

Cost of autism treatment spurs Nebraska HHS to reverse stance, oppose Medicaid coverage of it

By Martha Stoddard / World-Herald Bureau | Posted: Thursday, September 25, 2014 1:00 am



LINCOLN — Nebraska Medicaid officials have done an about-face on paying for highly effective but potentially costly children’s autism treatment.

A few months ago, the Department of Health and Human Services was seeking federal permission for Medicaid to cover the treatment.

Department attorneys filed a motion in court on June 23 saying HHS was “cautiously optimistic” about getting such approval.

But earlier this month, Kerry Winterer, the department’s CEO, sent a letter to federal officials questioning their authority to issue a directive requiring Medicaid coverage of the treatment.

He said this week that the state may pursue a legal challenge to the directive.

“What happens next depends on the response to the letter,” Winterer said.

The state reversal comes as advocates, providers and parents are looking forward to better private insurance coverage for autism treatment.

Earlier this year, Nebraska lawmakers mandated that some insurance plans cover autism diagnosis and treatment for children.

The new law is expected to benefit about 1,000 Nebraska children.

But it does not apply to all private insurance, and it does not apply to Medicaid, which covers health care costs for about 30 percent of Nebraska children.

Nebraska’s Medicaid reversal dismayed Cathy Martinez, a Lincoln mother of an autistic son and state advocacy chairwoman for Autism Speaks.

“Somebody’s going to have to help. There’s an epidemic,” she said. “We can’t bury our heads in the sand forever.”

Winterer’s recent letter addressed a July 7 bulletin from the Centers for Medicare and Medicaid Services that spelled out that Medicaid must pay for medically necessary services for children with autism.

It did not specifically require coverage of applied behavior analysis, a treatment method that has proved effective in helping autistic children learn to function better in the world. But it describes applied behavior analysis as one treatment method for autism.

Dan Unumb, executive director of the Autism Speaks Legal Resource Center, argues that the directive encompasses the treatment as part of requiring a broad spectrum of services.

Applied behavior analysis uses positive reinforcement and other techniques to change behavior.

It can eliminate symptoms of autism for some children and dramatically reduce them in others. But, depending on a child’s needs, it can be very intensive and expensive.

Martinez credits the treatment with helping her severely disabled son learn to read, write, dress and groom himself. It allowed him to be toilet trained and made him willing to eat a broader range of vegetables and proteins.

Now 11, he is in a regular classroom 70 percent of the day and has minimal behavior problems at school, she said.

He does not speak but can communicate by typing on a computer, which reduces the potential for frustration.

All of those achievements mean he will be more independent and require less state support as an adult.

But Martinez and her husband had to pay \$62,000 a year for five years of the treatment, refinancing their house, maxing out their credit and eventually declaring bankruptcy.

He now gets less intensive help paid for through a special Medicaid program for people with developmental disabilities.

Costs like those the Martinez family encountered are a key reason Winterer argues that the federal government cannot require coverage without going through a formal rule-making process.

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HHS officials calculate that the coverage could cost the state more than \$50 million a year. That's based on providing \$50,000 worth of treatment to an estimated 2,305 children per year. Medicaid is jointly funded by the federal government and the state.

Winterer said the estimate was based on the best numbers available, including an actuarial study done in 2011.

But Wayne Fisher, director of the Center for Autism Spectrum Disorders at the Munroe-Meyer Institute in Omaha, and Michael Wasmer with Autism Speaks, call the department's cost figure a "gross overestimate."

HHS used federal data showing that 1 in 68 children have an autism spectrum disorder in calculating how many children Nebraska Medicaid would have to cover.

However, Fisher said that autism spectrum disorder includes a wide range of symptoms and that only a small proportion of children with the disorder need the most intensive treatment. Older children generally need less treatment.

In addition, states that require private health insurance coverage of applied behavior analysis have found that half or less seek treatment.

A Missouri study of that state's mandate found that insurance claims for applied behavior analysis treatment averaged \$1,704 annually in 2013.

Until recent weeks, state Medicaid officials had been forging ahead with plans to implement the federal directive, when they reversed course citing costs and legal concerns.

The directive appeared to clear the way for settling a lawsuit that claimed Nebraska Medicaid illegally denies coverage for children with severe behavioral and mental health problems.

Nebraska Appleseed Center for Law in the Public Interest and the National Health Law Program filed the suit in 2012 in Lancaster County District Court.

It listed two boys as plaintiffs. One, identified only as K.D., was described as a 4-year-old diagnosed with autism and other conditions. The suit said a psychologist had recommended applied behavior analysis for him but Medicaid had denied coverage.

In May, attorneys for the boys and for HHS filed a joint motion asking for the case to be put on hold because HHS was seeking approval from federal Medicaid officials to cover the treatment.

Neither an HHS spokeswoman nor an Appleseed attorney said they could comment on the pending litigation, including how it fits with the department's current position on covering autism treatment.

Contact the writer: 402-473-9583, martha.stoddard@owh.com

UNMC hosts session on state insurance mandate

Nebraska has a new law mandating private insurance coverage of autism treatment, including up to 25 hours a week of an intensive treatment called applied behavior analysis.

The mandate takes effect for policies issued in 2015.

The law does not apply to plans sold through the new health insurance marketplaces and some other plans. Self-funded plans are exempt under federal law.

Information about the new law will be presented from 9 to 11:30 a.m. today at the University of Nebraska Medical Center's Durham Research Center Auditorium, 45th Street and Dewey Avenue.

People who are unable to attend in person can live-stream the event or watch a recorded version online at a later time.

For more information, go to <http://www.unmc.edu/mmi/news/neautismmeeting.html>.