

**From:** [Amy Haigh](#)  
**To:** [Pierce Annette](#); [CHETOCK Tara A](#); [1115 Waiver Renewal](#)  
**Cc:** [Neil](#)  
**Subject:** Public testimony for parent caregiver option  
**Date:** Saturday, December 4, 2021 8:53:15 PM

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Some people who received this message don't often get email from [amyb.haigh@gmail.com](mailto:amyb.haigh@gmail.com).

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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.

**From:** [Andrea Gisele](#)  
**To:** [Pierce Annette](#); [CHETOCK Tara A](#)  
**Subject:** Parent providers  
**Date:** Saturday, December 4, 2021 4:53:57 PM

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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 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 option 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

**From:** [getfitwithaudra@gmail.com](mailto:getfitwithaudra@gmail.com)  
**To:** [Pierce Annette](#)  
**Subject:** Parents as paid caregivers  
**Date:** Saturday, December 4, 2021 3:37:46 PM

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[You don't often get email from [getfitwithaudra@gmail.com](mailto:getfitwithaudra@gmail.com). Learn why this is important at <http://aka.ms/LearnAboutSenderIdentification>.]

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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 cares 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 is 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 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 supply's, 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

Do the best you can until you know better.

Then when you know better, do better!

Maya Angelou

**From:** [Emily Wagner](#)  
**To:** [Pierce Annette](#); [CHETOCK Tara A](#)  
**Subject:** Allowing Parents to be PSWs/DSPs to our Minor Children Testimony  
**Date:** Saturday, December 4, 2021 2:30:56 PM

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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 DNMT1 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

**From:** [Dawn Schoppe](#)  
**To:** [Pierce Annette](#)  
**Cc:** [CHETOCK Tara A](#)  
**Subject:** Allow parents to be paid caregivers to their minor children  
**Date:** Saturday, December 4, 2021 3:53:00 PM

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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 degree 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

**From:** [Ed Stracener](#)  
**To:** [Pierce Annette](#); [tara.achetock@dhsosha.state.or.us](mailto:tara.achetock@dhsosha.state.or.us)  
**Subject:** FW: Letter content  
**Date:** Saturday, December 4, 2021 4:59:14 PM

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**From:** [Ed Stracener](#)  
**Sent:** Saturday, December 4, 2021 3:10 PM  
**To:** [Ed Stracener](#)  
**Subject:** Letter content

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 supports 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 has done during this current and continuing pandemic. We are hoping the administrators will agree.

Respectfully Submitted  
Ed Stracener, QMHP

Let's Build Back Better!

**From:** [Emily P.](#)  
**To:** [Pierce Annette](#)  
**Cc:** [CHETOCK Tara A](#)  
**Subject:** Medicaid Waiver 1115 testimony  
**Date:** Friday, December 3, 2021 8:04:10 PM

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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-Hirshorn syndrome, hypotonic cerebral palsy, autism, microcephaly, upper airway restriction, unrepairable open palate, sensory processing disorder, hypotonia, g-tube 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 wheel chair 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 have 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  
503-875-8631

On Fri, Dec 3, 2021 at 8:54 AM Pierce Annette <[Annette.Pierce@dhsosha.state.or.us](mailto:Annette.Pierce@dhsosha.state.or.us)> wrote:

Yes Emily, here is the link where you can find information on the 1115 Waiver.

[this flyer](#)

Regards,

Annette

Annette Pierce

Administrative Support Specialist to Steph Jarem

OREGON HEALTH AUTHORITY

Health Policy and Analytics

[Annette.Pierce@dhsoha.state.or.us](mailto:Annette.Pierce@dhsoha.state.or.us)

Cell: 503-302-1919

<http://www.oregon.gov/OHA>

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**From:** Emily P. <[emilyferndayton@gmail.com](mailto:emilyferndayton@gmail.com)>  
**Sent:** Friday, December 3, 2021 8:39 AM  
**To:** Pierce Annette <[Annette.Pierce@dhsoha.state.or.us](mailto:Annette.Pierce@dhsoha.state.or.us)>  
**Cc:** CHETOCK Tara A <[Tara.A.CHETOCK@dhsoha.state.or.us](mailto:Tara.A.CHETOCK@dhsoha.state.or.us)>  
**Subject:** Re: Oregon Health Policy Board (OHPB) December 7th

Got it, I will send my written testimony prior to Saturday at 5pm. Is this where I can also ask community members to send written testimony to change the Medicaid 1115 waiver?

Regards,

Emily

On Fri, Dec 3, 2021 at 8:30 AM Pierce Annette <[Annette.Pierce@dhsoha.state.or.us](mailto:Annette.Pierce@dhsoha.state.or.us)> wrote:

Hello Emily,

Please submit your written comment to me or to Tara Chetock @ [tara.a.chetock@dhsoha.state.or.us](mailto:tara.a.chetock@dhsoha.state.or.us) 2 business days prior to the meeting.

Thank you I look forward to hearing from you.

Regards,

Annette

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**From:** Emily P. <[emilyferndayton@gmail.com](mailto:emilyferndayton@gmail.com)>  
**Sent:** Friday, December 3, 2021 8:15 AM  
**To:** Pierce Annette <[Annette.Pierce@dhsola.state.or.us](mailto:Annette.Pierce@dhsola.state.or.us)>  
**Cc:** CHETOCK Tara A <[Tara.A.CHETOCK@dhsola.state.or.us](mailto:Tara.A.CHETOCK@dhsola.state.or.us)>  
**Subject:** Re: Oregon Health Policy Board (OHPB) December 7th

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Yes Annette,

I am planning on providing both. Can my written information be sent at any time or does it need to be sent on December 7th?

Thanks,

Emily

On Fri, Dec 3, 2021 at 8:06 AM Pierce Annette <[Annette.Pierce@dhsola.state.or.us](mailto:Annette.Pierce@dhsola.state.or.us)> wrote:

Good morning Emily Fern Dayton,

I have you as registered to participate in our Monthly Board Call on December 7<sup>th</sup>. I'd like to confirm that you are still planning on providing both Oral and Written Public Comment **re: 1115 Waiver?**

Please submit your written comment to me or to Tara Chetock @ [tara.a.chetock@dhsola.state.or.us](mailto:tara.a.chetock@dhsola.state.or.us) 2 business days prior to the meeting.

Thank you I look forward to hearing from you.

Regards,

Annette

Annette Pierce

Administrative Support Specialist to Steph Jarem

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Health Policy and Analytics

[Annette.Pierce@dhsosha.state.or.us](mailto:Annette.Pierce@dhsosha.state.or.us)

Cell: 503-302-1919

<http://www.oregon.gov/OHA>

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Emily Fern Dayton, MS

She/They

Living in the occupied territory of the Kalapuya, Molalla, Klamath and Cayuse tribes who were violently attacked and forcibly displaced by white settlers in the 1851 Battle of Abiqua:

<https://historicoregoncity.org/2019/04/03/klamath-trail/>

<https://ndnhistoryresearch.com/2016/06/13/molalla-chief-crooked-finger-the-battle-of-abiqua-and-the-1851-molalla-treaty/>

Please support the Warm Springs Reservation's need for water infrastructure by donating to the Chuush fund: <https://mrgfoundation.org/the-chuush-fund-water-for-warm-springs/>

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Emily Fern Dayton, MS

She/They

Living in the occupied territory of the Kalapuya, Molalla, Klamath and Cayuse tribes who were violently attacked and forcibly displaced by white settlers in the 1851 Battle of Abiqua:

<https://historicoregoncity.org/2019/04/03/klamath-trail/>

<https://ndnhistoryresearch.com/2016/06/13/molalla-chief-crooked-finger-the-battle-of-abiqua-and-the-1851-molalla-treaty/>

Please support the Warm Springs Reservation's need for water infrastructure by donating to the Chuush fund: <https://mrgfoundation.org/the-chuush-fund-water-for-warm-springs/>

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 Austism 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 adaqueate care available for my children.

During COVID the boys 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 in 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 CHILDRENS NEEDS AND I WILL BEFORCED 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 adaqueate supports 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 to have to choose between survival and safety vs placing my son in 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

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Hello, my name is Jennifer Murphy. I am the mother of the Preston age 8 and Parker age 5. These boys are the absolute joy of our life. Every thing 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 Celliac, 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 recient diagnosed feb 2021 with type 1 diabetes.Parker is eager to learn every thing 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. Id 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 stabalize families. We cant find any one trust worthy, drug free, educated, or qualified to provide the life saving care to our children. My kids cant tell me how someone treats them or if someone hurt them. I cant trust any one under a nurse to run my childs insulin injections, to do the math, to check for keytones, to act with glucogon injection if he goes into a low in a seizure or coma. Diabetes made our life alot more intense . diabetes requires 24 hour care. The dsp and psw are not drug screened, i cant put my kids lifes in the hands of strangers. We dont have family and friends to hire. We cant allow the exposure with the covid, when our kids are sick they are often hospitalized, their immune systems are compromised. Workers cant come here sick! I have had one success ful dsp that ended up moving, she was wonderful. I run adds , i have posted and cant 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 roommates, 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, its not if it happens its when it happens. Fmla is not paid. in feb 2021 he took 7 weeks with parkers diabetes diagnosis we had to learn every thing 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. Its extremely hard for my husband to carry a career. I cant work. we have had my husband home this year 2 times and we experienced us as a family unit doing every thing together. and it was amazing! life was less stressful, we had money to pay every thing, not just live pay check to pay check. We have 2 kids, and both have alot of needs. I am forced out of

the work force, and i am actually working atleast 2 full time jobs. i am unseen, unheard, and i am doing all the work. Being a caregiver is different that just a parent. my kids have 12 drs together, and labs, and appoiments. Our kids recieve the most love, attention, and care with us their parents. We have major life goals and we love our kids.I will always be my kids best support. I cant express to you how one decision to allow paid parents, would benifit our kids, our family. please understand that our needs are all different, we are voicing to you, to please change this option. Being paid parent would help our families in many ways. Thank you for the time Mrs. Murphy

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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



**From:** [Jessica Langley](#)  
**To:** [Pierce Annette](#); [CHETOCK Tara A](#)  
**Subject:** Paid Parent Caregivers for Medically Fragile Children continuing after the Pandemic  
**Date:** Saturday, December 4, 2021 4:13:43 PM

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To whom it may concern:

I'm writing 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 lifesaving 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 pickup 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 waver request for parent. Care givers  
**Date:** Saturday, December 4, 2021 10:41:23 AM

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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 wheel chair bound and non verbal, our son Jason is our world. Although we are granted hours thru the state for a home health care aides, it is a constant struggle to find anyone who is dependable 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 help my family tremendously please fight for it. Joshua Widmer

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**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

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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 cares 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 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 supply's, 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  
**Date:** Saturday, December 4, 2021 12:01:26 PM

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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.

Taran has 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.

Taran 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 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 lock down 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  
**Date:** Saturday, December 4, 2021 3:31:02 PM

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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 Charlee 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:** [Lisa Ledson](#)  
**To:** [CHETOCK Tara A](#); [Pierce Annette](#)  
**Subject:** Medicaid 1115 Waiver  
**Date:** Saturday, December 4, 2021 4:39:10 PM

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To whom it may concern:

Minor children experiencing disabilities deserve healthy and thriving families supporting them. They deserve every opportunity. There is zero control over caregivers for children without disabilities and it is completely discriminatory against parents of disabled children to disqualify them as potential caregivers.

It is ludicrous to expect any human being to have a super power ability to be a primary caregiver inside the home AND perform duties for another entity in order to make income.

Caregiving for those with disabilities is absolutely a paid provider position and deserves only the best compensations, and in situations the parents of minor disabled children is the best choice for this paid provider position.

Please make a permanent change in the waiver for parents of minor disabled children to be considered as an a paid provider.

As an Emergency Department Registered Nurse for 14 years, I can assure you that the workload and skill required to care for children with disabilities in the home is that of a nurse.

Parents gain expertise that should be compensated for, it is what's best for the children.

Thank you,  
Lisa R Ledson RN, BSN  
she/her/hers  
C (503)949-6459

**From:** [Liz O](#)  
**To:** [Pierce Annette](#)  
**Subject:** Allowing Parents to be PSW.s/DSPs  
**Date:** Saturday, December 4, 2021 4:58:53 PM

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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 sheer support that he 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

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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 to deal with his medical condition or I am unable to meet the nursing meeting and trainings requirments 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 over worked 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, with out the hardships of unstable income.

Sincerely,

Mandi Winter

**From:** [Maria Rogers](#)  
**To:** [Pierce Annette](#)  
**Subject:** Allow Oregon caregiver dollars to be paid to parents  
**Date:** Saturday, December 4, 2021 11:55:17 AM

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To whom it may concerned

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 right to spend as much time as possible with his mom who loves him and cares and NOT with a stranger caregiver.

The parents enforced 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 enforced to deal with a stranger caregiver in their private environment (home) for 50-60 hours a week. This is big mental stress.

Sincerely,

Maria Jolley

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**From:** [Michael L Stevens](#)  
**To:** [Pierce Annette](#); [CHETOCK Tara A](#)  
**Subject:** ALLOWING PARENTS TO BE PSWs/DSPs TO OUR MINOR CHILDREN  
**Date:** Saturday, December 4, 2021 1:06:12 PM

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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

Michael L Stevens  
12960 SW 107TH Ct

Tigard, OR 97223

[\(971\) 361-6139](tel:(971)361-6139) - Home Phone

[\(650\) 307-3587](tel:(650)307-3587) - Mobile Phone

**From:** [Michael Paruch](#)  
**To:** [Pierce Annette](#)  
**Subject:** Please pay parents as caregivers (Medicaid 1115 waiver comment)  
**Date:** Saturday, December 4, 2021 5:00:02 PM

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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, antiseizure meds, rescue meds, oxygen, suction, and on and on, its 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 illness 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 benefit 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 careers. Most families like us the dad works the mom 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 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 drop everything and come home to support crisis 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, its a medical job much of the time; paying us relieves important pressure so we can focus on family, and contributing 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 main stream 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

<>

Sent from my iPhone

**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

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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

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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

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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

**From:** [Shasta Kearns Moore](#)  
**To:** [CHETOCK Tara A](#); [Pierce Annette](#)  
**Subject:** Fwd: Medicaid waiver comment  
**Date:** Friday, December 3, 2021 3:19:09 PM

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Please see below. Thank you,

Shasta Kearns Moore

Begin forwarded message:

**From:** Shasta Kearns Moore <shastakearnsmoore@gmail.com>  
**Date:** December 3, 2021 at 3:17:42 PM PST  
**To:** Shasta Kearns Moore <shastakearnsmoore@gmail.com>  
**Subject:** Fwd: Medicaid waiver comment

Shasta Kearns Moore

Begin forwarded message:

**From:** Shasta Kearns Moore <shastakearnsmoore@gmail.com>  
**Date:** June 29, 2021 at 11:54:57 AM PDT  
**To:** 1115WaiverRenewal@dhsoha.state.or.us  
**Cc:** Ayni.Amir2@dhsoha.state.or.us  
**Subject:** Medicaid waiver comment

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](https://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

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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 relieved 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

**From:** [Tara Stone](#)

**To:** [Pierce Annette](#); [CHETOCK Tara A](#)

**Subject:** Testimony to allow parents to continue to be paid to care for our children.

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**Date:** Saturday, December 4, 2021 5:32:30 PM

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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 sons safe space. The only place he should feel 100% comfortable. This nurse who led me to believe she cared and was there to give my a mental break so I could go to 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 my 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 nationwide children's hospital in Columbus Ohio who specialized 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 home bound 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 the 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 lives 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

Superman











Sent from my iPhone

**From:** [Tina Stracener](#)  
**To:** [Pierce Annette](#); [CHETOCK Tara A](#)  
**Subject:** Parent testimonial on K plan waiver  
**Date:** Saturday, December 4, 2021 4:43:58 PM

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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 basics 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 the 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 supports 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



**From:** [Veronica Yepez](#)  
**To:** [Pierce Annette](#); [CHETOCK Tara A](#)  
**Subject:** PAID CAREGIVER TESTIMONY  
**Date:** Saturday, December 4, 2021 3:10:15 PM

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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 often times 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 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 timecards 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 often times 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 doctors 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 doctors 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 Yopez

**From:** [Victoria Stottlemeyer](#)  
**To:** [Pierce Annette](#); [Tara.A.CHETOCK@dhaoha.state.or.us](mailto:Tara.A.CHETOCK@dhaoha.state.or.us)  
**Subject:** Parents accessing caregiver dollars  
**Date:** Saturday, December 4, 2021 3:41:43 PM

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To Whom It May Concern,

My name is Victoria Stottlemeyer 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. Allow parents to be paid as caregivers also does nothing to increase the cost associated with caregiver, 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 these 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 Stottlemeyer

# Oregon Overstates its HCV Chronic Cases by as much as 50%

Testimony for Health Policy Board, December 2021 (T. Busse – TomBusse@protonmail.com)

## How the Oregon Health Authority Accomplishes its Data Fraud:

Starting in 2014, the OHA at the instruction of Ann R. Thomas changed its laboratory-direct reporting algorithm to consider HCV antibody-positive cases that are RNA-negative or RNA-indeterminate as “probable chronic cases.” Dr. Thomas falsely claimed this was due to a CDC instruction. This is not true – in 2013 the CDC eliminated the confirmatory RIBA, but still required the RNA test. The consequence was in 2014, Oregon HCV cases increased by 25% overnight. Public health experts will lie and claim that they do this because patients are “lost to follow-up.” This ignores basic phlebotomy for HCV lab orders: two blood draws are made, and if the initial vial tested for HCV RNA is screened negative, the second vial is discarded. There is no “two visit test” for initial screening. Per Ann R. Thomas in a webinar on April 19, 2021, “in Oregon, if you are antibody positive you will be considered a case irrespective of confirmatory testing.” In other words, **even if the OHA’s Dr. Thomas knows that a person is confirmed negative, she will still count the case as positive for official statistics**, inflating the OHA’s numbers.

The webinar was part of an official OHA “Viral Hepatitis Collective” in partnership with a phony astroturf charity called “Caring Ambassadors” funded by the pharmaceutical industry and directed by a P/R and Lobbying firm called Shandwick International. Caring Ambassadors provides refreshments at Collective meetings and even writes copy used in official OHA powerpoints at mandatory staff trainings. The ED of “Caring Ambassadors” has failed to register as a lobbyist and sits on the OHA’s Viral Hepatitis Advisory Committee. This relationship between OHA staff and the drug industry evidences regulatory capture.

The increase consists entirely of 1. False Positives and 2. Cases that naturally cleared. These are used to pad Oregon’s numbers substantially, **fabricating a Hepatitis C epidemic in Oregon that does not exist**. The consequences are the **misallocation of resources by policymakers** and the possibility of net harm due to overscreening and overtreatment.

It is also unfair to put people in a surveillance system for a disease they don’t have.

By the OHA’s own admission in its HCV investigation guidelines documents, screening in low-prevalence populations cause **false antibody positives 50% of the time**. False HCV positives are a huge problem for people who 1. Have autoimmune conditions, 2. Are Black, 3. Are in the Veteran’s Affairs system, 4. Have had recent vaccinations (for example, a flu shot is administered at a doctor’s visit and the blood draw order is done the following day when raised antibodies cross-react on the HCV-ELISA).

In 2016 and again in 2021, the US Preventative Services Task Force and CDC broadened their HCV screening guidelines to include low prevalence populations outside the traditional “risk groups.” These screening orders are added by medical record software automatically and are even tied to physician reimbursement, so broadened HCV screening is being done into Oregon’s low-prevalence populations, amplifying the impact of the 2014 change beyond its already nefarious intent to inflate case numbers.

The result: the 2014-21 HCV increase in **Oregon “presumptive Chronic HCV” likely consists of 50% false positives**, doubling the state’s prevalence data. In national statistics, presumptive and confirmed cases are rolled together. Federal allocations are based on, “the more cases you have the more money you get,” so the OHA has a disincentive to correct its reporting.

## **Impact on Black Communities**

Oregon's Ryan White Integrated Planning Group has identified "Black Communities" as "at risk" and "disproportionately impacted" based on the OHA's faulty HCV prevalence data. For genetic reasons, people of sub-Saharan ancestry including Black Hispanics are likely to clear HCV-antibody seropositivity naturally 75% of the time (for whites it is about 25%). Therefore, an antibody positive without confirmation should be presumptive not-chronic in this race group. Because the OHA targets black communities for testing, "increased ascertainment" skews the data. In addition, all antibody tests in people of sub-Saharan ancestry are not calibrated for the generally stronger antibody response in Black People – a general false positive problem the CDC recognized in 2006 in respect to HIV tests but has done nothing about.

In OHA aggregate statistics, the practice of including false positives as "chronic cases" means blacks are disproportionately counted and public resources are wasted on targeting a misidentified risk group.

Medical Racism occurs when people by simple virtue of their race are unfairly targeted or labeled as carriers of disease. In the current disease construct, HCV seropositivity is due to risk behaviors, not the color of one's skin. In her webinar, Dr. Thomas made a racist comment when she observed racial data for Blacks was low in one category, stating "there must be something wrong here" – reflecting this "public servant's" bias that Blacks are inherently diseased and engage in reckless behavior such as sharing needles due to their color of their skin. It also reflects Dr. Thomas's ignorance or incompetence in interpreting antibody tests – for genetic reasons, lower HCV prevalence should be expected of Blacks just like higher HBV prevalence should be expected for Asians.

In her webinar, Dr. Thomas also made another racist and ignorant comment trying to explain HBV prevalence data, blaming Asian immigrants for HBV in Oregon. Immigration has nothing to do with HBV – genetic immunological differences cause HBV to resolve to chronic states in 1 of 1500 whites but 5% of Asians and HBV vaccination does not prevent acquisition of HBV chronic carrier status for those who are genetically susceptible. Immigration status has nothing to do with Asian HBV prevalence – something a competent "public health expert" should know.

In the bigger picture, risk behaviors such as substance use does correlate with socioeconomic conditions which are often rooted in systemic racism, and this can partially explain greater prevalence for HCV and HIV in some racial groups. It also suggest that a public policy alternative to using scarce public resources on screening and medication programs is to help lift people out of poverty and address socioeconomic disparities that cause some individuals to fall out of society and self-medicate.

## **Cronyism and False Claims in Oregon's Largest HCV Eradication Programs**

Oregon's largest HCV eradication program is funded by Gilead Sciences through the Multnomah County Health Dept. and is called FOCUS. The grant was snuck into the Multnomah County Board of Commissioner's consent agenda in 2018 at the behest of a County Commissioner whose son is an Executive Vice President at Gilead Sciences. FOCUS has been focus of a USDOJ false claims and kickback investigation and a \$3.2 Billion dollar Qui Tam action. It is a drug marketing scheme disguised as public health. The program has generated at least \$20,000,000 in drug sales charged to Medicare Part D and the Oregon Health Plan, and program administrators have rigged a way to bypass OHP preauthorization requirements: instead of establishing a 6-month RNA baseline to confirm chronicity, an in-house "robo-pill-mill" pharmacy at Portland's Central City Concern fronts the drugs, then completes the claim with the Oregon Health Plan six months later, lying in preauthorization documents that chronic status has been confirmed. I have hard evidence from the treating physician they are giving these toxic drugs to probable acute cases – a Non-FDA indication beyond the OHP formulary that is likely to cause net patient harm.

Of the 1000 individuals treated with very expensive Direct Acting Antivirals since 2018, **585 dropped out of the program and were lost to follow-up**. This means the Oregon Health Plan paid at least \$10 million in drug sale claims for people who pre-filled their prescription and disappeared. County health staff then falsely warranted that the patients had confirmed chronic status in order to complete the claim after the 6-month – paying out for a full-course of drugs for 585 patients who had disappeared. Then in public reports, public staff lied and said 100% of individuals treated completed their course of therapy. As corrective action, staff have started to pay \$15 gift cards to patients to show up for labs – basically a bribe to generate taxpayer-funded drug sales for Gilead.

Because Oregon's False Claims Act is deficient in lacking a private right-of-action, there is no current mechanism to correct for these false claims. Other red flags in FOCUS include Gilead Sciences writing powerpoint training slides for mandatory public staff trainings, Gilead Sciences writing copy for posters and brochures distributed in county health center. CMS Open Payments indicates \$20,000 in direct annual payments from Gilead to a doctor involved in the FOCUS program. FOCUS also pays for pizza parties to award staff teams who generate the greatest number of new cases and provides gift cards to county staff.

### **Wider Considerations for Hepatitis C in Oregon**

HCV became a reportable condition in Oregon only in 2005, and it is not a reportable condition in many US States. By the Oregon Health Authority's own admission, although a blood donation screening test was available starting in 1990, the existence of HCV was not proven and was inferred until about 2006 when cell culture models of modified molecular clones allowed for "validation" of PCR-based molecular tests that has been around since the late 90's. To this day, wild HCV taken in-vivo has never been propagated in culture. Furthermore, the linkage of HCV to hepatocellular carcinoma (HCC) remains hypothetical and unproven. In Egypt, where HCV prevalence is high, HCC prevalence is low. HCC prevalence is also low among healthcare workers, where HCV prevalence fails to contour to HBV occupational exposure in the 70's and 80's prior to widespread vaccination.

In other words, since HCV is said to have been around forever, Oregon as a state was doing just fine for 150 years before it started throwing money down the Hepatitis C black hole with little to show for it. The OHA's trigger-happy desire to blame a virus for the verifiable increase in cancer with no proof the virus caused that cancer causes public resources to be diverted away from controlling other potential carcinogens. Anecdotally, Gilead's HCV "miracle cures" actually cause HCC, and in a catch-22, clinicians blame the virus, not the treatment.

It is difficult to ascertain the role HCV plays, if any, in long term progressive liver disease because co-factors also present in historic risk groups: alcohol consumption, recreational and prescription drugs, the underlying medical condition requiring transfusions, obesity, poor diet, and environmental toxins. Since 2013, HCV Case Ascertainment primarily drives drug sales of a class of protease inhibitors called DAA's. The Cochrane Collaborative, the Oregon Pharmacy and Therapeutics Committee, and the British Medical Journal have all stated that there is no evidence DAAs produce clinical benefits and there is ample evidence that DAA's cause patient harm. The indicator trial for Sofvaldi, singled out in Oregon's Prescription Drug Transparency Report as a primary driver increasing health care cost, showed a doubling of absolute risk of serious adverse events including congestive heart failure and death, yet there is no evidence the surrogate endpoint "sustained virological response" has any predictive value for clinical events. DAA's are also very costly. The 2014 definition change by OHA staff seems timed to have put pressure on the P/T Committee to authorize DAA therapy under the OHP Medicaid waiver – at a time when PhRMA was threatening to sue the state over the issue.

Given that there is no evidence that HCV screening or DAA therapy provide any health benefit and ample evidence they provide public health harm, Oregon's scarce resources could be redirected toward suppression of Hepatitis C's known co-factors: drug and alcohol recovery services, anti-obesity programs, healthy diets, etc.

### **Misuse of Non-FDA Approved Tests**

Starting in 2018, FOCUS funded the development of a rapid HCV "all in one" screening test using a technology called Dried Blood Spot. The test is being commercialized by a Vancouver/WA company called Molecular Testing Labs ("MTL"), and it is not licensed or approved by the FDA, using the same regulatory loophole exploited by the notorious company, Theranos. This test was developed in Multnomah County health centers, and for the experimental blood draws, no institutional review board was convened, the clinical trial was not registered with the FDA, and patients were not provided with informed consent documents that their blood was being drawn for commercialization of a product by a private company. MTL had to settle over \$3 million in false claims with the US Dept. of Justice in two separate lawsuits, and the Doctor who is the sales Rep for MTL (Chris Hall) used to be a visiting scholar at a New York Eugenics think tank before he went on to run a national network of fundamentalist Christian and Mormon AIDS hospices that pushed gay conversion therapy before murdering their clients with lethal doses of AZT in the late 1980's.

The FDA has not approved any commercial test using Dry Blood Spot technology, and if large companies such as Abbott Labs can't get it to work, why is MTL able to market its test for use in Oregon? MTL claims its test is 100% specific and 100% sensitive, but there are no publicly-available validation studies to confirm this. FDA-licensed tests, for instance, include a package insert viewable on the internet describing the validation protocols. At a Caring Ambassadors Webinar, the OHSU doctor who commercialized the test (who also advises the OHA and is paid by Gilead to conduct industry friendly "continuing education" programs for the Oregon Medical Licensing Board), made statements that the test does produce false positives as well as false negatives. The whole point of eliminating the 2013 confirmatory RIBA in the screening algorithm was modern NAT tests were supposed to be more accurate than the NAT tests rolled out in the 90's – but this goes in the opposite direction. This invalid unproven test is being used to generate millions in OHP-funded prescriptions.

CDC guidelines and CMS regulations are abundantly clear: HCV screening should only involve FDA-approved tests.

**Testimony of Theodora Scarato to Oregon Health Policy Board  
(Please DO NOT READ REFERENCES)**

**The Oregon Health Policy Board must act to address the Oregon Health Authority Report on Wireless Radiation which has serious flaw and critical omissions. Several experts scientists wrote to the Governor and Oregon Health Authority requesting a retraction of the report.**

**Corrections will not suffice as the errors in the report are systematic. To start, the Oregon Health Authority has inaccurately defined the range for wireless frequencies and used inadequate search terms in its literature search.**

**Children are exposed to wireless radiofrequency radiation from numerous sources in schools- Wi-Fi routers, Wi-Fi laptops, cell phones, and nearby cell towers. Research has found increased cancer, damage to the brain and to reproductive organs from wireless exposures.**

**Children are more vulnerable to wireless radiofrequency radiation for the following reasons:**

- **First, there is deeper penetration of wireless radiation into the brain:** Children have smaller heads than adults with shorter distances from their skull to the brain center ([Morris et al., 2015](#), [Ghandi 2015](#), [Ferreira and de Salles 2015](#), [Wuart et. al., 2008](#)).
- **Children have thinner skulls and a higher conductivity of brain tissues allow higher intensities of RFR into the eye and brain.** ([Fernandez et al. 2018](#), [Christ et al., 2010](#), [Mohammed 2017](#)).
- **Children have more active stem cells in their bodies and** research shows that stem cells are more sensitive to microwave radiation ([Belyaev 2010](#), [Williams et al. 2006](#)).
- **Developing brains are more vulnerable to neurotoxic exposures:** Not only do children absorb higher peak doses in the brain than adults, their brain is growing rapidly, subject to different windows of vulnerability, and thus more susceptible to adverse impacts and environmental neurotoxicants. Exposures that take place during fetal development or early childhood may cause permanent brain injury, whereas the same doses may have little impact in adults ([Heindel et al., 2015](#), [Weiss 2000](#), [Lanphear 2015](#), [Redmayne and Johansson 2014 and 2015](#)).
- Children will receive a greater cumulative cell phone and wireless exposure than adults and are in school for hours every day ([Belpomme et. al, 2018](#), [Miller et al, 2019](#)).

Both [AT&T Mobile Insurance \(pg. 4\)](#) and [Verizon Total Mobile Protection \(page 10\)](#) state that coverage is excluded for pollutants, which is defined as including microwave wireless radiation.

**The Oregon Health Policy Board has a responsibility to provide oversight and to ignore this issue could result in serious liability issues.**

Verizon Wireless warns their shareholders in their [10-K form](#) that:

“Our wireless business also faces personal injury and wrongful death lawsuits relating to alleged health effects of wireless phones or radio frequency transmitters. We may incur significant expenses in defending these lawsuits. In addition, we may be required to pay significant awards or settlements.”

However Verizon does not warn its customers or those using wireless devices about risk. Public health agencies have a responsibility to the public and children's health. Please do the right thing.