



Tress Gehrke's Story

DAVID LEWELLEN

TRESS GEHRKE left her digital marketing job in 2012, confident that she could find another position quickly. She turned out to be wrong. But Oregon Health Plan, the name of her state's Medicaid program, helped stabilize her health.

Health history and employment history intertwine in uncomfortable patterns for Gehrke, who is now 46. She was diagnosed with diabetes in 2005, but as she remembers it, her primary care doctor "threw some medicine at me and said, 'Good luck.'" From then on, diabetes receded into the back of her mind. When she "left a job that was killing me," after several years of long work days and little downtime, in hopes of finding something better, health insurance was not her first consideration.

But she had to think about it as time passed and she dipped into retirement savings while hoping that nothing went wrong with her health — or at least, nothing more. When the Affordable Care Act became law, Oregon expanded its Medicaid program, and Gehrke was eligible in 2014, because she had no income. She harbored a fear that the program would find some reason to turn her down. But instead she got an appointment with a new primary care physician — who

looked at her chart, noticed she had diabetes, found that it was "out of control," and referred her to an endocrinologist.

The specialist and a team of other professionals helped Gehrke to manage her diabetes — including autoshield needles so that she could inject her own insulin for the first time, finding

a way around her severe needle phobia. "There was so much help and education and access to the resources I need," she said.

Gehrke found a job with health insurance in 2016 and went on to a better opportunity in 2017. As a contract employee, she is now not eligible for her employer's benefits and has to pay for an expensive plan through the ACA exchange. But overall, she says she is better off now.

"There is definitely stigma and a lot of misconceptions" in signing up for Medicaid, said Gehrke. "We have a real stigma about asking for help in this country. But it's OK — whether it's long-term help or short-term help. And don't think you know what's going on in another person's life. Medicaid is a safety net for all of us, whether we need it now or not."

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Jake Plue's Story

DAVID LEWELLEN

MEDICAID helps Jake Plue live independently every day, but it also saved his family from financial ruin when he was on life support.

Jake, 37, was born with an intellectual disability and has since been diagnosed with anxiety and other mental health conditions. He lives in Monroe, North Carolina, across the street from his brother, Kevin, and his family. The North Carolina Innovations Waiver pays for caregivers to come to his apartment and coach him on cleaning, cooking, shopping and budgeting. The waiver funds services for those with various intellectual and developmental disabilities who might otherwise have to stay in institutional care.

But reaching this level of stability hasn't been easy. Fourteen years ago, Jake came to live with Kevin and Melinda Plue and their two daughters. "There was no other option but Medicaid," Melinda said. "The disability diagnosis was an absolute lifesaver for him for health care." He lived with the family for two years and in a group home for three years before getting what Melinda called "the golden ticket" - acceptance in the North Carolina Innovations Waiver program that got him out of a group home and into independent living. (Since then, the wait list has grown even longer.) The waiver program paid for his security deposit and some basic furniture, which his family could not have afforded. It also covers caregivers who stop in to check on him on a daily basis. But the Plue family are Jake's primary caregivers, managing his anxiety and

advocating with landlords, social service agencies and employers.

Even though Melinda Plue is a professional disability advocate, caring for Jake is still stressful, she said. "He directs all his anxieties on the people he loves most. ... Caregiving is a difficult job, which is why I need outside help to provide that almost parental role."

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Jake has cycled through several living arrangements, but the current apartment across the street from his family seems to be the right combination of privacy and support. "It's our hope and dream that he can stay there forever," Melinda said. He currently works 15 to 20 hours a week at a pizza restaurant within walking distance of his house and has made friends with some of the other workers.

When Jake developed pneumonia in 2012, followed by acute respiratory distress syndrome, he spent a month in the hospital and more than two weeks on life support. Medicare and Medicaid covered 100 percent of everything; the bills totaled nearly \$1 million. "By the grace of God he survived that," Melinda said, "but we never would have recovered from that if Jake had been on my insurance." She is a social worker; her husband is a high school principal. "We work hard, we're both employed, we have insurance — but there's no way we could have done that. It would have ended us financially."



Cindy Bentley's Story

DAVID LEWELLEN

CINDY BENTLEY is living her best life, thanks in large part to a Medicaid program. Bentley, 60, was born with an intellectual disability due to fetal alcohol syndrome and was badly burned by a caregiver when she was 2 years old. Through her teens and 20s, she lived in foster homes and institutions. Later she joined the workforce, working in a nursing home and in retail and restaurant jobs before becoming executive director of People First Wisconsin, an organization of and for people with disabilities. But she never had a job that provided health insurance.

Medicare and Medicaid have covered Bentley since she was a baby. "I take plenty of medications, because I have seizures," she said. "But I don't think of myself as disabled. I go to work and do what other people do. I can speak for myself." She is also a dedicated Special Olympics participant and advocate.

She was diagnosed with breast cancer in 2012, and Medicare covered "surgery, chemo, radiation, the whole nine yards." But at one point, "I looked at a bill, and it was \$10,000. There's no way I could afford that."

Bentley is able to live independently with the help of IRIS (Include, Respect, I Self-Direct), a Wisconsin Medicaid waiver program that lets people with disabilities hire their own caregivers — a much cheaper arrangement than being

in an institution. In Bentley's case, she has hired a longtime friend to help with cooking, finances, reminding her to take care of her health and job coaching. "I can do certain aspects of the job," she said, "but if I have to write a report, I need help."

"She's the most qualified person in Wisconsin to lead a self-advocacy organization," said

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Lisa Pugh, state director of The Arc Wisconsin, "but she needs accommodations." Bentley, she

said, "shows parents that they can and should have high expectations for kids with intellectual disabilities. They add diversity; they have skills; they can contribute in several ways."

IRIS has survived attempts to reduce or eliminate it in recent years, thanks in part to lobbying by Bentley and other disability advocates. "Cindy is the shining star of what we hope that home and community services can mean in people's lives," Pugh said. "She's been a consistent voice to free our people (from institutions). That's the way she phrases it."

"For me, I'm set. I'm at a certain age where I'll be all right. But kids need what they need to make them grow," Bentley said. "They can treat the person in the community, if Medicare and Medicaid rules change. It's a lot cheaper."



Jill Radkowiec's Story

DAVID LEWELLEN

MEDICAID is meant to give people the health care they need — including middle-class graduate students.

Certainly Jill Radkowiec never thought she would need it when she enrolled more than a decade ago at optometry school at the University of Missouri-St. Louis. She was pursuing a career, and her husband, Daniel, was in his dream job, coaching track at the University of Missouri-Kansas City.

But in 2007, a car accident killed Jill's mother and left her father in need of constant home care. Her husband quit his job, and the health insurance that came with it, to move to St. Louis to care for her father. And four months later, when Radkowiec found she was pregnant, they had a problem. She had basic health care through the student clinic, but it wouldn't cover a pregnancy.

"So much changed in my life," she said, and she didn't know what to do. But a social worker at the clinic "helped me to understand that Medicaid is for pregnant women, and encouraged me not to feel embarrassed." At first, she said, "I was too prideful to accept help, but she said that Medicaid was for people like me, going through a rough time."

So Radkowiec applied for Medicaid and got it, without much trouble, and the program paid

the bills for her pregnancy and the birth of her daughter, now 10. Medicaid also covered her daughter's care when she was an infant, and care for the couple for a time. Her husband later got a part-time job.

"I knew how people might view me. But it would be devastating to have a baby without insurance," she said. And the social worker reassured her, "You're

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going to have a job in two years and you won't need the system anymore. That's what it's for."

Today, Radkowiec is a full-time optometrist at Central Missouri Eye Care Associates in Jefferson City. She helps Medicaid patients, both children with routine vision needs and adults with vision problems caused by eye disease. Since she went to work for the clinic in 2010, she has had the luxury of not worrying about insurance for herself or her family, which now includes three daughters.

She is aware that "some people make judgments based on what insurance you have. But you never know if it's going to be you who needs help."



Jackie Llanaeza and Irene Uligan's Story

DAVID LEWELLEN

BECAUSE MEDICAID helped her mother, Jackie Llanaeza was able to help others. Llanaeza, a nurse in Anchorage, Alaska, spent a lot of time in recent years worrying about the health of her mother, Irene Uligan. Her parents had moved from the Philippines to Alaska in 2003 to be near their daughter and to get First World health care. Her mother got a job as a greeter at Walmart, which included health insurance coverage, and stayed for 10 years.

But in 2013, Irene's health got worse; she suffers from diabetes, hypertension, anxiety, asthma and gastric reflux disease. She had to leave her job and lost the insurance that went with it. She applied for Medicaid and got only limited coverage for her medications for chronic conditions. In the meantime, her daughter paid for outpatient visits and lab work out-of-pocket, looked for discounts and negotiated payment plans with providers. When the Affordable Care Act took effect in 2014, Alaska initially did not expand Medicaid eligibility, and the family could not afford the plans offered on the exchanges.

Finally, in 2015, Alaska expanded its Medicaid coverage, and Irene was eligible. "It was like a domino effect," Jackie said. With the money that was freed up, she was able to help out relatives in the Philippines, and to pay for her daughters' col-

lege tuition. "And if the provider ordered a blood test or imaging, there was no worry or anxiety" about whether the family could pay for it. "Now I'm able to pay bills OK. I'm not struggling.

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When there are a lot of medical bills to pay, stress is high, and it can cause tension in a family."

Irene became a U.S. citizen in 2008, and at age 66, she is now eligible for Medicare. "That's another big relief," Jackie said. Her father, Primo, died in 2006, but she thinks the only reason her mother is still alive is because of Western health care.

"Lots of people out there may qualify for Medicaid, but they don't have family to help them," Jackie Llanaeza said. As a nurse, she was already accustomed to navigating the system more than most. "Maybe they came from other countries, they didn't go to school, they may be afraid."

But "health care is a basic right," she said. "Sick people, once they become well due to quality care, they are well enough to work and be productive. It is great to help them become well rather than neglecting them and letting them become a burden on the community."