**Subject:** FW: Canceled: Parent Caregiver Workgroup
**Date:** Monday, February 6, 2023 at 1:39:39 PM Pacific Standard Time
**From:** Sen Gelser Blouin
**To:** Sen Gelser Blouin
**Attachments:** image001.png

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**From:** Sen Gelser Blouin <Sen.SaraGelser@oregonlegislature.gov>
**Sent:** Friday, September 16, 2022 5:13 PM
**To:** Sen Gelser Blouin <Sen.SaraGelser@oregonlegislature.gov>
**Subject:** Re: Canceled: Parent Caregiver Workgroup

I thought it would be helpful to provide some clarification about where we are in terms of the process to create the statutory framework for a permanent paid parent caregiver program during the 2023 Legislative session.

**Bills are being drafted and will be heard concurrently**

Senator Knopp and I have both committed to introducing bills. It's my understanding that the primary difference between the two bills is that the Knopp bill would put a paid parent provision directly into the State Medicaid Plan for ***every*** child eligible for attendant care services. My bill would put it in a waiver and make it available to a ***narrower*** population of children with extraordinary behavioral and medical needs. Both bills will be introduced and considered.

**When can everyone see the language and provide responses/requests/edits/concerns?**
It's my understanding that Senator Knopp's bill is already with the Legislative Counsel and last we spoke it had not yet been returned to him. My request will be with Legislative Counsel by the end of next week. As promised, once that is finished I will share the details of what I've requested, in writing, with anyone that is interested.

The formal bill won't be available for anyone to see (including legislators) until it is completed by the Legislative Counsel, which could be as late as December 5. However, my office is creating an "interested parties" list and will email the official LC to everyone on that list as soon as we get the document back.

**Why is there a December stakeholder meeting?**
Next week is the deadline for legislators to request bills from the Legislative Counsel. These are the people who take our ideas and turn them into the formal language for bill introduction. Once we submit the requests, we have to wait for them to be completed before we see what it looks like. All drafts must be returned to members no later than December 5. In my experience it would be unusual for us to get big bills like this much earlier than that—but there is always that possibility. ***Regardless of when it arrives, I will send the offical LC to the interested parties list immediately upon receipt.***

Until we have that language back on both of the bills, we don't have anything to work from. The meeting on December 9 at 3pm is to allow for a broad stakeholder discussion about the language outside of the formal hearing process. This will also allow the opportunity for that discussion to inform changes that can potentially be made before the bill is introduced. The turnaround for that is quick, though, because bills must be submitted to the Secretary of the Senate no later than 5pm on December 21 for presession filing.

**Who is invited to the December stakeholder meeting and what will we discuss?**
Any interested party is welcome and encouraged to attend. I have organized this meeting to discuss the

language in the concept that I have asked to have drafted so that the community can see it before introduction and there is an opportunity to make some edits before introduction. We will be able to spend the meeting focused on feedback because the overview of the bill will happen in the morning at the Human Services Committee Hearing. If it is made available, the morning hearing will also have an overview of the Knopp LC. Any LC that is discussed at the hearing will be posted in OLIS for easy access.

### Why are there two bills? And which bill is moving forward?

These are two bills on the same topic that offer slightly different policy choices. There may also be additional bills. However, by having these two bills introduced and heard side by side we can facilitate a very clear discussion during the public hearing process in February. We will be able to see, in writing, the different policy choices proposed and hear testimony on them. We will be able to get non-partisan/neutral analysis by the Legislative Policy and Research Office and the Legislative Fiscal Office. The committee will then be able to make changes as needed to one or both bills based on the public process.

At this point, there is no way to know which bill will move forward or what the final bills will look like. However, having both of these bills means that the discussion is not limited during session and there is not a predetermined outcome—it is reliant on what is learned during the process and the decisions made by the committee as a whole. Based on past experience, I anticipate that if a single bill moves forward it will include a variety of things from both bills.

### What's the difference between and LC and a Bill?

An LC is a legislative concept. It is the official draft language of a measure before it is formally introduced. It is assigned an LC number (ie, LC 6798) when it is submitted to the Legislative Counsel. LC's are then submitted to be filed or introduced. When this happens, they are put into official bill format and given a House Bill or Senate Bill number (ie, HB 2442 or SB 741). That number NOT the same as the LC number. The bill is then first read on the floor of either the House or Senate, and then the presiding officer is able to refer it to a committee.

Measures that are filed for introduction by December 21 are "presession filed." This means they will be available on OLIS to the general public on January 9 when we meet for organizational days, and will be referred to committees in time to be heard in public hearing once we convene in February.

### When will the bills be scheduled?

It is hard to know for certain. However, if these bills are introduced and referred to the Human Services Committee and I am the Chair of the committee, I will schedule these bills within the first couple of weeks of session. This is to ensure we have plenty of time in the public process to find a long term policy that works. If they are in the Human Service Committee and I am chairing them, I will always schedule both bills at the same time—along with other bills in the committee on this topic.

### What engagement took place between ODHS, legislators and paid parent advocates to inform the development of the concepts being submitted?

I have been confused by statements that the agency and the Legislature (including me specifically) have failed to listen to or engage with advocates for a paid parent policy. It is my understanding that Senator Knopp and his team readily engaged and supported paid parent advocates to design a measure requests. I know that many, many legislators have listened intently and sought additional information on this topic. I also tried to dive into this with good faith and I believe ODHS has done the same. I can only speak to the points of engagement and research that I've done or am personally aware of the agency doing. I know that I've also had direct conversations with over 30 members of the Legislature about this issue. Here are some of the points of engagement that I can recall, though the list is not exhaustive and does not include similar sets of meetings with opponents of the concept of paying parents:

**2019**

- December 18, 2019- Meeting with parents (I believe it was Lisa Ledsen, Shasta Kearns and Shawn Brownstein), Representatives Keny-Guyer and Nosse and their staff, Leslie Sutton, Lilia Teninty and myself at the Capitol (just over one hour long)

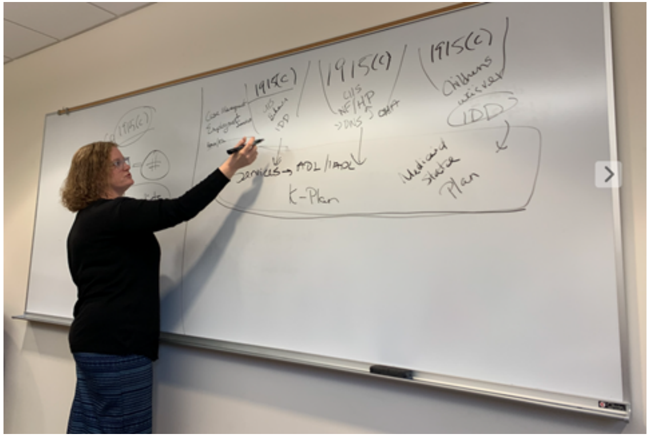

Photo: December 2019 meeting, with Lilia Teninty mapping out the Oregon DD System framework

**2020**

- April 14, 2020—I engaged in a Zoom meeting for over an hour with a group of parent advocates for paying parents.
- Spring 2020—I advocated for temporary program to respond to pandemic needs

**2021-2022**

- December 2021- ODDS/Lilia Teninty provided Zoom webinar on paid parent caregivers and barriers to permanent program at the time (based on CMS guidance applicable at that time)
- January-March 2022- ODDS/Lilia Teninty proactively engaged with CMS, other states and national organizations to probe what was permitted for Medicaid reimbursement post-Medicaid.
- February 2022- I was invited to Zoom meeting with parents, but invite was quickly pulled back because the date didn't work for the group after all (just logistics, this wasn't a negative thing). A new request to meet didn't come until April.
- April 2022- ODDS agreed to a meeting with families facilitated by UCP. That plan was disrupted due to conflict over format. ODDS then offered to set up meeting on their own and find a different facilitator. Lilia agreed to invite CMS to the meeting. This invitation was issued, but CMS did not respond or attend.
- April-August 2022—I read and responded to dozens of emails from parents around the state
- May 19, 2022—2 hour meeting between ODDS/ODHS and parent advocates—included Lilia Teninty (ODDS Director), Anna Lansky (ODDS Deputy Director), Fariborz Pakseresht (ODHS director)
- May 24, 2022-- 1 hour meeting between parent advocates and myself, moderated by Angela Donley from Senate Majority Office
- June 2, 2022- House Human Services Hearing on Paid Parent Caregivers
- June 3, 2022- Senate Human Services, Mental Health and Recovery Hearing on Paid Parent Caregivers, followed by comprehensive data request to ODHS. The presentation materials from ODDS can be found here.
- June 29, 2022- I had detailed exchange with Calli about process and timelines moving forward, including need to get the data requested from ODHS before meeting again
- July 5, 2022- Received request from Calli regarding EBoard request and provided comprehensive reply
- July 26, 2022- Comprehensive response from Lilia's team at ODHS posted to OLIS for public to access
- July 28, 2022- Additional 1:1 meeting with paid parent leadership team member, leading to significant shift in the structure and assumptions of the proposal I was drafting
- August 10, 2022- Submitted additional significant data and information request from ODHS related to

the numbers of children in a variety of categories
- August 10, 2022- 45 minute meeting (we went overtime) between myself, paid parent advocate leadership group, Representative Neron and Angela Donley from Senate Caucus Office
- August 10, 2022- Coordination meeting with Rep. Neron, Speaker's Office and House and Senate Majority Offices to assess efficient and effective strategy for this concept in 2023 session
- August 11, 2022- Sent email to Shasta and Calli outlining upcoming process, committing to send info about draft once submitted, committed to sending LC when received and setting time certain for 3pm December 9, 2022 for stakeholder meeting when LC concept is returned
- September 13, 2022- ODDS sends final set of data requested and that I need to finalize bill request (which should be complete by early next week)

Other engagement and information that went into the development of my request included:
- Read all written testimony from both hearings
- Read and responded to emails from dozens of families around the state
- Read all written testimony provided to the Oregon Disability Commission and the Oregon Health Policy Board
- Read the full packet of information/portfolio developed by the paid parent advocates
- Read the Q&A and request for action written by the paid parent advocates following the hearing
- Watched the webinar hosted by the Autism Society of Oregon
- Read all news interviews I could find including through Medical Motherhood related to this issue
- Listened to a variety of podcasts and radio programs and watching television news spots related to this issue
- Researched in detail the full State Medicaid Plans, kids' service options and paid parent provisions in a variety of states including Colorado, Arizona, California, Minnesota, Texas, Florida, Connecticut, etc
- Researched the provisions of the State Medicaid Plans related to attendant care for the 5 states that have adopted the K Plan/Community First Choice Act
- Met with other stakeholders concerned about this issue including brokerages, Disability Rights Oregon, SEIU, provider agencies, disability advocacy organizations and self-advocates
- Engaged in phone calls and meetings with over 30 members of the House and Senate from both parties
- Engaged in discussions with the Governor's Office, OHA, ODDS, the Speaker's Office, the Senate Majority Office and the Senate President's office
- Examined Oregon's current waivers and ODDS usage and enrollment
- Researched the Oregon Needs Assessment and service group assignment and implementation
- Research into the determination of "exceptional" behavioral needs including determination for CIIS, under current system and under new ONA process
- Sought clarity on employment law, parent rights and "Medicaid representatives"
- Researched history of DD Services in Oregon and reviewed the Lewin Report for better understanding of services on a waiver vs. the state plan

## What's Next

For now, we are in a bit of a pause as we wait for the language to come back so that we can enter the next set of discussions. With at least two bills, I anticipate a fruitful and comprehensive discussion through the Legislative process that will help us ultimately enact thoughtful policy.

My office is compiling an interested parties list. We will add everyone on this list to that distribution list. If you know others who would like to be included please email us at sen.saragelser@oregonlegislature.gov . That list will be used to distribute the information about the proposal once my drafting request is complete, the official LC when it is returned later this year, and information about hearings and other events related to legislative events related to paid parent caregivers. If you are on this list and DO NOT want to receive further updates, please let me know.

Thanks, and I look forward to the next steps in this process.

Sara

Senator Sara Gelser Blouin
Senate Majority Whip
Chair, Senate Committee on Human Services, Mental Health and Recovery
Sen.saragelser@oregonlegislature.gov
(503) 986-1708* 900 Court Street NE, Salem, OR 97301
Pronouns:  She/Her/Hers

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**From:** Shasta Kearns Moore <shastakearnsmoore@gmail.com>
**Date:** Wednesday, September 14, 2022 at 9:58 PM
**Subject:** Re: Canceled: Parent Caregiver Workgroup

Rep. Neron, friends, allies and policymakers,

Thank you for your work on this important issue. It is deeply disappointing that the workgroup needed to be canceled at the last minute but we understand — probably more than anyone — the pressure you were under to do so.

By this point in this process, thousands of people have put in thousands of hours of work, all with one core message: Listen to us.

Those with the power to change this policy before now did not listen to the 4,198 petitioners who signed our petition asking for the discrimination against parents as caregivers to stop.  They did not listen to the hundreds of individual families who wrote into organizations, government agencies and legislators. They did not listen to the arguments and testimony in our 114-page portfolio of support. They did not listen to the disabled children, like my son, who say they want this choice.
There were some who did listen. The Medicaid Advisory Committee listened and voted its unanimous support: *"These families have consistently shared the positive impact of the paid parent caregiver policy, including better care for their children, decreased time and anxiety related to the ongoing cycle of finding and training qualified caregivers, better health resulting in decreased emergency department use, and increased financial stability and housing stability for the entire family. These benefits are consistent with the State's health system transformation goal of family-centered, whole person care that supports health-related social needs in addition to treating medical conditions."*

The Oregon Disabilities Commission listened and voted its unanimous support, adding: *"We must also recognize that insisting upon a caregiver from outside of the child's home being considered the 'qualified' individual, despite the fact that it is the parents that will likely train the DSPs or PSWs, brings the training schools that individuals with I/DD were historically sent to, into the home. It would be nothing less than taking a step back in history via the child's front door."*

Senate Minority Leader Tim Knopp listened and has worked together with us to develop policy language that would offer this option to all children who need it.

We have children themselves who can speak to the need for this policy. We have former children, now adults, who want this policy. We have doctors and psychiatrists and faith leaders and agency owners and union leaders and many more. How are their voices going to be heard in the process moving forward?

I'm sure everyone here is familiar with the phrase **"Nothing about us without us."** The disability rights slogan is meant to push back against the tendency of institutional powers to talk down to, ignore and dismiss the voices of people directly affected when designing disability policy. The level of sacrifice I personally have had to make and that others from our team have had to make to be able to get a seat at the table in meaningful policy discussions is frankly ridiculous. We represent thousands of parents who do not have the privileges that we do to even attempt to advocate at this level. I have spent hours talking to them about their lived experience; I have sat with them as they cried.

Three parents who have been major contributors to our campaign have lost their children — Calypso, Baybeblue and Nic — since we began. In their honor and for the benefit of thousands of Oregon's most marginalized children, we continue to beseech every person on this thread to collaborate with us in designing policy that directly affects their lives.

We look forward to learning more about Senator Gelser Blouin's bill. Overall, we are thrilled that there seems to be a path forward for at least the highest-needs children to have this option in Oregon. But we have many questions and can foresee several problems if her concept stays — at least as we understand it from the brief verbal explanation — in its current form. That was at least part of what the workgroup was supposed to address.

It cannot be overstated how dramatically a paid parent-caregiver option would affect our lives and our children's lives, for generations to come. How can we work together to make Oregon the best place for disabled children to grow up?

--
**Shasta Kearns Moore**
Advocates for Disability Supports
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> On Sep 14, 2022, at 12:10 PM, ASO - Exec Dir <Tobi@autismsocietyoregon.org> wrote:
>
> Dear Representative Neron and Mr. Nieves-Valenzuela,
>
> Thank you for the work involved in setting up this workgroup and for letting us know of the cancellation.
>
> On behalf of the Autism Society and personally, I am very sorry that the decision was made not to convene the workgroup on Friday to hear the different perspectives from a wide variety of stakeholders on this issue. I think we work best when we all work together. The goal of the

working group to "bring together those who are impacted by and work within this system to find a path forward that builds upon the benefits we discovered during the emergency waiver" was something that I think is very much needed. Waiting until December to start a different workgroup with Sen Gelser Blouin does not sound nearly as promising to have legislation ready for the 2023 session on this important issue, especially since this is the first that I am hearing of this different workgroup.

I am concerned that a concerted effort is being made to *not* listen to the voices of the parents advocating for their minor children on this issue. This is very disappointing and, unfortunately, not a promising way forward to try to develop policy that supports and stabilizes children with disabilities in their homes.

Thank you again for your efforts.

Very truly yours,
Tobi Rates

On Tue, Sep 13, 2022 at 12:45 PM Jenny Hoyt <jenny@bokebowl.com> wrote:

> Hi Representative Neron,
>
> I'm very disappointed to hear that after so much work by yourself and the parent advocates, the workgroup was deemed unnecessary. I was looking forward to representing the hundreds of families within the United Cerebral Palsy network and I hope their voices will somehow be captured in order to inform decisions affecting them.
>
> It seems hard to try and build relationships without having collaborative meetings to come up with the best bill for Oregon's children with disabilities. I sincerely hope families will have a seat at the table.
>
> Thank you,
>
> Jenny Hoyt
> UCP Board Member
>
> On Tue, Sep 13, 2022, 9:50 AM Rep Neron <Rep.CourtneyNeron@oregonlegislature.gov> wrote:
>
>> Hello All,
>>
>> Sen Gelser Blouin and Rep Neron have discussed the work that needs to be done on behalf of children who rely on their parents to serve as their caregivers and decided that this workgroup will not be needed to advance legislation, so we are cancelling the scheduled meeting on Friday.
>>
>> We apologize for not following through on this particular workgroup. Sen Gelser Blouin has committed to leading on this issue. Out of respect for the Senate process, we would like you to direct your collaborative attention to engage with Sen Gelser Blouin's office and prepare for the stakeholder meeting that she is organizing in December. We stand ready to partner in the House with all who have come to the table to share your perspectives and look forward to participating in Sen Gelser Blouin's December stakeholder meeting.
>>
>> All the best,
>>
>> **Error! Filename not specified.**
>>
>> **Pablo Nieves-Valenzuela**
>>
>> Legislative Director
>> Office of Representative Courtney Neron
>> House District 26 | Aloha, Beaverton, Hillsboro, King City,
>> Newberg, Scholls, Sherwood, Tigard, Tualatin, Wilsonville
>> 900 Court Street, H-281, Salem OR 97301
>> Rep.CourtneyNeron@oregonlegislature.gov
>> 503.986.1426 | W: oregonlegislature.gov/neron

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**From:** Rep Neron
**Sent:** Thursday, August 18, 2022 11:59 AM

**Subject:** RE: Parent Caregiver Workgroup Invitation

Dear Advocates, Experts and Legislators:

I am following up on Rep. Courtney Neron's behalf to share an updated Doodle poll with options in early and mid-September. As a reminder, we are inviting you to join a working group to discuss a permanent policy allowing parents to serve as personal caregivers for their children. We are aware of two legislative concepts that are being created to address this issue, and would like to create a space for various affected parties to discuss and collaborate on what needs to be included in a long-term policy.

Thank you for your patience and ongoing work!

**Please complete this Doodle poll by next Monday, Aug. 22nd and let us know if you have any questions:**
**https://doodle.com/meeting/participate/id/bWngg2xa**

If you have suggestions for agenda items that you would like this group to discuss, please feel free to share those ideas as well.

Best regards,

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**Pablo Nieves-Valenzuela**
Legislative Director
Office of Representative Courtney Neron
House District 26 | Aloha, Beaverton, Hillsboro, King City, Newberg, Scholls, Sherwood, Tigard, Tualatin, Wilsonville
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**From:** Rep Neron
**Sent:** Friday, July 29, 2022 1:10 PM
**Subject:** Parent Caregiver Workgroup Invitation

Hello All,

I am writing to you today to invite you to join a working group on an issue that is emerging as a major topic during the 2023 session. We understand that you should be aware of the situation in which the emergency extension to the K-plan to allow parents to provide critical care to their children who receive Medicaid caregiver benefits is set to expire. What our working group will do is bring together those who are impacted by and work within this system to find a path forward that builds upon the benefits we discovered during the emergency waiver. We are seeking to develop a permanent policy that supports and stabilizes medically fragile children by allowing their parent(s) to work as caregivers.

Please fill out this Doodle poll by next Thursday, Aug. 4th so we can identify the time for our first workgroup meeting as soon as possible:[https://doodle.com/meeting/participate/id/bWnDVo4a](https://doodle.com/meeting/participate/id/bWnDVo4a)

This working group will be composed of parents, advocates, legislators, and agency staff, to bring together various perspectives and sources of information to support the strongest policy for the 2023 session. The group will initially plan to meet four times, once per week for an hour and a half.

It is important to us that we create a space that values all voices. If you see some perspectives that are not represented but should be, please let us know and we can always seek to expand our group. The list of individuals we have invited are:

Lilia Teninty and Roberto Gutierrez – ODDS/DHS
Gabriel Triplett, Shasta Kearns Moore, Jessa Reinhardt, Lisa Ledson, Calli Ross – Parent Educators
Megan Moyer – Disability Rights Oregon
Alice Longley Miller – Service Employees International Union
Leslie Sutton – OR Council on Developmental Disabilities
Em Braman – The Arc Oregon
Tammy Bakewell – OHSU
Tobi Rates – Autism Society of Oregon
Eva Rippeteau – AFSCME
Heidi Davis – TEAM Services Group
Jenny Hoyt – United Cerebral Palsy of OR and SW WA
John Griffiths – Oregon Self Advocates Coalition
Dave Kracke – Oregon Brain Injury Advocate/Coordinator

I sincerely hope that you can join us as we work together to solve this problem and find much needed relief for these families.

Sincerely,

Rep. Courtney Neron
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