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Utah mom: 'I would have died' without PCN, state's low-income health coverage

Health reform • If Utah doesn't expand its Medicaid eligibility, what will happen to those who don't qualify and now rely on the state's Primary Care Network?

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Thirty-six hours.

Without her daily insulin shots, that's about how long Jennifer Ericksen has before she could become unconscious and possibly die.

Once, while uninsured, she tried to ration her insulin. A friend found her passed out on a sofa and called for emergency help.

For the past three years, Ericksen's doctor visits, insulin and other drugs have been covered through Utah's Primary Care Network (PCN), which provides limited preventive health coverage to low-income adults and families who don't qualify for Medicaid or other government-funded programs.

But Ericksen and others like her may soon need another way to get care.

The agreement Utah struck with federal health officials to establish PCN is set to expire at the end of June. And with big changes coming to Medicaid in 2014 because of the Affordable Care Act (ACA), it's not clear whether the program will continue.

"I have a window of maybe a few days, where if I don't get [insulin], I'm dead," said Ericksen, a self-employed singing teacher and performer. "This is not one of these things where I can buck up and get through."

The 35-year-old was diagnosed with an extremely unstable form of Type I diabetes 10 years ago and lost her private insurance after a divorce. She recently remarried, but her new husband is unemployed and is uninsured.



Leah Hogsten | The Salt Lake Tribune Jennifer Ericksen picks up her son Miles from his kindergarten class, Friday May 10, 2013. Ericksen is among some 25,000 people who may lose their limited health care benefits provided through the state's PCN program if Utah fails to expand Medicaid and the U.S. government fails to renew the program. Ericksen has Type I Diabetes and a host of other health problems and could die within about 36 hours if she fails to get her insulin - a drug provided to her through the PCN program.

“Without [PCN] I would have died,” she said, “and I probably will if I don’t have a viable option.”

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‘Some people might be left out’ • The Affordable Care Act will require most Americans to have health insurance — either through public programs or private insurance — next year. It allows for an expansion of Medicaid eligibility so more low-income citizens and legal residents can qualify.

But states, which share the costs with the feds, can decide whether to expand. Utah Gov. Gary Herbert hasn’t said what the state will do.

If Utah opts out, it’s possible that many of the nearly 25,000 adults and children who depend on PCN could end up without access to care.

“It’s one of these transition issues of the ACA,” said Lincoln Nehring, senior health policy analyst for the advocacy group Voices for Utah Children. “Some people might be left out.”

Some PCN enrollees may qualify for federal tax subsidies to help them buy private insurance, but neither state health officials nor advocates for the poor can project how many may get that help.

“Without decent coverage, more people will seek care in inappropriate and more expensive settings like the emergency department. That extra cost goes unpaid and is borne by all of us,” said Matt Slonaker, director of Medicaid policy for the Utah Health Policy Project.

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‘I’m not so overwhelmed’ • PCN’s limited coverage provides doctor visits, prescriptions, dental care, vision care, immunizations and other services. It’s open to adults ages 19 to 64, with or without children, who earn 150 percent of the poverty level — \$17,235 for an individual and \$35,325 annually for a family of four.

Launched in July 2002 by then-Gov. Mike Leavitt, a former insurance executive, PCN’s goal was to provide greater stability for uninsured, low-income Utahns.

“It was viewed as an important innovation at the time,” Leavitt, who later served as secretary of Health and Human Services under President George W. Bush, wrote in an email. “Clearly it has been helpful to people.”

Cindy Rae Bytheway, who has been chronically homeless since her divorce about 13 years ago, said for her, “one of the big things has been to be able to get medications.”

Bytheway, 49, suffers from chronic health problems and needs 12 monthly prescriptions. She gets most of her care through the Fourth Street Clinic in downtown Salt Lake City.

Access to prescriptions “has meant I’m not so overwhelmed,” she said. “That’s taken a lot of pressure off me.”

Stabilizing her health has helped Bytheway move into a transitional housing facility. She’s enrolled in school and hopes to be working soon as a medical assistant.

“It scares me to think that if PCN goes away, that I won’t have even the basic care that I have,” said Bytheway. “I’d like to ask the governor to think about those of us out here in need because if we don’t have the basic care we need, then small things can become big, debilitating things.”

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The outlook for PCN • Utah has asked the Centers for Medicare & Medicaid Services (CMS) for permission to continue the \$8.8 million program — 70 percent of which is paid for by federal funds — but it’s not clear yet what the feds will do. During a discussion Friday, state officials answered questions from CMS.

Leavitt notes that if Utah expands Medicaid, there would no longer be a need for PCN. If the state opts out, however, PCN's future may depend on how well Utah negotiates with federal regulators.

"Based on what we are seeing in other states, CMS will likely require changes to the program," Leavitt said, including perhaps eliminating the 25,000-enrollee cap on PCN enrollment or expanding the program's limited benefits.

Guidelines released by CMS released in April indicate that limited benefit programs like PCN no longer "further the objectives of Medicaid." In a statement, CMS said it continues to discuss options with Utah's health department.

"We aren't foreclosing the possibility of renewal until the [new online insurance] marketplaces are in operation," CMS spokesman Mike Fierberg said.

Utah's Republican-controlled Legislature has emphatically opposed expanding Medicaid, citing concerns over costs and doubt about the federal government's ability to make good on its financial promises in the future.

But advocates such as Nehring argue that a recent state-commissioned analysis shows expansion could save the state as much \$131 million, even as it adds some 123,000 uninsured residents to Medicaid rolls over the next 10 years.

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'Make it a human being game' • The mother of a kindergartner, Ericksen said she'd like to sit with Herbert and explain that without continued medical care, her quality of life will decline. In addition to diabetes, her illnesses include polyglandular autoimmune syndrome, thyroid disease and adrenal disease.

The idea of losing PCN — or access to a PCN-like program — leaves Ericksen terrified.

"I'm not abusing the system," she said. "I'm doing the very best that I can to be self-reliant."

Ericksen hopes state leaders will make a fair and compassionate decision that supports communities.

"For people like me and my family, please consider, if this were your daughter, your niece with a disease like mine, would you want to see them go through it without assistance?" she said. "Help us. Instead of making it a numbers game, make it a human being game."

About PCN, Utah's Primary Care Network

PCN was created to help low-income Utahns who don't qualify for Medicaid coverage.

It's open to adults ages 19 to 64, with or without children, who earn up to 150 percent of the poverty level.

The plan offers limited coverage, which includes doctor visits, prescriptions, dental care, vision care, immunizations and other services.

Enrollees pay an annual \$50 fee and cover the costs of co-payments.

In fiscal 2012, 24,976 Utahns were enrolled. Of those, 13,705 were adults with kids and 11,271 were childless adults.

Source: Utah Department of Health

