A mom of a disabled child receives $5,000 a month through an Oregon paid caregiver program — but she's scared of what will happen when the payments stop this year

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Emily began receiving $5,000 a month in parent-caregiver payments in 2021 through Medicaid.

Her daughter is disabled and requires round-the-clock care, so she's unable to work outside the home.

The funding is temporary — it's set to end in October. After that, Emily isn't sure what she'll do.

In Silverton, Oregon, Emily and her husband, Michael, take care of their 6-year-old daughter, Juniper, who has multiple disabilities and complex chronic illnesses. Juniper requires specialized, round-the-clock care, which has impacted both parents' ability to work outside the home.

Juniper is predominantly G-tube fed, which means a tube is inserted directly into her stomach to deliver food and nutrients. Additionally, Emily tells Insider, Juniper sometimes has seizures from a common cold or flu that last anywhere from 30 minutes to two hours. The couple's last names have been withheld to protect their privacy.

Because Juniper is immunocompromised, the family have been isolating and taking extra precautions even before the COVID-19 pandemic started. "My spouse and I gave up our careers to care for her," Emily tells Insider. "As an educator and social service provider, I would bring home everything — the flu, respiratory illnesses, and other illnesses that would cause really severe effects that able-bodied kids are able to fight off."

Michael works 20 to 30 hours a week as a horticulturist, working outdoors while earning an average of $1,500 per month. He was unable to accept a full-time position because of Juniper's care needs. Money is very tight, Emily says, but a federal program introduced during the pandemic has offered needed support.

The family exhausted all forms of government aid to make ends meet

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The family has used several forms of government assistance to cover their needs over the years. Emily tells Insider, "We've gone through struggles. We've lived paycheck to paycheck for six years. We've been on SNAP [food stamps]."

Before the couple left their careers, they used the Children's Intensive In-Home Services (CIIS) program, which connects parents of children with disabilities and complex chronic illnesses with caregivers paid by the state. Parents themselves are not eligible to be paid as caregivers for their own children through this program.

"The problem is finding a qualified caregiver who will lovingly commit to our child's care, be vaccinated, wear masks consistently, take COVID-19 seriously, and commit to our family," says Emily. "We went through 10 caregivers in less than two years since they are not paid well."

She says their mortgage alone is $1,100; it eats up most of Michael's $1,500 monthly take-home pay. They receive monthly Social Security disability insurance payments, which help with some bills but aren't enough, and Medicaid covers some of their medical needs.

Relief came during the pandemic

In the past, Emily had to risk bringing home viruses that would trigger Juniper's seizures, or risk a new caregiver bringing in viruses. However, according to the Oregon Office of Developmental Disabilities Services (ODDS), paying parents of minor children with disabilities for their caregiving services was "prohibited" under Medicaid rules before the pandemic.

But in response to the COVID-19 public health emergency, the Centers for Medicare and Medicaid Services allowed parents to receive financial support to care for their vulnerable children and prevent them from contracting the virus.

"ODDS applied for and received approval for a temporary option that allowed parents of children with intellectual and developmental disabilities who have the highest service needs to serve as a paid caregiver," says a representative from ODDS. The funding for the program came from the Biden administration's American Rescue Plan, which became law in March 2021.

Now, through that Medicaid program, the family receive $5,000 a month for Juniper's full-time care. The ODDS office says this temporary program will end once the federal public health emergency expires, which is now scheduled to end on October 13, 2022 (it was previously set to expire in July). Unless the public health emergency is extended, the family will stop receiving monthly payments on October 13.

Emily doesn't know what she'll do when she stops receiving the parent-caregiver checks

While the October extension came as a relief, Emily and her husband are now worried about what will happen to their finances and Juniper's health if Emily needs to return to work.

"My husband and I are pretty concerned," says Emily. "I might have to go back to substitute teaching, which is definitely not safe because now they've pulled the mask mandate. I tried to apply for online positions, but there just aren't any, and they're really competitive."

The National Council on Disability reported in 2017 that people with disabilities are twice as likely to live in poverty as people without disabilities. Indeed, among individuals with disabilities, the poverty rate in 2019 was nearly 26%; for individuals without disabilities, it was 11.4%. So the family is far from alone.

"I don't know what to do," Emily says. "I've got my own invisible disabilities. My husband keeps saying, 'You need to get a job,' but there's a lot of days where I can't get out of bed. I have a lot of pain. We're nervous — a lot of people are really nervous about what'll happen when [the funding] ends."

Leo Aquino, CEPF

Leo Aquino (they/them) is a Spending & Saving Reporter. Before joining the Insider team, they covered relationships, sexual wellness, beauty, fashion and more, always uplifting stories of BIPOC and LGBTQ+ communities. You can reach Leo at laquino@insider.com.…

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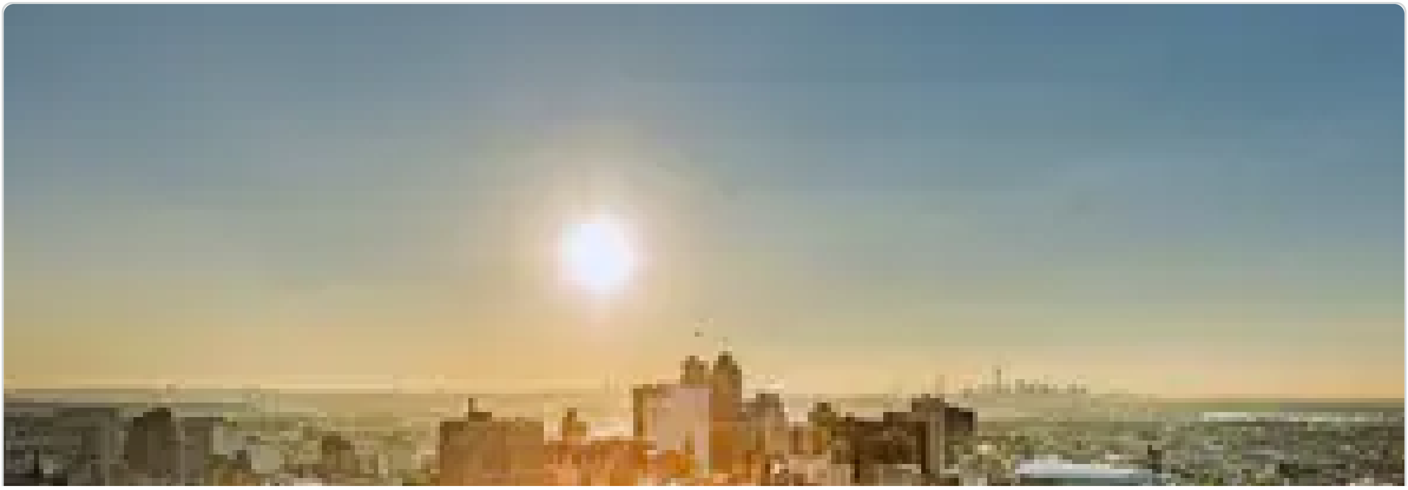

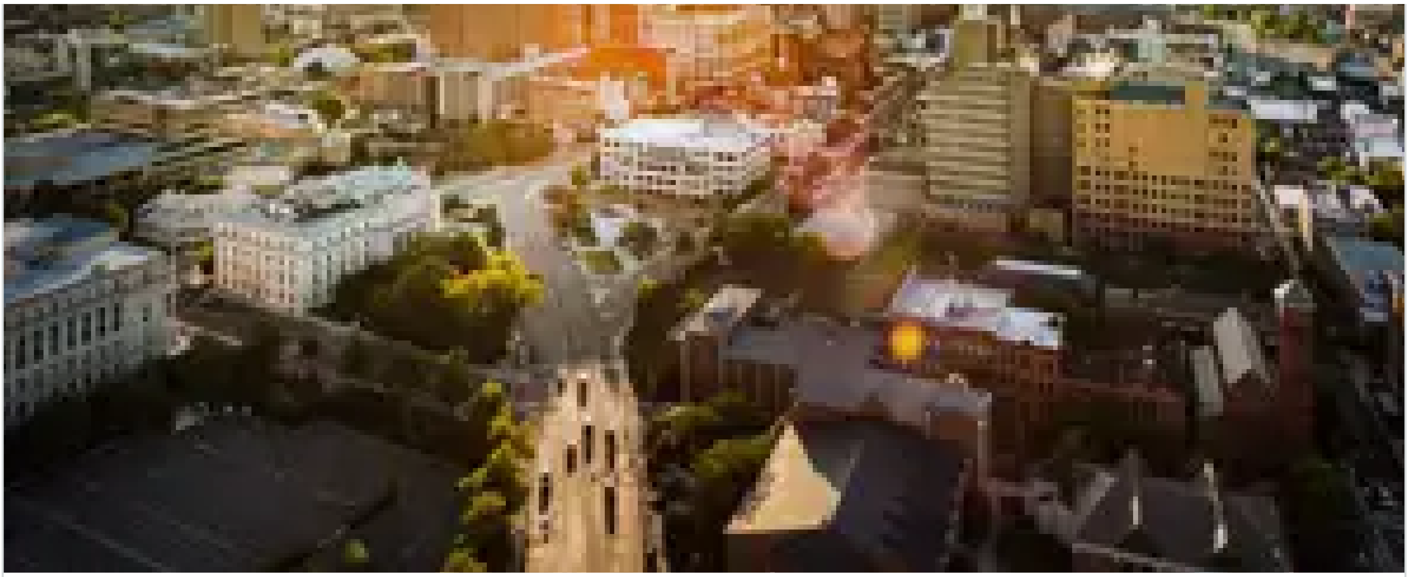

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