



Austin Jenkins/Northwest News Network

Lindsey Topping-Schuetz holds her nearly 3-year-old son Owen who qualifies for developmental disabilities services but has been denied them because of a lack of state funding.

Many developmentally disabled Washingtonians are denied services

By AUSTIN JENKINS
Northwest News Network

Three years ago, Lindsey Topping-Schuetz became a first-time mother when her son Owen was born. He was six weeks early and went immediately to the neonatal intensive care unit, where he spent the next 103 days.

But that was just the beginning of Owen's challenges and the family's stresses. Owen was born with two rare chromosomal abnormalities, including Cri-du-chat syndrome, also known as "cat's cry" syndrome.

In the short-term, Owen required around-the-clock care. He came home from the hospital attached to monitors and a feeding tube.

In the long term, he faced a lifetime of physical and cognitive limitations that would likely require intensive care and therapies. He might never walk or talk.

During Owen's first year at home, Topping-Schuetz requested services through Washington's Developmental Disabilities Administration (DDA). In 2018, when Owen was 2 years old, he was evaluated and found to meet DDA eligibility. In fact, Owen was determined to have such acute needs that he technically qualifies for institutional-level care, which can be an entitlement in Washington.

But there was never any question that his family wanted to care for him at home. Subsequently, a case manager determined that Owen and his family would benefit from services such as in-home nursing care, respite care and specialized medical equipment and supplies.

Then came the surprise: even though Owen was qualified, there were no paid services available because the Medicaid waiver program they were applying for, known as Basic Plus,

was capped. "I had no idea that you could have a child that was so significantly disabled with a black-and-white diagnosis and for the state to not do more to provide support," said Topping-Schuetz.

Topping-Schuetz and her family were not alone. The state of Washington has more than 13,000 developmentally disabled people on its "No Paid Services Caseload." About half of them are children. They are individuals, like Owen, who meet the criteria for state services but don't get them because the waivers are not an entitlement. The caseload also includes people who

viduals that are coming through our doors," Perez said.

It's not a new problem. Since at least the 1990s, demand for community-based DDA services in Washington has exceeded funding. After the U.S. Supreme Court ruled in 1999 that people with developmental disabilities should be served in the community, in the least restrictive environment, lawsuits were filed against the state, including by the Arc of Washington, an advocacy group. That lawsuit was settled in 2007, with a promise by the state to increase funding for community-based supports.

entitlement for those who meet eligibility requirements, ranks second in the nation.

"After a while, you get sort of angry because you see how state government supports other people and the system for people with developmental disabilities just stays," said Sue Elliott, the former head of DDA who is now the executive director of the Arc of Washington.

After Owen was born, Topping-Schuetz quit her job at Weyerhaeuser to stay home with him. Her husband, Ben, works for the city of Tacoma. In many ways, Topping-Schuetz said, they're lucky. The family has good health insurance. They have extended family nearby. Still, there have been financial challenges. And attending to Owen's special needs can feel overwhelming at times.

"It's exhausting. I'm tired. It's a 24/7 gig," Topping-Schuetz said.

Caring for Owen requires her to wear several hats — she's his mother, his nurse and his therapist.

"We didn't want or expect that the state would just take care of us, but we had hoped that they would support us to provide a better and best life for Owen, so I go between mad and sad and scared," Topping-Schuetz said.

It's unclear how long the family might have to wait for services. This past June, the family's DDA case manager wrote in an email to them: "Everyone who has been requesting the Basic Plus has been getting denied, unfortunately."

In the meantime, Owen will turn 3 this month and begin a developmental preschool through the Puyallup School District. He'll go for two-and-a-half hours a day, four times a week. It will be his mother's first regular break from being his full-time caregiver since he left the neonatal intensive care unit as an infant.

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have not requested or have declined services, according to DDA.

"We have a certain number of waivers that are funded and that's what we have to stay within," said Evelyn Perez, the assistant secretary who oversees the DDA at the Washington Department of Social and Health Services.

Perez recently told a panel of state lawmakers that demand for these services is growing by more than 10% a year.

"We don't come even close to the amount of indi-



Bebeto Matthews/AP Photo

Flavored vaping solutions are shown in a window display at a vape and smoke shop in New York. Washington is joining several other states in banning the sale of flavored vaping products amid concern over the mysterious lung illness that has sickened hundreds of people and killed more than a dozen across the country.

Washington state issues flavored vaping ban

By GENE JOHNSON
Associated Press

Washington on Friday joined several other states in banning the sale of flavored vaping products amid concern over the mysterious lung illness that has sickened hundreds of people and killed about a dozen across the country.

Gov. Jay Inslee issued an executive order asking the Department of Health to issue the emergency rule at its next meeting, scheduled for Oct. 9. The ban will apply to products containing nicotine as well as the cannabis extract THC. Inslee said the flavored products especially appeal to youth.

"We need to act for the public health of our people," said Inslee, a Democrat. "I'm confident this executive order will save lives."

The ban is necessary because even if a vaping ingredient or compound were conclusively linked to the illnesses, the state would have no way to identify which products contain the substance so they could be removed from store shelves, Inslee said.

President Donald Trump has said he plans to ban flavored vaping products nationally. New York, Michigan and Rhode Island are among the states

that have announced at least temporary bans, while officials in Oregon and California have urged consumers to stop using them. Massachusetts has gone the farthest, issuing a four-month ban on all vaping products — flavored or not.

Inslee also ordered health officials to work with the state's Liquor and Cannabis Board to develop legislation to increase oversight of vapor products, including requiring the disclosure of ingredients and increasing spending on anti-vaping campaigns aimed at teens.

More than 500 cases of the illness have been reported across the U.S. The Centers for Disease Control and Prevention is investigating but has not yet identified a common product or ingredient as the culprit.

This week, Juul Labs, the San Francisco-based company that controls about 70% of the vaping market, announced it is replacing its CEO and will no longer run TV, print or digital advertisements for its e-cigarettes. The company also promised not to lobby against a proposed U.S. ban on flavors.

Symptoms of the vaping illness can include chest pain, nausea, vomiting, diarrhea, fatigue, fever and weight loss.

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