent and 24/7 caregiver to a 6 year old who has a rare medically complex syndrome; it is impossible to hold down a job let alone a career for my spouse or I. Juniper has an extremely low seizure threshold, meaning she gets seizures from common cold/flu viruses. She also has extremely long and dangerous status seizures which frequently last 30 mins-2 hours.

Along with status seizures, she has Wolf-Hirshorrn syndrome, hypotonic cerebral palsy, autism, microcephaly, upper airway restriction, unrepairable open palate, sensory processing disorder, hypotonia, gtube fed, and is unable to walk or talk.

Due to her medical fragility, we were forced to give up our careers to provide adequate care for our child. I was a FT educator/social service provider; while my spouse was a FT lab technician. In my position, I was frequently bringing home germs and illnesses that would set off seizures and respiratory issues for Juniper.

My spouse now works a PT entry level position in order to provide support when medical emergencies occur. There have been countless occasions when I've had to call him home to support seizure emergencies.

We searched for caregivers to support our family, however many were not interested in supporting us long term as it was only a "stepping stone" job for them. We went through 10 caregivers in the span of a year and a half.

Through this experience I have had to manage the care workers, remote learning, PT/OT/SLP, and various medical specialists which is around 30 providers total to coordinate care, appointments and meetings.

All the while managing Juniper's medications, tube feeds, seizure emergencies, choking scares, and using suction and oxygen during emergencies to try to avoid calling 911 to have another ill trained Paramedic and ER Dr who are unsuccessful at supporting my child's various medical needs, all during a deadly pandemic.

I am asking all of you to integrate a family centered model of care. For those of us who have children who have medically complex conditions, we are the best trained caregiver.

We notice when our nonverbal child has the slightest change in disposition that means a seizure is coming on, and get oxygen and the rescue meds. We can assess when our child who has an extremely high pain threshold has injured herself. We know how to safely support her through life as a crawler and wheelchair user.

Please support Oregon's most vulnerable children, and allow parents to manage their DSP/PSW care hours allocated through Medicaid and managed through the Child Intensive In home Services program of ODDS in order to be Paid Parent Caregivers.

In May, after a long 4 year wait, Juniper was accepted into the CIIS program which due to the COVID-19 emergency started paying me to be their her caregiver.

This program has been a huge relief, as we had been struggling against insurmountable odds in order to pay our bills, keep up with home repairs and adequately support our child.
Unfortunately, the parent as paid caregiver program is set to end in January 2022. This will provide dire financial consequences and strains on families like ours.
Please support my little love by allowing me to continue to support her fully, she has so much love to give.
I look forward to your support with including the Parent as Paid Caregiver program in the new Medicaid waiver 1115.
Kind Regards,
Emily Fern Dayton, MS

I am writing to share my story. I am a single Mother to two differently able boys. One is 13 with an ectodermal dysplasias diagnosis who is preparing for his 46th surgery in the morning. The other is an 11 year old with Autism and a seizure disorder. We only have respite services for my 11 year old. I am a stay at home mom and full time student. The reality is that even after I graduate I will not be able to work because there is not adequate care available for my children. During COVID the boy's father lost his job when the mill he worked at closed. He needed work and I could not find a respite provider. ODDS does not require drug testing and I can not trust someone in my home with my children that I do not know. If they were using drugs it puts my children, my home, and insurance all at risk. Having the ability to employ their father has been life changing. The added support at home has allowed for bonding time with his children but also allowed me to have medical care and for me to be with my 13 yr old at OHSU with my other son for his medical needs. COVID rules are still the parent and patient only. Without the help of a respite provider my other child's needs are neglected and put on hold.
IF THIS WAIVER GOES AWAY I WILL NO LONGER BE ABLE TO MEET MY CHILDREN'S NEEDS AND I WILL BE FORCED TO PLACE MY CHILD WITH AUTISM IN A FACILITY OR IN STATE CUSTODY REMOVING HIM FROM OUR FAMILY AND HOME. WE CAN MEET THE NEEDS OF THE REST OF THE FAMILY WHEN HELP IS AVAILABLE BUT IF YOU TAKE THAT WAY AGAIN WE WILL HAVE NO OTHER OPTIONS.
Covid have taken its toll on many but for our family it provided the opportunity at a normal functioning home with adequate support because of this waiver. Allowing family to provide care for family is not able to be matched. No one else is going to care for my children like their father does. No one is going to understand their needs like their father does.
Please do not put me in the position of having to choose between survival and safety vs placing my son in a state to care for moving forward. Please understand that I love my children more than anything else in this world but I am only one person and I can not do this alone.
If you do not require drug testing how can you expect us to allow a stranger in our homes? You are asking us to put our entire livelihoods at risk.
Change is needed and it is needed NOW!
Sincerely
Jennifer Hagerty
3233177435 cell

From: Jennifer Murphy
To: Pierce Annette
Cc: CHETOCK Tara A
Subject: Allow paid parent dsp/psw for their own minor child
Date: Saturday, December 4, 2021 4:37:57 PM

Hello, my name is Jennifer Murphy. I am the mother of Preston age 8 and Parker age 5. These boys are the absolute joy of our life. Everything we do is for our boys. My husband works at a lumber mill to provide for our family. We have been married for 10 years. I have been home since Preston was born 8 years ago and he was in heart failure, waiting on surgery .Preston experiences Down syndrome, hypothyroidism,Gluten intolerance Celiac, colitis, Food protein intolerance, has had open heart surgery repair, air way surgery, he has a very weak immune system, he relies on a wheelchair and full care.Preston is an angel! Parker is our 5 year old and he experiences severe autism, and most recently diagnosed feb 2021 with type 1 diabetes.Parker is eager to learn everything he can, so much Determination. Both of our children together have 600 hours of paid k plan help offered. While this sounds like it would meet our needs, It is not. The k plan is not meeting our needs. I'd like to talk to you today about why we are seeking a change to allow Parents the option to provide the services to their own minor children.

The struggle: There is and has been for a long time a major staff shortage. This would stabilize families. We can't find any one trustworthy, drug free, educated, or qualified to provide life saving care to our children. My kids can't tell me how someone treats them or if someone hurts them. I can't trust anyone under a nurse to run my child's insulin injections, to do the math, to check for ketones, to act with glucagon injection if he goes into a low in a seizure or coma. Diabetes makes our life a lot more intense . Diabetes requires 24 hour care. The dsp and psw are not drug screened, I can't put my kids lifes in the hands of strangers. We don't have family and friends to hire. We can't allow the exposure with the covid, when our kids are sick they are often hospitalized, their immune systems are compromised. Workers can't come here sick! I have had one successful dsp that ended up moving, she was wonderful. I run ads , I have posted and can't find workers. An agency sent two 18 year old girls here to interview, we had no other options, we had given them a try. They happened to be roomates, and they quit on day 2 of training! We struggle financially with one income, my husband has to have two open fmla open at all times one for each son for when an emergency happens. In our life, it's not if it happens, it's when it happens. FMLA is not paid. In Feb 2021 he took 7 weeks with Parker's diabetes diagnosis. We had to learn everything to care for our son. luckily we got stimulus money to live off of. Then delta struck and we sheltered in place and I at that time began to get paid as my sons dsp. My husband had to return to work, after FMLA was exhausted. So now our exposure is greater to covid. I will say the boys did get their first covid shot last week. It's extremely hard for my husband to carry a career. I can't work. We have had my husband home

this year 2 times and we experienced us as a family unit doing everything together. and it was amazing! life was less stressful, we had money to pay everything, not just live paycheck to paycheck. We have 2 kids, and both have alot of needs. I am forced out of
the work force, and i am actually working at least 2 full time jobs. I am unseen, unheard, and I am doing all the work. Being a caregiver is different from just being a parent. My kids have 12 drs together, labs, and appointments. Our kids receive the most love, attention, and care with us and their parents. We have major life goals and we love our kids.I will always be my kids best support. I can't express to you how one decision to allow paid parents, would benefit our kids, our family. please understand that our needs are all different, we are voicing to you, to please change this option. Being a paid parent would help our families in many ways. Thank you for the time Mrs. Murphy

My name is Jenny Eckart Hoyt, and I'm a life-long Oregonian, and mom of two children, living in St. Johns. My son Emmett is 3, and my daughter Winnie is 5. Winnie is deaf/blind, has Cerebral Palsy, epilepsy, global developmental delay, and is non-mobile and non-verbal. Our children are the light of our lives, but raising a profoundly disabled child is not for the faint of heart. The difficulty surrounding the acceptance of our situations is no match for the amount of time, effort, fortitude, and advocating necessary to utilize the services we have at our disposal, specifically with the caregiver hours allotted for my daughter's "institutional level of care."

I want to talk about the importance of simplifying services for families of children with disabilities, in particular allowing the OPTION of paying parents directly for care. Covid-19 has put families who are in the Special Needs Community at a particularly high risk, because we can't have our children in the community, but we also minimized the amount of supplementary people entering our home to help. We are now relieved that days ago our 5 year old received her second Covid vaccine, but the caregiver/nurse shortage is particularly acute for families like ours. We've had only one caregiver in 5 years who was willing and able to work up to 35 hours a week, all the rest have worked around 5-10 hours because they were students en route to their careers in nursing, OT, etc. She was with us for a year and a half, still only utilizing 34% of my daughter's allotted monthly hours, and she recently left us to go care for a child who was closer to her new home. She gave us 3 days notice, and she has been our most professional PSW thus far! We also consider ourselves excellent employers, from the feedback we've received and our continued relationships with caregivers who have moved on.

It's an administrative, logistical, and mentally taxing job to find, train, schedule, and oversee caregivers on top of our already chaotic lives. This doesn't mean we aren't ecstatic when we have good help, but the cost of getting them to a point where they can give us actual respite is sadly often not worth the time it all takes. What are we supposed to do with the unfulfilled hours at no fault of our own? We are always taking up ads and networking to fill these slots. We are maxed out because we have to work outside the home and juggle our finances in order to provide for our daughter, yet aren't even legally allowed to use our caregiver hours to go to our jobs!

My husband and I are part of Portland's robust Restaurant Industry. We are both, seemingly at the top of our game, with my position as a GM of a local restaurant for the better part of a decade and my husband a chef. We both enjoy going to work, it is something that keeps us fulfilled, and more importantly keeps our mortgage paid. But both of our professional lives have changed dramatically since having our daughter. My husband and I both had no choice but to change from salaried positions to hourly after our (unpaid) maternity leave. The challenges that Winnie had were too much to leave her in anyone's care but our own. My husband and I for 5 years have manipulated our schedules to work opposite of each other in order to make it work. He now works at 3:30am, and I often work evenings. We were making a six-figure combined income before we had WInnie, and now we are lucky to make a little over half of that. We simply cannot work full time and keep up with her needs, appointments, and administrative work for services even when we have been able to have caregivers helping. I am lucky to log 18 hours a week in my job now, and that is with the absolute maximizing of my efficiency and current part-time caregivers. Both of our employers would love to have us work more, but miraculously we have not been penalized like lots of my friends in this position, and are able to cobble together a full-time work schedule between the two of us.

A reality that creeps in soon after your newborn is given earth-shattering diagnoses are two thoughts: 1.Will my child live a full lifetime like she deserves? 2.How will I take care of her for the rest of my life? The answer to these two questions for my family is: 1. Yes, because we will do everything in our power to keep her healthy and supported. 2. We will do it because we will find a way to keep her home with us where she belongs no matter what the cost.

We have made the choice even before we were introduced to Kplan and CIIS that we would care for Winnie indefinitely, and it has taken us years to accept that and embrace our situation.

This is Oregon's time to build on the ideology that has shaped the original foundation of the Kplan, that we are a "Community First " state, and that institutionalizing individuals has a human and financial cost not worth it to our most vulnerable residents. The Kplan has been a great step toward that mission, but needs to be updated with language to allow even more stability in our families. Parents should be allowed to be their children's PSW or DSP, and be compensated for the work they are doing. I'm deeply concerned about the coming tidal wave of disabled foster children or other family breakdowns here in Oregon. I have seen it first hand by multiple women who have all plainly said in one way or another, I can't work, I can't find caregivers, I have no other option but to surrender my child. Wouldn't it be cheaper and better for our citizens to invest in these families NOW before their families are destroyed?

The only people who can't be paid caregivers to minor children in Oregon are biological parents and criminals who can't pass a background check. We would like access to the money that has been budgeted and earmarked for our children that is otherwise inaccessible.

Thank you,

Jennifer Hoyt

To whom it may concern:

I'm writing to you today about paid parent caregivers for medically fragile children in Oregon. Currently Oregon is under an exception to Medicaid because of the pandemic that is allowing parents to be the paid caregivers of their medically fragile children. I urged you to continue this exception for Oregon's medically fragile children and their families. Being a paid caregiver for our medically fragile daughter has been a life saver for our family.

My four year old daughter Jennifer was born with a congenital heart defect and after open heart surgery at 11 months old; she is no longer able to maintain her airway. Because of this she has had a tracheostomy tube and ventilator for the last three years and may always need this life saving support. Since January 2021 my husband has been a paid parent caregiver for our daughter. This has allowed him to fully concentrate on her needs, therapies, appointments, supply orders and insurance issues. Him and I both no longer have to stress, worry and plan our employment around Jennifer and her needs. He is being paid to care for Jennifer and provide her the outstanding care she needs. This is nursing level care in our home which is best for Jennifer.

If paid parent caregivers are discontinued after the pandemic it will cause great hardship for our family. Jennifer needs a paid parent caregiver to take care of her now and in the future. With the current nursing shortage, there will not be nurses to pick up the care hours that my husband is currently providing.

Medically fragile children in Oregon are just that, fragile. They can't go to daycare or school without nursing or parent support. They have multiple appointments and therapies, along with medications and other needs. My daughter, like many medically fragile children, could be receiving care in an inpatient facility. But my husband and I have decided to care for her at home. Please continue to pay us for the nursing level care that we provide, that keeps Jennifer safe, healthy and out of the hospital.

If you have any questions, I would be more than happy to discuss them with you.

Sincerely,
Jessica C. Langley
Albany, Oregon

From: joshua widmer
To: Pierce Annette
Subject: Medicaid waiver request for parents. Care givers
Date: Saturday, December 4, 2021 10:41:23 AM

Annette,

I would like to please encourage you to find a way to include some language in the '3.5 T bill' that changes the federal language within Medicaid to include paying PARENTS in K-plan states (like OR) to be caregivers of our medically fragile and disabled kids. My wife and I struggle to provide for our deaf blind 4 year olds needs. He requires 24 hour care. Although he is wheelchair bound and non verbal, our son Jason is our world. Although we are granted hours through the state for home health care aides, it is a constant struggle to find anyone who is dependable and willing to show up on a consistent basis. Other states like Colorado allow paying parents. My wife used to practice medicine and has had to give up her medical career to care for our son. This program has helped my family tremendously. Please fight for it. Joshua Widmer

From: Katie n Brad Reding
To: Pierce Annette; CHETOCK Tara A
Subject: Allowing parents to be PSWs/DSPs to our minor children
Date: Saturday, December 4, 2021 3:04:11 PM

To whom it may concern,

Being a paid caregiver to my daughter has been a true blessing to our family. It has provided income to keep our heads above water, not live paycheck to paycheck, and to not have to worry and stress about covering all the bills by going without food or gas. It has allowed us to focus our attention and care FULLY on our daughter and her medical conditions.

We understand the state of Oregon believes parents of minor children should be charged to care for those minor children just as any other parent. However, we beg you to consider the extenuating circumstances that is our lives:

A) Our children are often sick due to their medical conditions which means we cannot go into work and rack up many sick days and often have to go without pay at a regular job.

B) The caregivers that are paid to show up often call out at the last minute or are complete no shows – again meaning we call out from our regular jobs and are often penalized for so many call outs. (Another topic is to pay said caregivers more as an incentive to work such a hard job that demands a lot of responsibility: someone's life).

C) The sheer number of appointments our kids have means we have to use all of our sick and vacation days before we go without pay to get them there – and again we look bad to our employer.

D) As parents we are unable to just drop our children off at a regular daycare or even with trusted family members to run an errand, have some personal time, or even go out to dinner with our spouse. We rely on paid caregivers as our only source of relief – when they decide to show up. The state of Oregon does not have medically fragile daycares. There is no one but US to rely on.

E) The cares of our children are often above and beyond those of typical children. Even bathing can take much more preparation, time, and clean up than a typical child's bathing routine. For example: Hoyer lifts, specialized chairs, special care around stomas and airways, pin sites, etc.

F) Maintaining supplies, scheduling caregivers/nurses, scheduling appointments, and dealing with insurance companies is beyond what a typical parent has to schedule and maintain.

Our children receive the best care from us when we are paid caregivers because we are not stressed about another job and our performance or attendance there. We are able to fully commit to the fulltime job of caring for our children and all that encompasses like: ordering medications and supplies, maintaining equipment, sanitizing their areas, spending countless time on the phone with insurance companies, doing their home physical/occupational/speech therapies, and so much more.

By staying at home we also reduce the risk of exposure to bacteria, viruses, and other contaminants.

By paying us to be a caregiver for our child it has also funneled money into our local and surrounding communities.

Please improve and update the Kplan to allow even more stability for our children by allowing parents to be paid caregivers. As parents, we are the people who know the child best and put the child’s best interests first. We should be compensated for the incredible work we do. It is much cheaper to pay the parents than to have to put the child in foster care because the parent is unable to maintain a job and insurance for the child. The only people who can’t care for our children outside a state of emergency are biological parents and criminals unable to pass a background check. We would like access to the money that has been budgeted and earmarked for our children that is otherwise inaccessible.

Sincerely,
Katie Reding
31121 NW Claxtar St
North Plains, OR 97133
503.347.5530
bkreding@yahoo.com

From: kelsey smith
To: Pierce Annette; CHETOCK Tara A
Subject: Parents as caregivers

My name is Kelsey Smith, and I am mom to a beautiful almost 10 year old boy named Taran who has quadriplegic Cerebral Palsy, Short Bowel Syndrome (he's missing more than 70% of his intestine), Cortical Vision Impairment, and Auditory Neuropathy (deaf/blind).
Taran had his first 4 bowel removal surgeries before he was 8 days old, and spent almost 6 months in the NICU.

Taran has had 31 surgeries (to date), many of them life threatening, and extensive. He requires care 24/7, to ensure safe breathing and positioning, as well as keeping him engaged and happy. He is a vibrant little boy, trapped in a body that doesn't work.
I have always been Taran's primary caregiver. I work 24 hours a day, even with extra help. With Taran's 16 medical specialists, as well as the literal dozens of therapists, teachers, etc, I will never be able to work a job outside my home. Coordinating appointments and care for Taran in addition to my role of managing my household and parenting my other children proves much more than a full time job.

We are committed to caring for Taran in our home. We cherish him, and would NEVER consider sending him to an institution. That said, finding long term help that we can trust for Taran is next to impossible, though we continue to open our home in attempts to find that "unicorn psw". Though it's likely hard to imagine having strangers (never the same people, for long) in your personal space at all hours of the day, this has become our reality. Our "normal".

The pandemic has provided some shockingly positive side effects for our family.
Taran has not had to be hospitalized since January of 2020. The lockdown meant less exposure to the outside world, and therefore a much healthier environment for our son. Our world got much smaller, but also much safer for Taran.

Being able to contribute to the household income these last 7 months has been life-changing for us. It has allowed us to slowly crawl on top of our debt, and has given great reprieve to the constant financial and emotional pressure that the financial care of a medically complex child creates. In addition, the constant burden of searching for more outside help has been greatly reduced.

This money has already been earmarked for Taran. It just makes sense for me to be able to be paid to care for him, doing something that I will do regardless.
Please, please consider keeping this indefinitely.

Sincerely,
Kelsey Smith

From: Lenore Eklund
To: Pierce Annette; CHETOCK Tara A
Subject: ALLOWING PARENTS TO BE PSWs/DSPs TO OUR MINOR CHILDREN

To Whom It May Concern,
Please allow parents to be paid PSWs/DSPs for their minor disabled children. I am Mom to 5-year old Charlee, my daughter with cerebral palsy who is non-verbal and non-mobile. It is incredibly difficult to find qualified caregivers who can do the daily work needed to support Charlee or who can stay on with our family when we have been in the hospital during any of our 5 neurosurgeries and recoveries. I have not been able to work since Charlee was born because I don't have reliable support to be able to have any semblance of a schedule for myself. Our family subsists on the income Charlee's dad makes at his restaurants. We have had to rely on WIC and SNAP to get by at times and it was agonizing when the pandemic hit and we had no idea what the next months held for his restaurants.
Being Charlee's paid caregiver has given our family stability for the first time since Charlee was born. Having finances to make our family work has opened up time and space for our family. In May, Charlee had a spinal fusion in Oakland, California. Charlee's dad was able to be with us through the surgery and recovery because we didn't have to worry about lost wages if he took the time away. Without the time and effort it takes to figure out how to make ends meet, I was able to devote myself to work with Charlee on PT post surgery. Since January, Charlee has been able to make choices using a communication device, which in the past I never had time or capacity to work with her on. It wasn't our plan for me not to work when I was pregnant with Charlee. We envisioned placing her in child care while I continued my career. Capable and reliable caregivers seem non-existent for the level of medical needs Charlee has. This temporary allowance has changed everything for our family. It will be crushing if it is taken away. I love Charee so much and I want to be present for her without the anxiety and stress so I can give her the best support I can.
Sincerely,
Lenore E. Eklund

From: Liz O
To: Pierce Annette
Subject: Allowing Parents to be PSW.s/DSPs

Hello,
I wanted to give my opinion as to why I believe special needs children need to be cared for by their parents. These kids excel in the care of the people who have been there from day one. I have seen the difference in the care between nurses or the parents' care and it is night and day. I am invested as I see the care and support and how much my grandson has excelled with support of his parents' care and avocation in his at home schooling and the shear support that his receives. These children are in need of more and it's not because of what someone caused, but due to the fact that they were dealt the card of early births or genetics.... and now of being special needs...
These special kiddo's need support, care, love and acceptance. It helps them grow, learn and feel accepted.
To many nurses it is a job. ..to the parents it's their child's future and this is important. Please understand the importance of the parents caring for their child. Staying home to completely care, nurture, teach, and advocate for their child.
Thank you for listening,
Liz Ouellette

From: Mandi Winter
To: Pierce Annette; CHETOCK Tara A
Subject: Paid parents for minor children
Date: Saturday, December 4, 2021 10:41:27 AM

To whom it may concern,

I am reaching out to you with my testimony on why parents with children with disabilities should be paid to care for their children.

I am unable to work because my child has a severe medical condition that requires around the clock medical assistant. I can not keep a PSW working enough because they either feel uncomfortable dealing with his medical condition or I am unable to meet the nursing meeting and training requirements for them to work. I have lost 3 jobs because I can't get the support I need for my son at home. His school calls also around the clock because he needs to come home, due to his medical condition interfering with his class time. I have to be available on a whim if this happens. They expect me at the school in under 15 minutes to get him. It is such a burden to work and be a good parent,and still make ends meet. My children deserve more than an overworked stressed out mother.

Please consider helping parents like me. We aren't asking for free money, we are asking for help to take care of our children as best as we can, without the hardships of unstable income.

Sincerely,
Mandi Winter

From: Maria Rogers
To: Pierce Annette
Subject: Allow Oregon caregiver dollars to be paid to parents

To whom it may concern
I'm a mom of disabled child with uncontrolled epilepsy seizures Lucas Jolley. Please allow parents to be paid caregivers for our disabled children. This is my disabled child's right to spend as much time as possible with his mom who loves him and cares and NOT with a stranger caregiver.
The parents are forced to work full time jobs in order to pay bills, then off work for FREE keep doing caregiver's jobs. This is physically and mentally exhausting.
Or parents are forced to deal with a stranger caregiver in their private environment (home) for 50-60 hours a week. This is a big mental stress.
Sincerely,
Maria Jolley
Get Outlook for Android

From: Michael L Stevens
To: Pierce Annette; CHETOCK Tara A
Subject: ALLOWING PARENTS TO BE PSWs/DSPs TO OUR MINOR CHILDREN

Dear Oregon Department of Human Services,

My name is Michael “Mick” Stevens. I am a parent of an eleven year old girl named Jillian. We call her Jilly. Jilly was born with Cerebral Palsy and was recently diagnosed with Autism. She is a quadriplegic and has very complicated needs to keep her safe and healthy. Additionally, she has many health and physical problems not commonly associated with CP or ASD. We moved from Idaho to the San Francisco Bay Area when Jilly was an infant because she needed specialized care that was not available in Idaho. Shortly after that I quit my full time job to be her permanent stay-at-home caregiver. California offers a program called In Home Supportive Services (“IHSS”) that allowed me to stay with her and reduced the impact of losing half of my family’s income. With this program, I was able to care for Jilly and advocate for her in a way which greatly reduced unnecessary illnesses and injuries while allowing her to meet her maximum potential.

We moved to Tigard, Oregon in the Spring of 2017 to be closer to family. We were shocked that Oregon does not have a similar program to pay parents and we began to search for a Personal Support Worker or Direct Support Worker to assist Jilly so I could return to my career. To date, we’ve exhausted lists of agencies provided by Washington County Developmental Disability Services and Children’s Intensive In-Home Services but have been unsuccessful in acquiring a single PSW or DSP outside of a couple of family members that have occasionally stepped in to help. At this point I’m not feeling certain that we could find a caregiver, but I am certain that no paid caregiver could ever give the support that a parent can. My daughter comes first, which means that I will go without sleep or meals if her needs require it. I will get on the floor with her in painful and uncomfortable positions to work on fine motor skills or range of motion stretches. I'm not young anymore and she is growing in weight and length. I have permanently injured my back lifting and transferring her between her bed, wheelchair, stander, gait trainer, and the floor. No paid caregiver, no matter the salary or benefits, will sign up for this. I am on my own. The temporary rule to authorize parents to be paid caregivers is making a huge difference. Please consider making this a permanent change. Thank you very much for your time.

Very truly yours,
Mick Stevens

Dear Tara, Annette, and OHA committee members,

Thank you for your work. We are family but never expected to need Medicaid or other social safety net benefits but six years ago everything changed.

I will say more but my main message: please make changes to the Medicaid 1115 Waiver to allow biological and adoptive parents to also be paid caregivers. I am requesting that parents be paid the same hourly rate as DSP/PSW's.

Background if it helps you understand why this is so important:

As you know, medical science and technology is helping more people survive and even live from home. My daughter is one such story but we can't possibly do it alone and I have already spent my retirement to leverage her survival. She has a rare genetic syndrome requiring 24/7 medical caregiving (we qualify for 400 hrs/month through the kplan plus respite), all day tube feeding, anti seizure meds, rescue meds, oxygen, suction, and on and on, it's a full time job for 4-5 people if you honestly look at labor disbursal. My daughter is a lovely young person Who makes the world a better place but "it takes a village to raise her" including 20 plus specialists, therapists, three case workers... People in our situation often lose their job and or career, physical, and mental health. It's documented that we die earlier and get diseases or illnesses sooner than typical parents.

Everything is upside down for our family (my daughter can't eat orally but is hungry all the time, she can't talk but she communicates nonstop, she can't walk but she gets around our house and Human crawls up on the table with enthusiasm for life and learning and engaging), but surprisingly because of the emergency rule change paying us for some of those hours we have been able to keep our bills paid and to get off SSI and SNAP. We are lucky in a way, that she qualified for CIIS, we have been thinking about moving to California for the lifeline of paid caregiver benefits for my spouse. As you know The state of California and Colorado have succeeded to pay parents of children who have qualifying disabilities and or are medically fragile.

As a parent and 24/7 caregiver to a 6 year old who has a rare medically complex syndrome, it is impossible to hold down a job let alone a career. Most families like us, the dad works and the mom is curious, but I can only work part time and she was working part time but my daughter has been hospitalized 12 times in her six years with almost weekly crisis issues.

My spouse stays home to do caregiving and virtual school. I work a PT entry level position in order to provide support when medical emergencies occur. There have been countless occasions when I've had to drop everything and come home to support crises and even emergencies. Reliable caregivers are hard to find and keep as it doesn't pay or provide living wage benefits.

OHA claims a family centered model of care. For those of us who have children who have medically complex conditions, we don't actually get to parent like typical families, it's a medical job much of the time; paying us relieves important pressure so we can focus on family, and contribute to society in the best way we can.

I have been amazed to learn how many ways disabled people contribute to our society. I was raised in a mainstream family and community and a very ablest culture. Life is so much more rich when everyone has a chance to succeed. Paying qualifying parents as caregivers allows people with medical complications and disabilities to have healthy caregivers and as a result better lives which is better for all of society.

We are going to post a video to talk about our lives and to actually share our very private caregiving story. If anyone struggles to understand the context please go walk through the Oregon State Hospital and read some of the stories of what people like my daughter experienced before society became more open. Paying parent caregivers is part of that upward trajectory that is part of a bigger progress still in the works.
Unfortunately, the parent as paid caregiver program is set to end in January 2022. This will provide dire financial consequences and strains on families like ours.
Michael Paruch
Silverton Or

From: Oriana Horneck
To: Pierce Annette; CHETOCK Tara A; 1115 Waiver Renewal
Subject: Medicaid Waiver - Allow Parents as PSW/DSPs
Date: Saturday, December 4, 2021 10:53:29 PM
Some people who received this message don't often get email from oriana.campbell@gmail.com. Learn why this is important

To Whom It May Concern:

I am writing to express my support and share my experience in regards to permanently allowing parents to be paid caregivers for their child on the medicaid waiver. My son, Avery, was born with an extremely rare form of a genetic epilepsy called KCNA2. From birth, he has exhibited severe developmental and cognitive delays. He requires 24-hour care to assist him with activities of daily living and constant monitoring for seizures, vomiting, and aspiration.

As a family, we are thankful to have PSW hours that cover most of the day. But what people need to realize is that just because he is allowed those hours, does not mean they are filled. It is very challenging to find enough experienced, reliable, and long-term caregivers. It takes a while to train PSWs to adequately care for Avery. He is nonverbal and therefore it requires a lot of time to learn to read him through his movements and vocalizations. The difference between someone knowing how to read Avery or not is huge. He faces food intolerance through his g-tube, so if a caregiver cannot tell if he's full, uncomfortable, or in discomfort with his food, he will vomit, putting himself at risk of aspiration that can send him to the hospital for days on end. As his parents, we have not been able to simultaneously hold two full time jobs since Avery was born, almost 6 years ago. His complex needs have forced one of us to be home to care for him. No daycare is suitable or can make enough accommodations for him. And while he just started kindergarten, it is still challenging for both of us to work full time. Avery has numerous doctors appointments, therapy sessions, and occasional surgeries, all of which will take him out of school and require one of us to take time off work. Additionally, Avery's care when he is with us is so demanding that it is exhausting to hold a full time job AND meet his needs the rest of the day and night. All of this does not even factor in the financial burden our family has faced by only being able to have one parent working a full time job for five straight years.

In the 10 months that parents have been allowed to be paid caregivers, our family has saved more money than the past five years combined. It is the first time we have had two incomes at the same time. The money we are able to save will go directly towards a down payment on a house in the future. And we won't be able to buy just any house. It will have to be wheelchair accessible, or easily modified to be accessible. There are so many additional factors families like ours have to consider and so for a parent to be a paid caregiver, it relieves just one of the major challenges we face.

Attached is a photo of Avery. He deserves to have an amazing life despite the obstacles he faces. When he receives quality care, he is happy, healthy, and makes progress developmentally and cognitively. I hope that our story has brought a little more light on the issue and has helped you to see the impact decisions like these have on us and other families.

Sincerely,
Oriana Horneck

From: Pamela Keuneke
To: Pierce Annette
Subject: Parent testimonial on K Plan Waiver
Date: Saturday, December 4, 2021 4:33:11 PM

I am a nurse retired from a career caring for mothers and babies which informs my understanding of this subject. But mostly, I am the mother of a mother caring for her profoundly disabled daughter that gives me a truly keen perspective.

It is very important to understand this is not about parents asking to be paid to care for their own children. This is about parents needing to be reimbursed for the hours spent becoming the ‘experts’ of their own profoundly disabled children. Everyone embarking on parenthood should be committed and ready to take on the challenges of raising a child but these are extraordinary challenges that no one could prepare for. And as a result, all of the planning that did happen is out the window. No longer can mom (or possibly dad) return to the job or career that was to supplement the cost of raising this child while at the same time the cost of doing so has increased exorbitantly. The parent is thrown into the role of full-time caregiver.

My granddaughter, June, could be living in a facility at a huge financial cost to society. But, my daughter and her husband made the decision to keep her in the family home. As a result, June receives a level of care she could not ever receive, in even the best of facilities, where caregivers split their time with other residents and employees come and go. Mom has been a constant in her care from the beginning and often even in the hospital setting is the one directing care as the doctors and nurses turn to her for help. She understands June's needs at a level no one else can. She has become an expert on the care of June.

Because of the huge toll caring for her daughter has taken she has no time to participate, as planned, in generating income. And at a time when the financial need is greater than anyone could have anticipated.

So, why, when qualified caregivers are impossible to find shouldn’t the most qualified person be reimbursed for her care? Other states have found their way to this reasonable answer, so Oregon needs to step up and help these families – many of who are on the brink of emotional and financial despair.

Pamela Keuneke

From: Penny FitzMaurice
To: Pierce Annette; CHETOCK Tara A
Subject: Allowing Parents to be PSWs/DSP"s to our minor children
Date: Saturday, December 4, 2021 3:20:17 PM

To Whom it May Concern,
I am writing to plead for this change to happen. As the mother of a child with multiple rare disorders, requiring full time care, it's been impossible to return to work. My son's disorders require that he has direct one-on-one support at all times, so day care and traditional babysitting is not attainable for us. This has caused me to not return to work as I would have to call off work too often to retain a job. I recently even opened a food cart, but was unable to survive the pandemic due to childcare issues. We have hours available to us via the state for a PSW, for 4 years now, and not once have I been able to utilize a consistent PSW/DSP. Allowing me to be his paid PSW would relieve such a huge burden on our family and be absolutely life changing. It would also relieve a huge burden on the system as a whole. Please, please make this happen!
Thank you for your time,
Penny FitzMaurice

To Whom It May Concern,

Thank you for the opportunity to provide comment on Oregon’s
1115 Medicaid waiver.

At the height of the COVID-19 pandemic, more than 3,200 people
signed a petition requesting that Oregon allow parents of disabled
children access to caregiver dollars during a time when it was
dangerous to have workers in their homes.

At the time, there was a lot of support for the idea but the request languished for months in some unseen process while families suffered. Finally, in late-January 2021, Oregon announced that parent-caregivers could access these dollars... but only temporarily.

Although it is a temporary and limited program, our community has already seen immense benefits. Families of disabled children report they are happier, healthier and more financially stable.

For my family, the additional income has meant we could make payments on a desperately needed wheelchair van and tuck some money away for our son’s future in an ABLE account.

We believe there is support on the federal level for Medicaid reform, especially when it comes to the care economy. We also believe there is public support at the local level for this reform.

We don’t pretend to understand the complex regulations and politics at work in the middle that are blocking this from happening. But we do know where there is a will, there is a way. Indeed, there are several states where parents of disabled children are allowed this lifeline. Let’s offer it to Oregon families, too.

We respectfully request that this waiver process include a request for Oregon parents to stop being excluded from caregiver jobs for their minor children.

Thank you,

Shasta Kearns Moore

P.S. For a detailed list of reasons why parents should be allowed to be paid caregivers to minor children, click here.

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Shasta Kearns Moore
MedicalMotherhood.com

From: Sylvia Triplett
To: Pierce Annette; CHETOCK Tara A
Subject: Medicaid waiver written testimony
Date: Saturday, December 4, 2021 2:38:28 PM

To whom it may concern,
I am writing to ask you to please make the Oregon medicaid changes necessary to allow parents of disabled children to be paid caregivers for their children. The temporary allowance of this through the pandemic relief has been life changing for me and my family. When my son was born nine years ago with multiple disabilities I had to stop working (I formerly worked in the social work field) to care for him full time and have continued to care for him ever since. Being paid for his caregiving now allows our family to be comfortable, provide him with things he needs for improved quality of life and relieve an immense amount of stress. I have heard similar stories from other families in our community and feel strongly that making this a permanent change would be extremely beneficial to keeping disabled children with their families and living the quality of life they deserve. Thank you for helping to make this crucial change.
Thank you,
Sylvia Triplett

To whom it may concern
Hi, my name is Tara Stone. I have a son who just turned 6 years old. Ashton, my miracle who I spent 20k just to get pregnant with. He spent 730 days in the NICU fighting for his life. I know the state would rather us use “professional nurses” but I would love to explain just our experience. I will give the short version. My son was physically abused by a “professional RN” who was sent to my home, my son's safe space. The only place he should feel 100% comfortable. This nurse who led me to believe she cared and was there to give me a mental break so I could go to the grocery store, I came home to Ashton having welts up and down his back. This same nurse after she was fired by the nursing company continued to claim hours stating age was at our home and was collecting money from the allowed hours per month Ashton qualified for. So there’s 2 headaches and trauma for someone hired by the state to “help” my husband and I out.
2nd: another nurse who was hired as a professional nurse to give me a break and allow me to potentially go back to my career didn’t know how to turn on an oxygen tank or operate his trilogy ventilator or had never changed a trach or gtube and had no idea how to set up or run his feed pump. So I literally had to hold her hand her whole 12 hour shift to the point where as a mom I didn’t feel confident in her abilities to leave her alone with my son. So she got to collect all the paychecks when ultimately I felt like she was just visiting and I was doing literally all the work. Defeats the purpose of respite care.
3rd: a nurse came to work claiming she had allergies. Long story short she called me on a Saturday stating she was in urgent care with a respiratory virus. That Wednesday Ashton was in the emergency room being diagnosed with RSV. If you know anything about bronchopulmonary dysplasia you would know that RSV could have been deadly. The lungs I had been protecting for years she was careless and lied about her symptoms. Ashton was in the emergency room 2 times and the pediatrician 4 times in 3 weeks.
4th: nurse carelessly overdosed Ashton with diuril because she was rushing through the end of her shift. Resulting in Ashton getting sick and dehydrated for peeing out too much fluid.
5th not nursing related, but nurses have damaged parts of my house carelessly moving around the home. I have debts in the wall from their bags, notebooks, chairs being pushed around, dropping things. They don’t care because it’s not their home.
I delivered Ashton at 27 weeks 2 days pregnant. He was 2lbs, 1oz and only 13.25 inches. I went into a coma due to HELLP syndrome. It took the neonatologist and RT 10 minutes to get ashtons heart going and lungs open. First hospital wasn’t able to treat anymore so we transferred to Randall Children's Hospital at Emanuel. 5/16/17 Randall advised me to end ashtons life because they were out of options. I told them I will never give up on Ashton. I went on Facebook and found a nationwide children’s hospital in Columbus Ohio who specializes in BPD (lung disease) . We were flown by medical jet to Ohio 9 days later where we stayed for 18 months. The last 6 years I have been in survival mode but I have done it because as a parent you sacrifice and would do anything for your child.
Earlier this year we learned about parents being able to claim the hours to care for their kids. Because of this my husband was able to take our home out of forbearance, because of this he was finally able to start paying the mortgage again. We were finally able to fix our truck which was unsafe for our family. My husband is no longer experiencing chest pains from the daily

stress living less than paycheck to paycheck. We are working on catching up with PGE, water bill and phone bills. Credit cards aren't how we wanted to provide for our family and it got to that point because there was no way I could work and still be present for ashtons full schedule. Ashton does homebound kindergarten because with all his diagnosis his medical team won't allow him to do in person school so we have Kindergarten 3 days a week where the teacher comes to the home. We also have OT, PT and Speech therapy 3 days a week. Days that we don't have therapy and school at home, we go to meridian park for OT and PT. February we start speech at randall therapy which will be outpatient once per week. The rest of our free time we have to fit in all of his specialist appointments. There's no way that I would be able to return to my career at The Standard with his weekly schedule where I'm not allowed to take personal calls or take time off without it affecting my position.

My son has cerebral palsy, Spina Bifida Occulta, bronchopulmonary dysphasia, cortical visual impairment, sensory disorder, visual processing disorder, severe oral aversion, medical ptsd, non verbal, low tone unable to walk or stand.

Being able to provide for my family while knowing that my son is 100% safe and protected and feeling loved and building our bond with each other. I wish you could see our lives just the last 6 months how this financial assistance has benefited my family alone. I just pray that others realize that these kids are better off with their parents and not someone just doing their job. This is our life that we have fought to keep. I appreciate your time and allowing us to send you our testimony.

Sincerely, Tara Stone

Here's a look at my family. my real life

To the Policy makers,
I'm the mother of a sixteen year old girl who is part off the CIIS program due to her profound disabilities and her need for 24 hour hospital level care. June's diagnoses include but are not limited to: cerebral palsy, catastrophic and uncontrolled epilepsy, chronic lung disease which requires a tracheostomy and a ventilator, Osteopenia (brittle and easily broken bones), developmental delays, she is also non verbal and non mobile. June is unable to perform even the most basic of self care like moving to a new position in her bed, this means everything she needs to survive and thrive must be done by someone else. Caring for her requires an immense amount of knowledge, energy, and fortitude, it is not a task that many are capable of and I as her mother am the most qualified as I have demonstrated over the past sixteen years. In fact there were many years where even Providence Child Center (hospital respite) was unable to care for her so we could have a break because with her ventilator settings and no Respiratory therapist the respite center for medically fragile children couldn't handle her needs. The toll this level of care has taken on myself and my family over the years is impossible to put into words. Through CIIS it has been determined that June is eligible for 559 hours of combined nursing and PSW hours to help keep June in her home where she belongs. But with the current nursing and caregiver shortage as well as the shortcomings of the K plan we are only able to fill half of the nursing hours which it has been determined we need. As for a PSW aside from family it simply would not be safe to have someone care for June who is not a nurse, the complex level of care and need to keep a cool head in the very likely event of a life or death emergency is too great. So during the almost two years now of this Pandemic the workload has doubled for me and the one thing that has kept us afloat is access to the taxpayer dollars that have already been allocated to our family. Though my workload has increased to a level that is not sustainable, the level of stress in our household has decreased dramatically. While we are desperate for more nursing and will have our night shifts filled as soon as there are nurses available, the one saving grace has been that I am getting a paycheck after 16 years.

I want to make it very clear, caregiving at this level is above and beyond parental responsibility. Having a child with this level of disability is something you cannot plan for, it does not discriminate, and could happen to anyone. That is why as a society we have chosen to be a "Community First" state and to put support in place to keep children like my own in their homes. So how has having an income relieved so much stress in our family? The best example I can think of is that this is the first year we were just able to pay our taxes without having to seriously consider selling our home that has already had modifications (Provided by CIIS) to make it functional for our family. We didn't have to ask for money from our family, worry about what we should sell, we just paid our taxes, and put that worry aside for another year. When I am exhausted from staying up with my daughter for the two nights a week that we do not have nursing I am able to have our groceries delivered, or a pizza when I'm too tired to cook. If June needs something I can just buy it, I don't have to spend hours jumping through hoops to get something as simple as a door threshold covered. No quotes from three vendors, no insurance denials, no sitting on hold when I could be caring for my girl, I just buy it. There are so many ways in which not being financially strapped has opened up my time so that I have more of it to spend just playing with my daughter. Not to mention I am just happier, it was never in our plan that I would not work, I want to contribute to our family in a financial way and we certainly have needed it but until now that simply was not possible if we wanted to keep our daughter at home.

We chose her, but at a huge financial cost, even at a minimum wage job over these past 16 years I would have pulled in about 300k which would have gone a long way in providing financial security for our future as a family. Please change the ruling to make this change permanent. Our families need it desperately.

Though I am very hopeful that this change will be made permanent I am also aware that it could be revoked at any time. If that were to occur now or in the near future it would be disastrous. The nursing and caregiver shortage has not abated, us families with medically fragile kids cannot find care, we are barely keeping afloat. If this support is revoked I fear the impact it will have on the families but most importantly the medically fragile children who have been able to remain at home against all odds even through a pandemic by the sheer love and effort of their parents.

Please put families first,
Tina Stracener

Hello my name is Veronica Yepez. I'm a parent to a special needs child, I have a Bachelors Degree in Social Work, and I teach yoga when my schedule allows for some extra income.

I've lived in Oregon for 8 years. I moved to Oregon away from all my family & support systems in Nevada so we could have better access to a Children's Hospital because Northern Nevada doesn't have one. My daughter has a rare genetic syndrome known as 4P minus or Wolf-Hirschhorn Syndrome, she is 9 years old. The first few years of my daughters life consisted of many ambulance rides, being life flighted, many hospital stays and way too many surgeries to count with more surgeries coming up in the near future. My daughter has seizures that sometimes make her sick for a whole week afterwards or land us in the emergency room or staying overnight in the hospital when we can't get the seizures to stop. She's also wheelchair bound and non verbal, she depends 100% on someone to do everything for her. She requires quite a bit of medical equipment and medications on a daily basis. She's getting so big that I'm the only one who can carry her. I'm a single parent and recently lost the two personal support workers we had due to the pandemic. I was very grateful for those workers but they oftentimes didn't know how to understand what my child was needing or how to interpret her noises as a form of communication so it never felt like I was actually getting a break for myself.

When I found out that parents were being paid as caregivers I was excited because I had to quit teaching yoga over the past year so my daughter could have hip surgery. During that time I was told by medical professionals that I would have to go into quarantine if I wanted to be the 1 person allowed to be with her in the hospital for her surgery. I did as instructed and continued to quarantine afterwards for my child's safety. Her surgery was in July and she is still recovering today and needs me to do physical therapy with her 6 times a day. Her major surgery before that left her in a spinal halo and bedridden for 6 months just to give you an idea of how long it takes for her to recover from these medical procedures. I asked our social worker if I could apply to be a paid caregiver but I was denied. I was told that I needed to go through the same approval process that other caregivers go through such as going into downtown Portland and getting fingerprinted along with an extensive background check. I was also told that unless I have a family member living in the same city that could sign my time cards and verify that I'm actually taking care of my daughter for the times that I'm logging then I don't qualify. Like I mentioned before, all my family lives in Nevada and I'm a single parent so I don't have anyone in Portland to sign my timecards. The Social Worker told me that it wasn't worth the trouble of me trying to find a babysitter to go to the Portland office for fingerprinting and a background check because I wouldn't be eligible due to the fact that I have a misdemeanor battery charge on my record from 10 years ago. I was attacked and defended myself but also got charged with battery because I left the scene rather than calling the police first. It's an embarrassing charge on my record that I wish wasn't there but I learned a lot from the experience. I really don't have the money to pay for attorney and court fees to get it expunged off my record since I'm not able to hold a regular job while taking care of my daughter's needs and homeschooling her. It's not fair and quite frankly it hurts for the State to consider me an unsafe paid caregiver to my own child because of something that happened over 10 years ago. I mention this because prior to being a mom I was a Domestic Violence Advocate in a Women's and Children's Shelter. During my time there women would oftentimes come into the shelter with battery, assault or domestic violence charges on their record because they would try to defend themselves against their abuser and were sometimes the ones who went to jail and were

charged for it. This is especially true for women of color who are discriminated against more so than others. These women were good people and good mothers but unfortunately had those charges on their criminal record making it difficult for them to find housing and work. I'm sure there are many other parents like myself who could greatly benefit from this program but are considered ineligible because of their background check, not being able to find childcare to go through the fingerprint process, and or they don't have someone to sign their timecards to prove their actually taking care of their own child. I want parents to be paid caregivers permanently in the State of Oregon but for the approval process to be easier for us and less of a burden. We, special needs parents already have so much on our plates to deal with why make us go through the 3-6 week background check process. I know I'm a good mom, I get my daughter to all of her doctor's appointments, I constantly advocate on her behalf to get her everything she needs to have a safe, comfortable, and happy life. It's hard not having any income of my own and being dependent on child support and when that doesn't come through at times we depend on SSI or food stamps which no longer covers the monthly housing expenses since the pandemic has caused the cost of living to increase. Our rent increased by over $300 but I was fortunate enough to have an understanding landlord who lowered it a little after I explained our situation. Still SSI only paid around $700 a month and my rent cost more than that. In the past I used to go to the blood banks to donate blood to make some money to fill up my car's gas tank to get my child to her doctor's appointments. I don't say these things so you can feel pity for me and my situation but so you can maybe get a better understanding of the challenges that we parents to special needs children face. I love the State of Oregon and how we Oregonians take care of our people the way that we do so I ask that you please make it a permanent thing for parents to be paid caregivers to our children and that the process be easier and more accessible for us to get approved to do so.
Sincerely,
Veronica Yepez

To Whom It May Concern,

My name is Victoria Stottlemyer and I am the mother of a vivacious, loving and happy 5-year-old girl with disabilities. My daughter, Elliana has cerebral palsy, epilepsy, a feeding tube and global developmental delays. Our journey has been tough and between her father and I switching back and forth we have mainly been surviving off of one income for most of her life. Having a child with disabilities is a lot of work and more than a full-time job in itself. There are so many aspects to my daughter's care including frequent appointments, hospital visits, special diet restrictions, medication administration and refills, physical, speech and occupational therapy, blood work, and the administrative work including fighting with insurance, ensuring we have the supplies she needs and coordinating her DD caseworker check ins, and this is just a small overview. These are things that fall on parents regardless of having other caregivers in their lives. Allowing parents to be paid as their children's caregivers allows the time and energy spent doing these things to be compensated and can relieve some of the stress due to needing to work a full time job to survive and then come home and work twice as hard. I know a huge struggle of mine has been having to miss work and call out due to my daughter's needs, such as being sick, having doctors' appointments and the lack of a caregiver.

Finding and keeping PSW's/DSP's has proven to be nearly impossible. Finding ones who are reliable is even harder. Having to rely on strangers to care for my daughter seems cruel when her father and I are the people who know how to care for her the best, but in doing so are financially burdened due to not being allowed to be paid. As parents of a disabled child, we have to take on the role of caregiver on top of being a parent regardless of the support of an outside caregiver. Allowing parents to be paid as caregivers allows children to receive the best, most personalized care, reduces various burdens on parents, and allows children to stay in their homes instead of being forced into foster care or foster homes due to the parent's inability to support them. Allowing parents the option to be paid as caregivers would give us more support, not less. There are tons of caregiver hours unused and not because we don't need the help but because it is so difficult to find. Allowing parents to be paid as caregivers also does nothing to increase the cost associated with caregivers, since the money is already there and simply being utilized and redirected.

My daughter is the absolute light of my life. I would do anything for her and that includes fighting for her, and other children to be taken care of by the people who know them best. All we want is the option to care for our children ourselves and receive the same rights to compensation that strangers are. COVID has really brought to light the difficulty surrounding caregivers for our children and once the pandemic ends, difficulties will still exist.

I hope you are able to see how important this is to our children and our families. Parents of children with disabilities deserve more support. I appreciate your time and look forward to a time where there is one less barrier to supporting our children and keeping together families.

Thank you

Victoria Stottlemyer

Addendum 1 5/15/22

Alliance Services Support Letter

ALLIANCE SERVICES
WWW.ALLIANCE-SERVICES.ORG

May 11, 2022

To Whom It May Concern:

Alliance Services is a Medicaid Provider Agency for Intellectual and Developmental Disabilities (I/DD) located in Newberg, Oregon. We are writing in support of multiple parent groups advocating for legislation that would allow parents of minor children to be paid providers for children with a disability/medical condition.

The Covid-19 pandemic amplified the existing shortage of disability services caregivers. This environment has created adverse effects for many parents of minors, often jeopardizing their ability to maintain employment outside of the home due to their child's medical needs.

We have seen firsthand how employing parents of minors, through a provisional Covid Waiver from the federal government, has benefited families during the pandemic. For health and safety reasons, parents of medically fragile children need to decide who can come into their home to provide care for them. Especially, since many medically fragile children, cannot get vaccinated or the vaccine does not offer the same level of protection due to compromised immune systems. The pandemic is not over, and Covid will continue to present significant needs.

Currently, 26 states allow legal guardians to be paid providers, so we believe there is no federal prohibition and we believe a similar state allowance would be in the best interest of our customers. This statement is made knowing that a personal representative monitors service delivery to prevent undue stress for the parent. Additionally, the assigned case manager can visit the family more often, and respite hours can be authorized.

Alliance Services believes that allowing parents of minors to be paid providers for their loved ones is the right thing to do for Oregonians in need of support. It is a person-centered approach that helps with the current workforce crisis and improves the health and safety of the child by controlling those who are in the home.

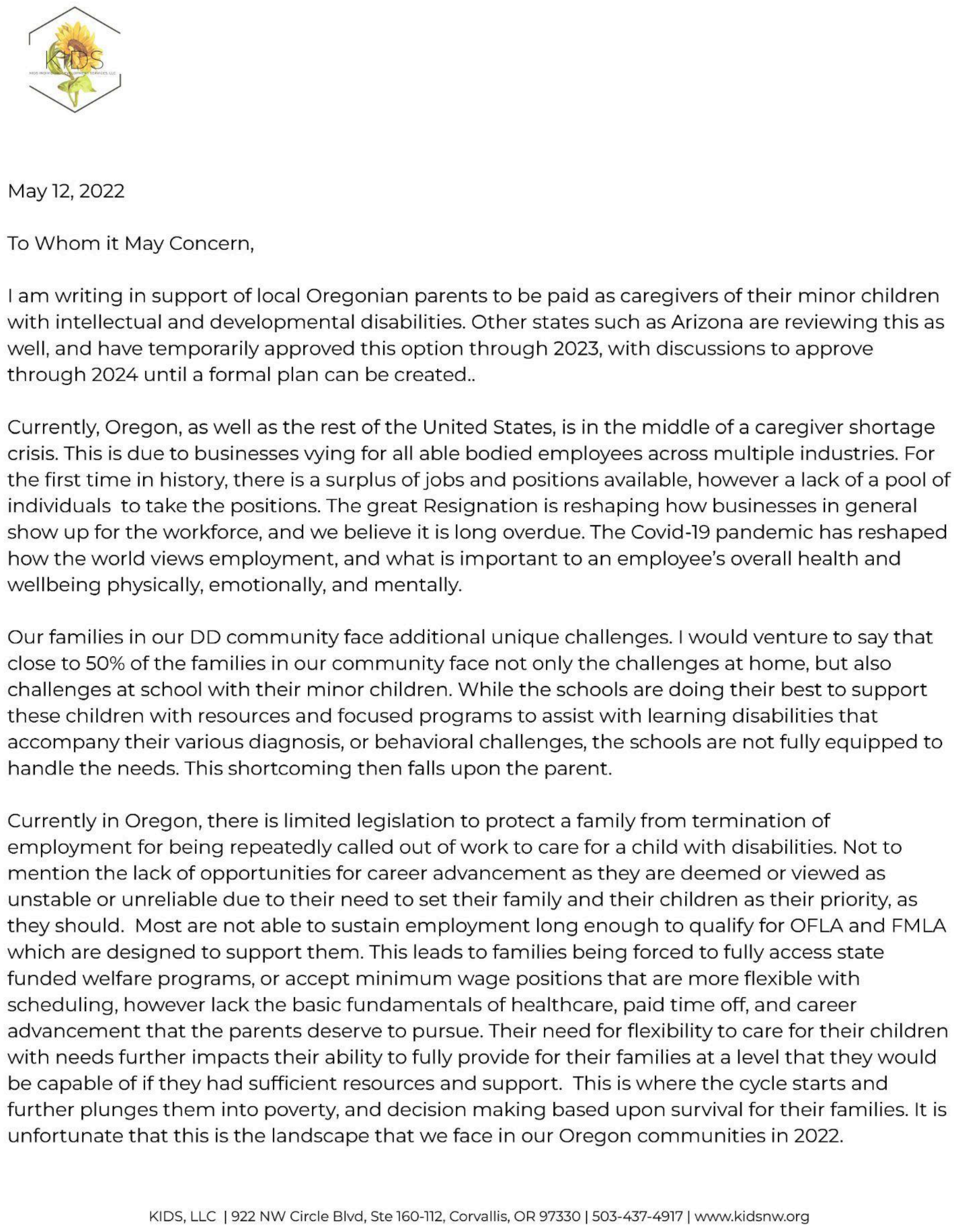
Please feel free to contact me with any questions.

Sincerely,

JB Stockslager
CEO
JB@alliance-serivces.org

Alliance Services
www.alliance-services.org

KIDSNW Support Letter



May 12, 2022

To Whom it May Concern,

I am writing in support of local Oregonian parents to be paid as caregivers of their minor children with intellectual and developmental disabilities. Other states such as Arizona are reviewing this as well, and have temporarily approved this option through 2023, with discussions to approve through 2024 until a formal plan can be created..

Currently, Oregon, as well as the rest of the United States, is in the middle of a caregiver shortage crisis. This is due to businesses vying for all able bodied employees across multiple industries. For the first time in history, there is a surplus of jobs and positions available, however a lack of a pool of individuals to take the positions. The great Resignation is reshaping how businesses in general show up for the workforce, and we believe it is long overdue. The Covid-19 pandemic has reshaped how the world views employment, and what is important to an employee's overall health and wellbeing physically, emotionally, and mentally.

Our families in our DD community face additional unique challenges. I would venture to say that close to 50% of the families in our community face not only the challenges at home, but also challenges at school with their minor children. While the schools are doing their best to support these children with resources and focused programs to assist with learning disabilities that accompany their various diagnosis, or behavioral challenges, the schools are not fully equipped to handle the needs. This shortcoming then falls upon the parent.

Currently in Oregon, there is limited legislation to protect a family from termination of employment for being repeatedly called out of work to care for a child with disabilities. Not to mention the lack of opportunities for career advancement as they are deemed or viewed as unstable or unreliable due to their need to set their family and their children as their priority, as they should. Most are not able to sustain employment long enough to qualify for OFLA and FMLA which are designed to support them. This leads to families being forced to fully access state funded welfare programs, or accept minimum wage positions that are more flexible with scheduling, however lack the basic fundamentals of healthcare, paid time off, and career advancement that the parents deserve to pursue. Their need for flexibility to care for their children with needs further impacts their ability to fully provide for their families at a level that they would be capable of if they had sufficient resources and support. This is where the cycle starts and further plunges them into poverty, and decision making based upon survival for their families. It is unfortunate that this is the landscape that we face in our Oregon communities in 2022.

KIDS, LLC | 922 NW Circle Blvd, Ste 160-112, Corvallis, OR 97330 | 503-437-4917 | www.kidsnw.org

Attendant Care and Respite Care are designed to give additional support to the families we serve, however with the shortage of caregivers, and the structure of our current system leaves significant room for shortages, and inconsistencies for the families in need, further debilitating the families ability to find solid ground to establish a foundation to build up on for their family.

By allowing parents of their minor disabled children to provide support, we are able to solve multiple problems at once. The parents are able to be compensated for the time that they are providing support to their children, assisting their children with growth and development. They are able to provide for their family and receive benefits from the agency they work with as an employee to include Medical, Dental, Vision, 401k, and paid time off. They are able to build up their retirement fund, which will impact the overall medicaid fund when they retire as they will have less reliance on our State Medicaid funding for their senior years. They are able to create relationships with other parents and caregivers to potentially find Respite caregivers to support them in taking a break to save their mental health, improving their overall parenting and caregiving impact on their family.

Having an agency oversee the parents as employees ensures that the intended regulatory compliance expectations are met, and the parents are held to the same standard as an organic caregiver or DSP through their agency. The parents are receiving ongoing personal development support, providing additional training not only on their child, but on childhood development in general, additional behavioral training, diagnosis training and current treatment or support protocols, and the opportunity for career growth and advancement. Further improving the level of care and support within the organic family unit which has the potential to impact future generations.

We believe that giving parents of minor children with disabilities the ability to work as their paid caregivers provides much needed support and solutions to multiple concerns plaguing the state. The parents earn a fair living wage.

The parents have the potential to be relieved of government assistance such as:

- Medical for the family
- Housing assistance
- Tanf
- And other state funded programs

By employing the parents, the agencies help to fund these efforts through their employee funded programs. We further develop these parents in employment related opportunities, giving them a fighting chance at changing the narrative for their future generations, and lessening the impact on the State of Oregon for other government funded programs. We as employers are willing to do our part to change the narrative of this story, however we need the support of the state to offer the approval to allow us to do so and allow parents of minor children with disabilities to do the work and be compensated for it.

I look forward to any questions you may have, and any discussions that may be forthcoming on this matter.

Sincerely,

Kathy Lehmeyer
CEO / Founder
kathy@kidsnw.org

Joieful Agency Support Letter

To Whom it may concern:

Prior to starting my agency, I worked with Seniors and Disabilities for nearly 20 years. The caregiver shortage and high turnover has been, in my opinion, an ongoing problem in many healthcare fields for many years. This isn't new and shouldn't be a surprise to anyone who has spent 5 minutes working in any healthcare field.

You see, the challenge is more than just finding and retaining a care provider. Sure, at one time you probably could find a warm body to through into many households but is that the point of what we do? No! Now, even warm bodies are hard to find, and even if you could who would encourage that? Certainly not someone claiming to advocate for the ID/DD community! Whether it's my child or your child the point behind what we do it so create a better quality of life for the individuals we support, provide them with opportunities and choices that will develop and guide this individual into their adult years. Help them make strides towards and achieve goals that will empower them to be involved, successful members of our society as the grow.

Without care providers who are truly focused on making a difference and are dedicated to doing more than just checking a box we will continue to find the ID/DD population struggling in growth, development, and progress towards goals. I can teach anyone to provide caregiving tasks, but I can't teach compassion, passion, empathy or how to actually care. Who could possibly be more passionate and driven to provide the needed support then the Parents? Who could possibly be more prepared, equipped and driven to help these individuals achieve their ultimate goals?

Why also is there a separation between a parent of someone who is over 18 can provide care but not parents who's children are under 18? A child's motor (physical), language and communication, cognitive and social/emotional are all being developed at a young age, there is so much that can be accomplished if given the right environment and provider. Do we not think that the role of a parent of a child under the age of 18 is not equally challenging and in some cases harder than the role of a parent of child over the age of 18? There is an obvious disconnect in the rules.

The truth is this. Agencies like Joieful struggle to find good, quality Direct Support Professionals. I had 10 interviews scheduled on Monday, 1 showed. I pay $20 to start, I pay full benefits, offer PTO, Paid Holidays, I pay their birthdays off. I have a turnover conversion of 2% year over year. I am doing all that I can to find and retain Direct Support Professionals, but the truth is there is still a massive shortage.
I have over 80 families waiting for a DSP. Why on earth would you take away the providers these individuals have in a time where we all know we can't replace them. Does the ODDS actually believe that no care provider is better than having one? Or are they hoping we fill roles with warm bodies who don't truly care and are just there to check a box and get paid?

If ODDS is truly serious about making a difference in the ID/DD world there is no possible way you can look past the advantages a child has when 1. having a care provider and 2. having a care provider that is there to make a difference. We live in a world that no one is going to be more passionate about making a difference in their child's life than the parent. Take away the money element. Would you rather a child be with a parent or a stranger? In any situation. If they are scare, hurt, frustrated, embarrassed, struggling, etc.. Would you rather a child go through that with a parent or with a stranger? How about you? If you were having a difficult time, would you rather be supported by a loved one like a parent or a stranger?

There are hundreds if not thousands of children in the ID/DD community who's future can be positively changed if ODDS would change the rule. Who wouldn't want to make that kind of difference?

Jill Chuculate
CEO/Founder

170 W. Ellendale Ave. STE 204, Dallas, OR 97338
www.joiefulconnections.com
505-606-6555
SPD103873 DZ1404

Support Letter: Julie Hargraves, LCSW Mental Health Therapist

Julie Hargraves LCSW
444 Masyn Ct Roseburg, OR 97471
May 11, 2022
RE: Paid Parent Caregiver Policy
To Whom this May concern

I am a Licensed Clinical Social Worker and I would like to take this time to express my support of the "Paid Parent Caregiver Policy." Paid Family Caregivers Policy provides the needed assistance to help families so they may remain in the home caring for their disabled children versus the parent working outside the home. In my practice, I work with both children and adults with emotional and behavioral problems. I am a witness to the difference it has made in several children's life when a parent is able to stay home and provide the care for their child. When parents are given this opportunity to stay home versus working outside the home, they not only are providing quality care to their children, but also meeting that child's emotional needs. Who better to provide for the needs of a disabled child than their parents? When a child's emotional needs are met, I see thriving children. When parents are given the opportunity to stay home and provided with the monetary support of being their child's caregiver, I see thriving parents. A child's healthy development depends on their parents. Paid Parent Caregiver Policy can give families the opportunity to stay connected and they can give that child a better quality of life because the mental health of children relates to their connection with their parents. The benefits are endless in my personal and professional opinion. Not only does Paid Parent Caregiver Policy support quality care, mental health, and family values, but it also can significantly reduce costs to Medicare, Medicaid, and private insurance, Paid Parent Caregiver Policy can be known as the foundation of the nation's long-term care system resolution by providing parents the opportunity to provide the many long-term care services and supports received by persons with disabilities of all ages. Parents providing these services will lessen the burden on the State's financial system, lessen family's burdens, and improve quality of life for these families. It is my hope that policy makers will view the Paid Parent Caregiver Policy as being an effective policy that should be continued because well-adjusted families create healthy strong communities.

Sincerely,
Julie Hargraves
LCSW Mental Health Therapist

Addendum 2 5/23/22

Support Letter- National Council on Severe Autism

NCSA NATIONAL COUNCIL ON SEVERE AUTISM

Dear Director Teninty, Director Hittle, and Chair Gelser,

Among Oregon's families supporting children with disabilities are a subset of families we know as "extreme caregivers." They support children whose disabilities are so devastating that they must devote 24/7 attention to them, often sacrificing their jobs and income for this purpose.

These families have found that little outside help is available owing to the strenuousness of the labor and complexities of the work, such as challenging behaviors, complex transportation needs, and recognition of medical issues such as absence seizures and respiratory concerns. Families in Oregon have seen unqualified, inconsistent, and potentially abusive workers in their homes, though in many cases outside help is not available, at all — a situation worsened by the pandemic.

Allowing parents and family members to serve as paid caregivers is a win for children, families, and Oregon. Attendant care hours are already determined, approved, and budgeted. The only thing stopping thousands of children from getting the care and support they deserve is a single Oregon Administrative Rule.

This caregiving goes far beyond what anyone would consider normal parenting. This is not remotely like "paying parents for what they are already expected to do." These extreme caregiving situations include, for example, keeping a nonverbal 15 year-old who hits himself and scratches off his skin safe from self-injury, preventing a severely 8 year-old autistic girl with a cognitive age of 18 months from eloping or ingesting rocks. Diapering a 200 pound young man who suffers violent meltdowns. Careful monitoring of a disabled teen with autism and suicidality. These parents and family members engage in Herculean work to care for Oregon's most vulnerable and need your support.

National Council on Severe Autism urges you to not cut them off from life sustaining support on July 15th, when the 1135 Waiver ends. **These families are desperate for help and are relying on you to extend this reasonable, and cost efficient, solution**.

Thank you for your consideration. Please do not hesitate to contact us with any questions.

Very truly yours,
Jill Escher

President
National Council on Severe Autism

Support Letter- Ashley Hrouda

May 16, 2022

I have been working in Child Welfare for four years and I have seen firsthand why it is so important for parents to be allowed to be the paid in-home caregiver for their children. During my four years at Child Welfare, it has been my job to assess child safety. I worked for three years in Protective Services, it was my job to determine if children were safe enough to remain in the care of their parents or if the Agency needed to intervene. For the last year I have been the Permanency Caseworker, it's my job to provide families with services and tools that influence them to be safe parents. These families being financially stable is imperative for the well-being of children with disabilities. When a family is financially stressed, they aren't able to provide their child with all their physical and mental health needs. When parents are stressed, they are more likely to have less patience with their children, which can lead to neglect, physical abuse, and mental abuse. Children with disabilities require more patience than the average child. It is healthier for children with disabilities to have consistent care. There is no consistency in these caregivers. Caregivers often lack the understanding of what the children need, why they need it and how their disability makes them different from other children of similar age.

The caregivers who are employed are not drug tested, background checked, specially trained, or educated. These parents not only have lifelong experience with their child, but they also have to do research to learn how their child functions, their strengths, weaknesses and any delays they may have. These parents are becoming professionals in their child's disability and the DSPs have no education background. The majority of them do not care nearly as much as a biological parent will and it seems they are looking to make easy money instead of being invested in the child's health, and mental well being. At this time, it is challenging to find a caregiver, let alone a caregiver that meshes well with the family dynamics, child's needs, parent's needs, and schedules. It would be beneficial for the children, their parents and other family members for the parent to receive the money allotted to caregivers. Most of the time the parents must stay in the home with their child even if a caregiver is present. If the parent is required to be home with their child and is unable to work due to having to care for their child, then it only makes sense to pay the one person who truly treasures these children.

Sincerely,

Ashley Hrouda

Employing Family as Caregivers

May 17, 2022

Cara L. Coleman, JD, MPH, Associate Editor, Pediatrics

Blog: Family Connections with *Pediatrics*

Providing high-quality care to children with medical complexity (CMC) requires more than a team of skilled doctors, nurses, and therapists. Families also play a vital role. Yet, families are sometimes not systematically valued in their role as providers of essential care, which has significant consequences for families and society. Anchored in one family's story with home healthcare that is typical of many other families also trying to care for their CMC while earning a living, this month's *Pediatrics* features a Family Partnerships article, "Employing Family Caregivers: An Innovative Healthcare Model," which describes Colorado's response to this challenge (10.1542/peds.2021-054273).

What are some of the challenges with home health care for children?

The article begins by sharing the story of the Blakely family. Mrs. Blakely's story highlights the significant time and effort that she spent on healthcare at home, as well as the effect it had on her family, health, and ability to work outside the home. The authors then share some of the data that support this story:

- Although only 3 in 50 children with Medicaid are CMC, they account for 1 in 3 dollars of Medicaid spending
- This spending on care for CMC does not account for the substantial, daily, unpaid medical care provided by their family members
- At least half of US family caregivers spend > 21 hours per week providing unpaid healthcare at home for their children
- An understaffed, underfunded, and undertrained pediatric home health workforce leads to care that is unreliable and of poor quality

What is Colorado's response to these challenges?

In 2001, families, community advocates, and Colorado lawmakers established a program (the Paid Family CNA Model) within Medicaid to allow family members, including parents, to be paid as certified nursing assistants (CNAs) for their own CMC. To begin, the family member (including the parent or legal guardian of children under age 18) must complete a standard assessment tool to see if the child qualifies for CNA care. Next, the family member must complete an approved nurse assistant training program and pass a written and clinical exam. Once licensed, the family CNA must be hired by a home health agency where they will be paid the same rate as other CNAs to care for their child.

The authors reflect that other states may have been slow to adopt similar models based on the belief that these models require an increase in budget. In fact, the article states that such programs are “budget-neutral” because the states’ duty to provide home healthcare to eligible children does not change, regardless of whether family members or others are paid for CNA services.

The authors conclude the article by noting challenges, future needs and ways to support a family CNA program, such as:

- The need for respite options in paid family caregiver models
- How to support family members who want to use their CNA license to qualify for future work elsewhere
- The importance of ensuring that the care team and family find time to discuss, and stay updated on, needs for home health care
- Connecting with family-led organizations to find the best care options for the child and advocate for healthcare system changes. Family-led organizations are staffed by families of CMC who have personal and professional expertise with systems of care.

How can you use this article?

1. If you are not already connected with a family-led organization in your state, follow these links to find out more information:
    - Family Voices is a national family-led organization: familyvoices.org[i]
    - Family-to-Family Health Information Centers (in every state, 5 territories and 3 tribal groups) are funded by the federal government to provide information to families, providers, and professionals to navigate and transform systems of care: Affiliate Archive - Family Voices
    - Parent to Parent USA (with chapters across the country) provides emotional support to parents of CMC: P2P USA | Supporting Parents Nationwide
    - The National Federation of Families (with chapters across the country) advocates on all levels for families of children with mental and behavioral health and substance use: National Federation of Families, Family Voice, Family Peer Support (ffcmh.org)
2. If your child qualifies for home healthcare and you struggle to fill approved shifts, provide the care yourself, and/or care for your family while also working outside of the home, talk to a family-led organization or your child’s doctor to find out if your state has a model of paid family caregiving.

3. During the COVID-19 public health emergency, some states allowed families to be paid to provide care for their children under age 18. Although this may have been temporary, some states are talking about how to build a permanent model to pay family caregivers. Connect with a family-led organization to find out how to join in such discussions.

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[i] The author of this Family Connections with Pediatrics is the Director of Policy and Advocacy at Family Voices and also a CO-PI in Home Health Care Policies Are Target of New Foundation Grant | Lucile Packard Foundation for Children's Health (lpfch.org).

Addendum 3 5/27/22

Autism Society of Oregon Support Letter

Autism Society
Oregon

Dear Ms. Reinhardt, Director Teninty, Ms. Hittle, and Sen. Gelser,

On behalf of the Autism Society of Oregon, I am writing to express our strong support of expanding and making permanent the temporary parent caregiver program. This program has been in effect for the past 14 months for parents of minor children to the benefit of the families impacted and we agree that it should continue.

The Autism Society of Oregon is not in agreement with the letter sent by the Oregon Developmental Disabilities Coalition, and would not have signed on to it, had we been requested to do so.

Please feel free to contact me with any questions. I am currently out on vacation but will return to the office on Wednesday, June 1, 2022.

Very truly yours,

Tobi Rates
Executive Director
Autism Society of Oregon

Addendum 4 6/1/22

Support letter from Karma Clarke-Jung, Autism Consultant
May 31, 2022
To Oregon's Policy MakersI am a special educator with over 30 years of experience in the field, currently working as an Autism Consultant for Early Intervention and Early Childhood Special Education in Douglas County. I am writing this letter to encourage the Oregon Self-Advocacy Commission to support changes to the Oregon Administrative Rule OAR 411-37-0020 2(b)(A) that would make it possible for parents of qualifying children to be paid as their child's Personal Support Worker (PSW).

The Covid crisis exacerbated already existing PSW shortages in Oregon. Because of this, Oregon enacted a 'pilot program' that for the first time allowed a parent to be paid as their child's caregiver or PSW. Impacted families report significant improvements in their children's lives because of this, including health benefits, stress reduction in the family, increased participation in community events and more. Unfortunately, the highly successful pilot program is set to expire on July 15th OAR 411-37-0020 2(b) (A) is changed.

I myself am not the parent of a child with disabilities significant enough to qualify for the K Plan, however my work takes me into the homes of many families for whom this is the case. Often parents are struggling to make it all work, trying to make it financially even though taking care of their child is already a full-time job and limits their outside employment options. In my role as the Autism Consultant, I do my best to connect families with community resources that theoretically will lighten their burden. Often I tell them about CLCM (Community Living Case Management) first, knowing that this is how they will be able to eventually access a PSW, someone who can work with their child directly in their home for a significant number of hours. Theoretically, that is. Unfortunately, the reality is that more and more often families I've worked with report back to me that, after jumping through all of the hoops, being assigned a CLCM case manager, having their child evaluated, and finally being allotted a specific number of hours per week for PSW services, **no qualified PSW can actually be found**. This reality is not acceptable. This reality hurts the most vulnerable of children and their families.

The Paid Parent Caregiver pilot project that Oregon enacted because of Covid temporarily fixed this problem. Paying the parents to step into the PSW role has very real and tangible benefits for these children and their families, as I'm sure you can see by reading some of the parent testimonials. Paying a parent to be the child's PSW puts an end to the absurd scenario I encountered in one family, where the mother of a child who is significantly impaired with autism worked as a PSW for a different family, while struggling to find a PSW for her own child at home!

The monies for clearly needed PSW services have already been set aside for children with the most severe of disabilities via the K Plan. If we are serious about making sure these kids actually get the services they need, having the option of paying parents to be PSWs makes sense for everyone

.

Karma Clarke-Jung
Autism Consultant

Addendum 5 8/25/22

Support Letter from Oregon Disabilities Commission

Oregon
Kate Brown, Governor

Department of Human Services
Oregon Disabilities Commission
500 Summer St NE, E-02
Salem, OR 97301
OregonDisabilities.Commission@odhsoha.oregon.gov

Oregon Department of Human Services

August 10, 2022

To:
Governor Kate Brown and Rosa Klein, Governor's Office
Lilia Teninty, Director Office of Developmental Disabilities
Services (ODDS) Dana Hittle, Interim State Medicaid Director
Oregon Health Authority (OHA)

From:
Oregon Disabilities Commission (ODC)

Re:
Paid Parent Caregivers Permanent Policy

During the July 14, 2022, Oregon Disabilities Commission (ODC) meeting, ODC Commissioners listened to testimony from 11 families regarding the temporary Public Health Emergency (PHE) policy allowing payment to parents who serve as Direct Support Professionals (DSPs) and Personal Support Workers (PSWs) for their children who require Children's Intensive In-Home Services (CIIS). These families consistently shared the positive impact of the paid parent caregiver policy, including better care for their children's specific needs, more reliable coverage, decreased time and anxiety related to the ongoing cycle of finding and training qualified caregivers, better health resulting in decreased emergency department use and hospitalization, increased financial stability, and increased family cohesion. These benefits are consistent with Oregon's health system transformation goal of family-centered, whole person care that supports health-related social needs, in addition to treating medical conditions.

Prior to the PHE, families describe an unworkable situation with an inadequate supply of caregivers that were able to consistently meet the specialized needs required of DSPs and PSWs. Too often, families were left with an allocation of hours that were not used and therefore had no value in supporting children with intellectual/developmental disabilities (I/DD) and their families. We must also recognize that insisting upon a caregiver from outside of the child's home being considered the "qualified" individual, despite the fact that it is the parents that will likely train the DSPs or PSWs, brings the training schools that individuals with I/DD were historically sent to, into the home. It would be nothing less than taking a step back in history via the child's front door.

"Safety, health and independence for all Oregonians" An Equal Opportunity Employer

On behalf of the ODC, we respectfully submit this letter in support of a permanent policy allowing parents to serve as paid DSPs and PSWs, and request that as an initial step, OHA and ODHS facilitate a meeting in which families can have a direct dialog with a CMS representative who can share options available to Oregon and details about the policies in place in other states.

Sincerely,

Mark King, ODC Chair Marsha Wentzell, ODC Vice Chair

<u>ODC Commissioners</u>
Brooke Eldrige
Jenny Schoonbee
Joanna Wilson
Nancy Peterson
Patrick Wilkus
Roxie Mayfield
Tata Blakely
Tim Roessel

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ODDS Answers to Post Senate Hearing Follow Up Questions Requested by Committee

ODDS Answers to Senate Interim Committee On Human Services, Mental Health and Recovery Post-Meeting Follow up Questions Requested by Committee

Addendum 6 9/27/22

Support Letter from Douglas System of Care

Douglas System of Care

SYSTEM OF CARE
DOUGLAS

September 26, 2022

To: Governor Kate Brown, Sen. Knopp, Sen. Gelser-Blouin, and Dir. Lilia Teninty

500 Summer St. NE, E-02

Salem, OR 97301

From: Douglas System of Care

Re: Paid Parent Caregivers Permanent Policy

During the COVID-19 pandemic, Oregon children with significant medical, behavioral, and mental health needs were temporarily able to have their parents as their paid in-home caregivers through Oregon Developmental Disabilities Services. The benefits were immediate and dramatic. Families reported their kids were healthier than they had been, their homes stabilized, and there was a reduction in hospital admissions. This successful program must be made permanent and expanded to all children receiving in-home caregiver support.

Children are assessed for their needs annually with determinations made about the number of support hours needed above and beyond typically expected parenting duties that they require in order to be safe, happy, and healthy. The existence of an in-home caregiver program is only reaching its goals of supporting disabled children if the services are able to be used. Families report labor shortages and system complexity as barriers that prevent access to allotted attendant care hours. In addition, many families are not able to bring outside support workers into their homes due to the severity and complexity of their child's behavioral and/or medical support needs.

Oregon's in-home caregiver program seeks to assist developmentally disabled children with their support needs, but it falls short of this goal when the service it offers cannot be accessed by the children who need it. A paid parent caregiver program enables more children to access this necessary support. The paid parent caregiver program has been shown to meet Oregon's ethical, strategic, and legal obligations to ensure person-centered care. It provides stability and needed support for our state's disabled children, reduces hospitalizations, improves outcomes, and affords these children the ability to live and thrive in their own homes, in their own communities.

We support this paid parent-caregiver option for children in Oregon and ask you to please join us. Support legislation for a permanent paid parent-caregiver program that includes all children receiving in-home caregiver supports in Oregon.

Sincerely,

Douglas System of Care Executive Council

Robin Hill-Dunbar, The Ford Family Foundation

Dr. Greg Brigham, Adapt

Sarah Wickersham, Douglas C.A.R.E.S

Bryan Hinson, Douglas ESD

Desta Walsh, DHS

Carol Eck, Mercy

Dr. Douglas Carr, Umpqua Health Alliance


500
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MAN SERVICES BUILDIN
NOTHING ABOUT US WITHOUT US
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THE PANDEMIC ISN'T OVER FOR US!
Economic Justice
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WHY WON'T U MEET WITH US
OREGON'S DISABLED CHILDREN CANNOT LOSE THEIR BEST QUALIFIED CAREGIVERS
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KEEP OREGON FAMILIES STABLE
Public Health Emergency Doesn't End For Parents
NO FAMILY LEFT BEHIND