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Oregon Faces Scrutiny Over One-Of-A-Kind Hurdles to Children's Health Care

Advocates say low-income children in Oregon deserve the same guarantee of health care that every other state has.

Cainan Molzer (far right), 17, of Medford, poses with his family. | COURTESY JOE MOLZER

by BEN BOTKIN | THE LUND REPORT

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Cainan Molzer of Medford was born with a rare genetic disorder that can thwart the growth of children's bodies and slow the development of their minds.

Now 17, he first started taking growth hormones to combat the condition, called Prader Willi Syndrome, when he was 2 years old. The federally-funded Oregon Health Plan, however, cut off Molzer's coverage for the treatment when he was 16. It did so despite the recommendation of Molzer's doctor, as well as studies attesting to the therapy's benefit. The treatment costs $20,000 a year, and his family, which has belonged to the low-income state program all his life, is in no position to pay it.

The Molzer family's experience illustrates how a cost-cutting measure in the Oregon Health Plan — once a darling of national health reformers — has, for some, become a case study in how states can evade their obligations under federal law.

Federal law requires that state Medicaid programs cover all medically necessary physical, dental and behavioral health care for children of low-income families.

But one state has secured an exemption, or federal waiver, that deviates from the law's requirements: Oregon. Its Medicaid-funded program covers more than 400,000 children — more than 1 in 3 in the state.

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Oregon's unique twist makes it very difficult for kids with certain conditions to obtain treatment.

Now, as the state seeks to renew federal approval of the Oregon Health Plan's specialized waiver from Medicaid requirements, the state's alone-in-the-nation approach toward children's benefits has become a target for parents, providers and advocates. National advocates have also put a public spotlight on Oregon.

"Any kid on Medicaid should get whatever medical test they need and if those find a need, Medicaid has to cover (it)," said Paul Terdal, a father who for a decade has fought to ensure the state program covers the needs of autistic children, in an interview.

In a recent letter to the state from the Oregon Center for Children and Youth with Special Health Needs, a state public health agency, two pediatric physicians called the state's approach "fundamentally racist" and "unacceptable."

Joan Alker, a researcher for the Center for Children and Families at Georgetown University, said: "Why is the state trying to limit benefits for children when there isn't any particular rationale to do that?"

Oregon's stance on children's care has also sparked concerns for state and federal employees, according to Oregon Health Authority emails obtained by The Lund Report.

In an email last month, an Oregon Health Authority analyst recounted her interaction with a federal Medicaid official, saying the official's exact words were, "I don't know how Oregon got away with this for so long."

State officials, however, argue that Oregon's approach is more transparent than other states. "There's some confusion out there around what the (state) waiver is," said Jeremy Vandehey, the state's health policy director, at a recent meeting of the Oregon Health Policy Board, the appointed board that oversees his agency.

State officials maintain that Oregon's system doesn't necessarily block kids from receiving benefits. That's because families can appeal denials of care to the Oregon Health Authority. And the state's network of Medicaid insurers, called coordinated care organizations, can still approve care in individual cases.

Maze Of Red Tape

But the reality for families and children is more complicated.

Cainan's father, Joe Molzer, a computer repair technician, said their struggle has dragged out across the last 15 months through at least five failed attempts to get coverage that include other strategies, such as attempting to qualify for treatment through different drug manufacturers. Frustrated, he cites medical studies that show the hormone treatment has health benefits for people with Prader Willi Syndrome into adulthood, including with energy and cognition.

Since going off growth hormones, the father said, his son's energy is lower and it's harder to concentrate. It's also forced him to go on other, less effective medications.

These new challenges come as his son is at a crucial stage in his life. A junior at Logos Charter School in Medford, he wants to be a primatologist in the mold of Jane Goodall. At times, he stays up until 11 p.m. to complete his homework and is a straight-A student. He's also active in his community and volunteers at Crater Rock Museum, which has rock and fossil exhibits.

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"When I think about the people that are running OHA and the state in general, they would run on a platform of: 'Look, we are a compassionate state; we want to take care of our people,'" the father said. "Why are we not worried about the people that have been dealing with this for months or years?"

'Below The Line'

Members of the Oregon Health Plan, get their claims for medical service approved — or denied — based largely upon a number.

Care under the Oregon Health Plan is authorized based upon what's called the "prioritized list of health services." The lengthy list ranks treatments based on factors such as the condition's impact on a person's health and the effectiveness of a treatment.

For example, medical care for pregnant women is at the top of the list. Experimental treatments with a low chance of success are lower on the list.

The list stems from 1993 reforms that sought to expand coverage to the working poor by rationing care to focus on the most cost-effective treatments. That required a special waiver from Medicaid law, and every five years it must win federal approval to be renewed.

As part of its program, Oregon updates the prioritized list each year. A 13-member Health Evidence Review Commission hears testimony from providers, patients and others to rank new treatments or move existing treatments up or down the list when new information comes in.

From there, it sets the line — a numerical point — for what conditions and treatments qualify for coverage based on available funding.

For 2021, the line was set at 471.

Claims for treatments numbered 1 to 471 can qualify. But anything "below the line" — 472 and higher — usually faces a denial of coverage. When the system works, a cosmetic surgeon will tell an average-looking Oregonian that their Oregon Health Plan coverage won't cover a taxpayer-funded nose job because it's well below the line for coverage.

When the system fails, children fall through the cracks.

When Children's Needs Don't Make The Cut

Molzer's claims paperwork demonstrates the role that Oregon's prioritized list system plays in whether children get the treatment they need.

The denial letter from the CCO, Jackson Care Connect, classified his rare condition as a "human growth hormone deficiency."

"The Oregon Health Plan (OHP) has a list of medical conditions called the Prioritized List," the Nov. 2, 2021 denial letter says. "OHP only pays to treat a condition if it is on this list between line 1 and 471. Your condition, adult growth hormone deficiency, is on line 652. This means it is not covered by the OHP because it is 'below the line' of coverage."

Requests for services that are outside the prioritized list are reviewed on a case-by-case basis, said Becca Thomsen, a spokesperson for CareOregon, which provides Oregon Health Plan insurance benefits for Jackson Care Connect and two other coordinated care organizations in the state, Columbia Pacific CCO and Health Share of Oregon.

“As a health plan, we use the state’s prioritized list as floor — not ceiling — for determining services for members,” Thomsen said in an email. “When we receive requests for services outside of what the state covers based on their prioritized list, we review information on a case-by-case basis and make a determination of eligibility. If services are denied, members can appeal directly to our organization for additional review.”

Nearly a year and a half after the first denial, Cainan is now taking three medications he wasn’t taking 15 years ago and that don’t work as well. The Molzer family’s case continues to drag on with no end in sight.

“It’s not friendly or fun,” his father said.

Oregon Stands Alone

In 1967, as part of President Lyndon B. Johnson’s New Deal, Congress passed the children’s health portion of Medicaid. It’s called the Early and Periodic Screening, Diagnosis, and Treatment program, or EPSDT. It requires all Medicaid-eligible children under 21 receive access to periodic physical, dental, vision and hearing checkups.

Significantly, the law also requires that all states provide any medically necessary health care for children, even if it’s for a service that adults on Medicaid would be ineligible to receive.

As part of Oregon’s waiver, however, the federal Centers for Medicare & Medicaid Services agency allows the state to apply its prioritized list of services to restrict the benefits for children mandated by federal law.

Oregon is the only state to restrict federal children’s health benefits in this way.

While the federal Medicaid program picks up most of the costs for low-income care in Oregon, any significant increase in children’s health benefits could cost the state budget tens of millions of dollars or more.

Renewal Period Triggers Criticisms

The Oregon Health Authority is now preparing to negotiate its new Medicaid plan with the federal Centers for Medicare & Medicaid Services.

The state’s proposed Medicaid waiver renewal will run from 2022 to 2027. The waiver system is designed to let states experiment with new ways to provide services. Oregon employs the waiver to use coordinated care organizations to manage care.

The renewal’s public comment period, which ended Jan. 7, tapped into longstanding concerns among advocates, patients and providers.

Advocates for people with disabilities have long viewed Oregon’s rationing system with suspicion, saying purported measures of cost-effectiveness are inherently unfair to their clients.

Disability Rights Oregon took the lead in penning a letter to the Oregon Health Authority as part of its public comments on the Medicaid waiver. More than 50 other groups have signed onto the letter, which asks Oregon to end the waiver’s restriction, saying Oregon “too often fails to give children the care they need.”

The Epilepsy Foundation and its Oregon chapter also voiced concerns about the practice’s impact on the 5,400 children in the state with epilepsy. The state’s coverage of anti-seizure medications is not enough to meet all their needs, the letter said.

"They frequently have related developmental disabilities or mental health needs, yet the current (children's health) waiver excludes treatment for disorders common in children with developmental disabilities, including selective mutism, conduct and impulse disorders, deformities of the upper body and limbs, sleep disorders, and pica," the letter said, calling the restriction a "step in the wrong direction."

'Fundamentally Racist Policy'

In another letter commenting on the state's waiver request, pediatric physicians at Oregon Health & Science University called the federal children's health benefit a "critical protection (that) must be part of the OHP."

The letter is signed by Dr. Benjamin Hoffman of OHSU's Doernbecher Children's Hospital and Dr. Dana A. Braner, physician-in-chief of Doernbecher Children's Hospital. They sent the letter on behalf of the Oregon Center for Children and Youth with Special Health Needs, a state public health agency.

It said children in low-income families have higher rates of asthma, heart conditions, hearing problems, digestive disorders and elevated blood levels, among other issues.

"EPSDT serves as the safety net for children's health, and the backbone of the Medicaid program for children," the physicians wrote. "Waiving that provision fundamentally discriminates against children. Further, as children of color are disproportionately served by OHP, the … (children's health) waiver is a fundamentally racist policy. As equity is a core tenet of OHA's operational principles, this is unacceptable. Children are not little adults, and their health needs must be considered separately from the adult health system."

In an interview with The Lund Report, Hoffman, the pediatrician, said, "There are some things that exist below the line that are pretty big deals."

While the most severe form of acne can get coverage, Hoffman said, some of the most prevalent forms of acne that need treatment fall below the line.

"That can have a significant impact on self-esteem," he said.

For seasonal hay fever allergies, pediatricians also face obstacles. Antihistamines for seasonal hay fever that don't cause sedation, such as Claritin, are not covered through Medicaid. Only antihistamines that cause drowsiness are covered. That creates challenges for pediatricians and families trying to balance their child's allergy with the need for their child to be alert for activities such as school.

"We know that the intention of our wonderful Oregon Health Authority and the people behind the original creation of the plan and the waiver was to make Oregon the best," said Julie Scholz, executive director of the Oregon Pediatric Society. "We want to keep leading the pack and not drag behind."

National Experts Weigh In

Advocates and experts on the national scene echo the concerns. The federal children's health benefit that Oregon restricts "is universally acknowledged as being essential to meeting the needs of low-income children," said Jane Perkins, legal director of the National Health Law Program, a North Carolina-based organization that advocates for health and civil rights for marginalized people in the health care system.

"Over the years, Congress has done nothing but make it clearer and clearer and clearer to states that this program is an essential one," she added. "So to have a state waiving this coverage is … a concern."

Joan Alker, a longtime Medicaid policy researcher, is executive director and research professor at the Center for Children and Families at Georgetown University McCourt School of Public Policy. The prominent think tank has been spotlighting the Oregon waiver renewal on its website.

“Oregon is the only state in the country that has this broad waiver of (the federal children’s health requirement), and there’s simply no good reason at all for it, and it needs to go away,” Alker said.

As for the argument that families can file an appeal with the health authority, she said, that’s not a solution.

“That’s just added bureaucratic red tape on low income families,” Alker said.

Oregon Health Authority Responds

In a statement, Vandehey, the Oregon Health Authority’s director of health policy and analytics said Oregon is “committed to providing equitable and comprehensive treatments and services to children and adolescents on the Oregon Health Plan.”

As for the criticisms, Vandehey added, “We take such concerns very seriously and have researched these issues at the staff and Health Evidence Review Commission levels. OHA is addressing several of the concerns using our HERC process, which is public and accountable.”

The health authority also works closely with the state’s coordinated care organizations to make sure they offer well child checks, preventative services and other screenings, Vandehey said.

Health authority officials also contend that the prioritized list adds more transparency to the Oregon Health Plan so people can see what’s covered and what isn’t, and have an avenue to get treatments added above the line.

Vandehey said it’s important to recognize, “there’s a transparency element of this, even if it means some things aren’t covered. … That often doesn’t exist in other states.”

Vandehey also said the word “waiver” is a misnomer. “What we’ve been committed to as a state and as an agency is to providing comprehensive treatment to both children and adults on the Oregon Health Plan.”

He said the state has been working to improve access. For example, over-the-counter drugs for children were being denied, and that needed to be clarified for providers rather than changing the prioritized list, Vandehey said.

Vandehey said the state’s Medicaid waiver application will be submitted in February. At that point, Vandehey said, he expects to hear feedback from CMS and negotiate with the agency on the overall waiver application. That process will last several months.

“I won’t be surprised if we get questions not just on this, but you know, on a variety of things about how we’re running the Oregon Health Plan,” Vandehey said.

Health Authority Analyst Flags ‘Deficits’

It’s not just people outside the agency raising questions.

Teri McClain, an Oregon Health Authority Medicaid policy analyst, highlighted problems with the state’s system in a Dec. 1, 2021 email thread that included other health authority staff and the Oregon Pediatric Society.

McClain recounted her interaction with Susan Ruiz, who oversees children’s oral health for the federal Medicaid program for the Pacific Northwest region.

“All states must follow ALL requirements of the program,” McClain wrote in the email. “Susan’s exact words were, ‘I don’t know how Oregon got away with this for so long.'"

McClain went on to describe the "deficits for Oregon."

"Leadership here are sticking to their current practices of only approving (children's health) services that are above the HERC List Line," McClain said in the email.

McClain added that due to the "misunderstanding about Oregon's waiver rights," the health authority "is denying treatment to EPSDT-eligible children that need services which are below the line."

McLain wrote that she believes federal officials will make Oregon rewrite its waiver so children's benefits are consistent with federal law: "Basically, they are handling it on their end."

In an earlier Sept. 16 email to CMS, McClain wrote that "Limiting (children's health) benefits may save money in the short term, but it is truly nonsensical when it comes to long term health outcomes."

She also stressed the need to educate people within her agency.

"I am hoping that this will be spelled out really well during the next (federal) review of the waiver … because right now, trying to teach these folks about EPSDT is like trying to convince them that Big Foot exists," she wrote.

A spokesperson for the federal agency declined to comment.

Orthodontic Care Denied

Orthodontic care illustrates the problems in how Oregon's waiver works, and how the state recently tried to start fixing it.

Christian Moller-Anderson, executive director of A Smile For Kids, said braces — even for children with severely crooked teeth deformities — often fall below the line for coverage.

His Oregon nonprofit organization works with orthodontists to help children obtain braces for severe cases that go well beyond cosmetic improvement, such as teeth growing in a crooked angles, crowding the mouth, or interfering with chewing, eating and overall oral health.

It's a service that will be below the line for at least another year. Orthodontic braces are ranked at line 618.

Currently, coverage above the line only covers craniofacial anomalies like cleft lips or cleft palates.

Moller-Anderson said orthodontic care is crucial for a child's overall health and braces set them up for success in school and work.

Children with a severe need for orthodontic work face problems such as trouble "eating, speaking, sleeping, smiling and normal social relating, Moller-Anderson told the Oregon Health Policy Board last week.

"It can affect both the physical and emotional development of children," Moller-Anderson said. "Its impact can be felt over a lifetime and the loss of achievements and education, possibilities in employment and a reduction in overall health and wellness including mental health."

He urged officials to reconsider their request to seek the EPSDT waiver as part of the state's Medicaid application.

In response to such concerns, Oregon Health Authority officials are recommending that the commission move the ranking of orthodontic care higher up the prioritized list so children can qualify, November's Value-based subcommittee meeting records from the Health Evidence Review Commission show. But it won't be quick. State officials estimate that the work to set systems up for orthodontic work won't be in place until at least January 2023, records show. That includes analysis work to determine any rate changes for coordinated care organizations and dental care organizations.

The current below-the-line system for orthodontic work shows how the effect of the state's restriction is difficult to quantify. A family on the Oregon Health Plan will often be told by the orthodontist that Medicaid doesn't cover braces, Moller-Anderson said. At that point, the families often give up and no claim is filed.

Dr. Cole Johnson, a Salem orthodontist, works with A Smile For Kids and provides charity care at a discounted rate for families, including children in foster care.

"It's tough," Johnson said. "Kids, they're like they want some victory in their life."

COURTESY PHOTO

CiAna and her mother, Sheena Powell.

One family he helped waited years for braces.

Sheena Powell of Salem was unable to get braces for her daughter through Medicaid. One provider pegged the cost at $8,000 to $10,000, which was out of reach.

Powell said her daughter, CiAna, 17, needed braces in middle school. Her teeth were gapped together and pushed together up front. Four teeth needed to be pulled because her mouth is small.

It wasn't until the teenager connected with Johnson's program that her daughter got braces last year.

She was 16 years old.

"It does a number on a person not just, of course, about straightening your teeth, but mentally and it has her looking at herself differently," Powell said.

The teenager said her confidence is up now since she got braces. In the past, she wanted to cover her mouth. Class presentations are easier too.

She encourages others in her situation to not give up.

"Take it day by day," she said. "It took a lot for me to understand that."

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