MEDICAL
MOTHERHOOD

FEB 27, 2022 • 15M

Oregon's disabled children are about to lose their best-qualified caregivers

A temporary program keeping vulnerable families afloat sunsets April 16

Feb 27, 2022

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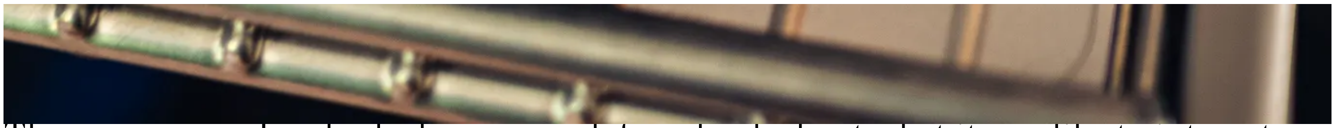
"It's been a very frustrating process to uproot everything," — Jessica Franklin, mom of two


NO!



Three years ago, I embarked on research for a book about what it was like to interact with the morass of government services as the parent of a child with complex disabilities. The book was a victim to pandemic forces, but through my research I came to the conclusion that the our support systems are entirely too complex and must be simplified in order to fulfill the mission of helping these families thrive.

I have many thoughts on how to simplify our systems. One easy — I thought — way to do that would be to allow parents to be paid as caregivers under Medicaid. We have a patchwork of Medicaid programs across the nation, but in my state, Oregon, children are able to qualify for in-home caregiver hours. Why not allow parents access to those jobs?

I don't consider myself a political activist but I have since met many, many parents who wondered the same thing and together we have built a movement. I lent my writing skills, my knowledge of government workings and my research ability to this effort. I want more control over the tax dollars my own son has been allocated, yes, but my driving force has been the passion and fear I have seen from other parents. I find I don't really set pen to paper until I'm fired up at the injustice of other people's stories.

This week, major developments have occurred in this effort. The Medicaid Advisory Committee unanimously voted to approve a strongly worded letter asking Oregon to come up with a path to paid parent-caregivers. Then, our movement sent a letter to the governor, signed by nearly 80 political, medical, religious, organizational and business leaders, also asking for this change. A petition for this same effort has garnered 2,600 signatures and climbing.

COVID-19 did not break a system that was working well — it revealed how dysfunctional our system already was. My hope is that we can use this new common understanding to build a better system moving forward.

With that background, I wrote the following opinion piece this week for my old stomping grounds, the Portland Tribune:

Jessica Franklin didn’t want to leave Oregon. Her family and friends were here. Her life was here.

“We want to be home,” Jessica said. “Oregon is home and it has been home since I was 5 years old.”

But as a single mom to 12-year-old Chase, who needs round-the-clock medical care, and his neurotypical older sister, she couldn’t provide more than poverty for her children in Oregon’s system. So, Jessica was forced to abandon her natural support system to move to California, where parents like her are allowed to be their disabled child’s paid in-home support worker.

The prevailing argument in Oregon is that Jessica shouldn’t be paid because her caregiving labor — the same labor that our state would happily pay someone else nearly $20 an hour to perform — is her son’s “natural support.” Allowing her to be compensated for it — thus valuing her work and improving her children’s financial safety net — would violate some sacred bond of motherhood, goes this line of thinking.

It's ridiculous. It was clear to everyone how ridiculous it was when COVID-19 made our nearly-impossible caregiver system entirely impossible. While families were drowning in the 24/7 solo care of children who typically require teams of people, the state reluctantly agreed to ask the federal government for a waiver to allow parents of our highest-needs children the option of officially performing that job.

That was put into effect a year ago and the results have been stunning. You can read dozens of stories of the impact of that change in public testimony to the Medicaid Advisory Committee. Parents who hadn’t been able to work since their child’s birth, or onset of symptoms, were suddenly able to afford specialized toys, clothing, medical equipment, enrichment activities and freedom from financial worry. Their children were healthier and happier under the new stability, saving the state untold millions in hospital bills, foster care placements or group home fees.

Kårun and Shari Virtue know exactly how radically a family’s life can change when the prohibition against parents serving as paid support workers no longer applies. Parents of six children, their two youngest had intellectual disabilities that made everyday life very challenging. Kårun is a disabled veteran and Shari could not work due their children's needs and the state's rule against using paid caregivers to go to work. They lived for years below the poverty line on Kårun's veteran's benefits.

"We were unable to do almost anything with them," Kårun wrote recently in a letter to the state. "We could not afford to take them to the movies, go shopping, or go to McDonalds."

But then, one day, the oldest of their two disabled children turned 18. Suddenly, the state was willing to pay Shari to be a personal support worker and, practically overnight, the family was able to provide hobbies, outings and therapies for their two disabled children that they never could afford before.

This is what hundreds of Oregon parents of young children newly experienced in the last year: A government program that actually worked to provide their family the direct, person-centered support and care that their children deserve.

So, of course, they are shutting it down. When the federal public health emergency ends on April 16, so does this special rule. These families will go back to the untenable situation they lived in before the rest of the world learned what it was like to live like us — unable to work, unable to access a proper education for their children, unable to go on simple errands, and constantly terrified of a medical disaster.

The state of Oregon performs a meticulous analysis of the extra work each child on this program requires — then says it will only compensate strangers to perform these highly skilled functions, never parents. No, never the people who are biologically and psychologically most likely to be invested in their children's success, not the people with the most training and experience. Those people — the best-qualified candidates, really — are banned from these jobs.

I don't get it.

If we want a debate about whether providing caregiving to disabled children is a public need, let's have it. If we want to argue that actually filling the caregiver hours that — not one but two — annual state assessments say our children require is too expensive, let's do it.

But if the real problem is that we expect parents — let's be frank: mostly young women — to give up their lives, their health, their sanity and their financial stability for the medical conditions their children happen to have, say it.

If we want them and their disabled children to live in stress and poverty, banned from income, savings or retirement plans, say it.

If we want to perpetuate the trauma, the ableism and the sexism of our current support system, say it.

Medical Motherhood's news round up

Snippets of news and opinion from outlets around the world.

• From Marie Claire: "How You Can Help the People of Ukraine"

(Several charities on this list of 13 organizations helping Ukraine during the conflict aid children. One of them is:)

> 2. The Voices of Children Foundation
>
> Voices of Children is an organization that provides no-cost psychological support to Ukrainian children who are impacted by armed conflicts like this one. Their services include art therapy, traveling psychologists who specialize in trauma, and assistance programs for individual families. You can donate to this essential foundation, and we encourage you to also check out their digital storytelling project, in which Ukrainian children talk about what it's like to grow up in or near a war zone.

• From KTVZ: "Fewer than half of K-12 PE teachers use high-quality instruction with disabled students, OSU study finds"

> "I think the important thing here is that training matters, and there's still a lot of room for improvement when it comes to physical educators serving students with disabilities," said Sam Logan, co-author on the study and an associate professor in

> OSU's College of Public Health and Human Sciences. Logan studies kinesiology and adaptive movement, with a focus on young children with disabilities.
>
> [...]When educators don't employ specific strategies to make PE accessible for students with disabilities, those students often end up sitting on the sidelines, Logan said.
>
> "I don't suspect that it's an individual-level behavior that they're purposefully excluding children with disabilities, but it's a lack of training and confidence in strategies to include children with disabilities," he said.
>
> Through his work with IMPACT, a motor skills fitness program for disabled children at OSU, Logan sees dozens of kids with mobility and other challenges fully engaged in physical activity every week.
>
> "Obviously you have to meet these students with disabilities where they are, but also the opportunities to engage in physical education should be provided," he said. "There's a lot of research about the link between motor development and lifelong physical activity, and the importance of fundamental motor skill development in young children especially. A lot of the skills you learn in elementary school carry throughout life."

• From Oregon Public Broadcasting: "Bill to help Oregon students with disabilities not likely to pass this session"

> Oregon Sen. Sara Gelser Blouin said she received a call from Gov. Kate Brown on Wednesday that a bill she sponsored, Senate Bill 1578, would not pass during the 2022 short legislative session.
>
> The bill, which was supported by both Republicans and Democrats, is aimed at directing the Oregon Department of Education to more quickly investigate and resolve allegations brought by families of students with disabilities who say they are not receiving an adequate public education.

• Finally, Investopedia came out with a new resource for families of those experiencing disability. Check out A Financial Guide for People With Disabilities and Their Families for tips on ABLE Accounts, special needs trusts and social security disability insurance. It’s a good primer for someone who may never have heard of some of these programs, such as new parents.

Medical Motherhood is a weekly newsletter dedicated to the experience of 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.

Follow Medical Motherhood on Facebook, Twitter, TikTok, Spotify, or Instagram or, visit the Medical Motherhood merchandise store to get a T-shirt or mug proclaiming your status as a “medical mama” or “medical papa.”

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.

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