MEDICAL
MOTHERHOOD

MAR 20, 2022 • 15M

The case for paying parents of disabled children

Direct support is the simplest solution to the complex problems we face

Mar 20, 2022

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“When Oregon finally allowed parents to be paid as caregivers it was too late for us.” — Celia Vander Velden

Photo by Keith Sheffield Photography

I’ve spent most of the last year in this newsletter defining a problem: raising disabled children is difficult in ways few on the outside understand — and accessing supports from our government is usually a big part of the problem.

In compiling the news briefs at the end of each issue, I’ve also seen how the lack of true and fair support is a widespread problem across the United States, and throughout the world.

This week, I joined Oregon parent advocate Matt Faler on his podcast Mindful Inspiration Champion to outline one possible solution to this problem: allow parents of minor children to be paid through existing caregiver programs. We were joined by two fellow supporters of the idea to allow parents to be paid caregivers: emergency room nurse Lisa Ledson and disability services coordinator Gabriel Triplett.

Watch “Labor of Love: Episode 73” of Mindful Inspiration Champion on YouTube or Facebook or listen wherever you get your podcasts.

We represent four of the approximately 300 Oregon families, according to a new article out in The Lund Report, who are currently allowed to have paid parent caregivers under a temporary program. This program was only authorized during the federal Public Health Emergency for COVID-19 and only for parents of children who qualify for 60 hours a week or more of in-home caregiver help.

It’s a solution that gives disabled children direct benefit of the money taxpayers allocated to them and it’s helping them achieve improved health and stability without all the usual barriers. On the scale of government programs, the cost was not prohibitive. According to The Lund Report article, it has cost $11 million so far. By comparison, Oregon’s Office of Developmental Disabilities Services recently announced it has $300 million in recovery funds to figure out how to spend.

But this program will soon evaporate. State leaders have firmly resisted requests to make the rule change permanent and expand the program to more of the 4,100 families of minor children who qualify for what’s called Home and Community-Based Services.

That is, until this week. Lilia Teninty, director of the Office of Developmental Disabilities Services, sent out a short missive on March 15 finally acknowledging that there are “options” for paying these parents through Medicaid, but that they “need to be reviewed and assessed for their budget impact and viability.”

It’s a step in the right direction.

Unfortunately, it will be too late for little Calypso. Celia Vander Velden lost her 10-year-old daughter last July. The Douglas County mother recently wrote me a heart-wrenching letter about the situation.

“I believe my daughter would be alive, had we as parents been paid over the years,” she wrote. “Had we been provided financial stability, without an ax over our necks from reports of rescinding that stability. I will have to exist with this realization for the rest of my life, as a hollow shell of who I used to be when my *mijita* was by my side.”

Vander Velden said she felt trapped in an unsafe living situation because it was the only apartment she could afford and that was accessible. Calypso required round-the-clock care.

“She died because we were living in an exhausting overwhelming state,” the Eugene mother wrote. “The state should not have been making our lives harder and should finally acknowledge that financial stability is a human right and our children’s special needs should not be used as a weapon against us.”

I’m adding her testimony to the pile of gut-churning stories I’ve heard since starting this medical motherhood journey. Like Jessica Franklin, a single mother who had to move out of Oregon to find a paid parent caregiver program that would lift her and her two children out of poverty. Or Kårun Virtue, a disabled veteran whose family is finally out of poverty now that her I/DD children are older than 18. (I wrote about both of them in this piece.) Or any of the dozens of other parents who wrote in to the Medicaid Advisory Committee last December.

I know how they feel. I’ve lived it and I’ve studied it. Each week on Medical Motherhood, I have done my best to validate these feelings in others in this journey and explain the issues to those kind souls outside of it who care.

I started last May with explaining the complicated web of services that I have to manage due to my sons’ extra care needs. I don’t think anyone outside of this life truly understands the sheer number of people we have to interact with to get help. I call it Special Needs World:

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Special Needs World

“I interacted with no fewer than 12 healthcare providers, their representatives, or insurance companies today. It might have been more. But this is medical motherhood. I tend not to complain about the sheer amount of administrative work that goes into managing a family that includes a disabled person or persons. But today, I'm complaining. Because I'm t…

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Then, I showed you how the monetary help most Americans think exists— Social Security disability benefits — are actually extremely difficult to access and a paltry amount of money once you do:

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What you need to know about Social Security's benefits for disabled children

“It’s a nightmare.” — Mellani Calvin, Social Security advocate since 2001…

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I also found data showing how rare two-income households are when children happen to need high levels of care.

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Working motherhood is even harder if your child has a disability

“Everyone needs care. What we need now is for society to value caregiving, as well as the people who provide that care.” — Caitlyn Collins I’m racing down the freeway at 1:59 p.m. with my heart in my throat. The sheer number of balls I am trying to keep in the air takes my breath away…

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Despite this lack of income, disabled children are also more expensive to raise and parents often have to skimp on extras like presents and vacations just to get their basic needs met.

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Disabled children cost more — and not for the reason you think

“(Parents of disabled children) were often compelled to reconstruct and renegotiate every aspect of their lives.” — Dobson, Middleton, Beardsworth (2001) Does everyone …

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I argued that lack of attention to these issues — ignoring the need for caregiving and care tasks across ages and abilities — is having massive consequences to our economy and society.

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Our systems were built on unpaid and underpaid female work. They are crumbling without it.

Listen now (9 min) | Hey folks, I'm trying out Substack's audio feature this week. (It's a trial feature here on Medical Motherhood — I only had time for one take so it's far from perfect!) Please let me know if you find it useful…

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I showed how even people inside the health insurance and mental health service systems say they are seriously broken. I explained how we parents are traumatized and sleep-deprived. I pointed out that we deal with loneliness and burn out and the oppressive threat of illness or death.

But in spite of all of that, we love our kids deeply. Our lives are enriched by them. We experience joy and magic that other parents can't even imagine. And we do incredible things when we get access to the right resources.

It's too late for Celia and Calypso. But we can and should make sure that the families of disabled children have the resources they need to thrive and live their best lives.

If you live in Oregon, consider coming to a COVID-safe rally March 24 at the Capitol in Salem. Participants will drive decorated vehicles around and demand that parents have a seat at the table while Oregon's Office of Developmental Disabilities Services explores its "options." Get more details and RSVP here: Family Caregivers Car Caravan at the Capitol. I will be there and I plan to interview folks and share their stories in next week's edition.

Correction: An earlier version of this issue incorrectly identified Celia Vanderbilts Velden's location. She lives in Douglas County. The link to the Facebook event was also incorrect and has been fixed.

Medical Motherhood’s news round up

Snippets of news and opinion from outlets around the world. Click the links for the full story.

• From The Guardian (United Kingdom): “Disabled people facing ‘impossible choices to survive’ in cost of living crisis”

> As the UK steadies itself for a rise in energy bills next month at the same time as state benefits are cut in real terms, leading disability and poverty charities including Scope, the Joseph Rowntree Foundation (JRF), Leonard Cheshire, and the MS Society have said that disabled people and their families will be put under severe financial pressure.
>
> They warn that disabled people could be pushed to use food banks and unwashed soiled clothes in order to prioritise keeping lifesaving medical equipment such as ventilators running, as well as other vital goods. Disabled people typically have higher energy needs than the wider public, while being more likely to be in poverty.

• From ProPublica: “Lawmakers Approve Payments to Parents of Children Who Died of Catastrophic Brain Injuries”

> Following up on action taken last year, the [Florida] Legislature voted to give $150,000 stipends to parents whose children were once enrolled in a state program called the Birth-Related Neurological Injury Compensation Association, or NICA, but had been dropped from the rolls when the children died.
>
> Families of surviving NICA children received identical stipends last year as part of a comprehensive slate of reforms, but the families of children who died were left out, even though some had spent themselves into poverty trying to keep their children alive.
>
> The reforms were implemented after a series of stories by the Miami Herald and ProPublicadocumented how parents in NICA had to beg for help from the program,

> which was supposed to provide "medically necessary" care to certain children left severely disabled by oxygen deprivation or spinal injury at birth. Parents complained that they had to plead, often in vain, for medication, specially equipped vans, in-home nursing care and home modifications, to which they were entitled under the NICA statute.

- From ADDitude Magazine: "Free Guide: Signs of Dyslexia at Every Age"

> When symptoms of dyslexia are left unidentified and interventions missed, it can cause psychological, academic, and professional harm. Yet, studies show that, when a child's symptoms are identified early, their scores on self-esteem rating scales mirror those of their non-dyslexic counterparts. Early identification is essential.

Medical Motherhood is a weekly newsletter examining the policies and practices in raising disabled children.

Get it delivered to your inbox each Sunday morning or give a gift subscription. Subscriptions are free, with optional tiers of support. Thank you to our paid subscribers!

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Do you have a question about raising disabled kids that no one seems to be able to answer? Ask me and it may become a future issue.
