

Legislature backs plan to insure kids with autism

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Families in Arizona with autistic children are set to be among the first in the country to have expensive cutting-edge autism therapy covered by private health- and disability-insurance plans.

After weeks of grass-roots lobbying by parents and emotional committee testimony, lawmakers have approved one of the first insurance mandates of its kind in the nation.

The bill blocks insurance companies from denying coverage for the diagnosis and treatment of autism, including coverage for behavioral therapy, which can cost tens of thousands of dollars a year.

The Senate on Monday passed the bill, which was approved by the House last week. It now awaits the governor's signature.

If signed into law, it is expected to result in greater access in Arizona to behavioral therapy, which experts say can have dramatic impacts on the lives of autistic children.

Elizabeth Emken, vice president for government relations with the national non-profit Autism Speaks, said the law would put Arizona at the forefront of a national trend. Three other state legislatures have passed similar laws requiring insurers to cover behavioral therapy, Emken said.

"These are evidence-based, medically necessary treatments that should have been covered a long time ago," said Emken, whose teenage son has autism.

"Autism is treatable," she added, echoing the mantra repeated by advocates at the state Capitol for weeks.

Nineteen other states and the District of Columbia have laws that require coverage of some autism treatment.

Giving a chance to treat

The prevalence of autism has skyrocketed over the past two decades. About one in 150 children nationwide has some form of the disorder, according to the Centers for Disease Control and Prevention.

Autism was long thought to be untreatable, a life sentence for children who sometimes never

learned to speak or care for themselves and often ended up institutionalized. As such, many insurance companies have denied coverage for autism, even therapies that would be covered under a different diagnosis.

But advancements in therapy have been shown to significantly improve the lives of autistic children.

Experts say that many children who get Applied Behavior Analysis, a type of intensive behavioral therapy to improve speech and social skills and reduce disruptive behavior, are able to improve enough to function in regular classrooms.

Some even lose their autism diagnosis completely and become indistinguishable from the peers, supporters say.

Still, without insurance coverage, many families have not been able to afford the treatment. Others with private insurance have turned to limited state programs or gone deep into debt to pay for the treatment.

Char Ugol of Scottsdale said two years' worth of therapy for her 4-year-old son, Steven, has cost more than \$118,000. The family has paid about \$45,000 out of pocket but was lucky to be selected for a pilot program that covered the cost of the rest of the therapy.

Last week, she handed out colored copies of a drawing Steven did of the Arizona flag, a testament to how much therapy has improved his abilities, she said.

Ugol began writing to lawmakers last year pushing for the bill, which was named Steven's Law after her son. She has since been among a contingent of parents who held a candlelight vigil at the Capitol, have flooded committee hearings and walked door to door in lawmakers' districts pushing for the bill. They were helped by former insurance-company lobbyist Gretchen Jacobs, who has become an insider-advocate on autism issues after her daughter was diagnosed with the condition.

"People came with their kids, and it put a face on the issue," Ugol said.

A long journey to change

After Senate Bill 1263, the initial bill sponsored by Democratic Sen. Amanda Aguirre of Tucson, began gaining steam, insurance-industry representatives sat down with lawmakers to craft a compromise, which was amended onto House Bill 2847 sponsored by Rep. Bill Konopnicki. Initially, insurers and employer groups opposed the mandate.

In return for insurers signing off on the bill, advocacy groups agreed to a moratorium on any further insurance-coverage requirements for autism until 2011.

"They sat down and were honorable and reasonable, and we appreciate that they worked with us and made it easier for everyone involved," Jacobs said.

But Regena Frieden, spokeswoman from Blue Cross Blue Shield of Arizona, which participated in the compromise agreement, said her company still opposes the bill.

"We remain opposed to the Legislature designing our customers' health-benefit plans," Frieden said in an e-mail.

Still, she said the company was glad advocates worked with them to resolve concerns the company had with the bill.

Under the proposal, benefits would be capped at \$50,000 a year for behavioral therapy for children up to age 9 and \$25,000 a year for children ages 9 to 16. It covers medically necessary behavioral therapy for children with autistic disorder, Asperger's syndrome or pervasive developmental disorder.

It does not apply to individual insurance policies or the policies of small businesses with fewer than 50 employees.

Lisa Glow, chief executive officer for Southwest Autism Research & Resource Center, said treatment centers are already struggling to meet demand for therapy because of the growing number of children diagnosed with autism.

But she said she believes once insurance companies reimburse for treatment, it will allow groups like hers to be able to recruit more high-quality therapists to the state.

Opponents to the bill blasted the proposal for its potential to raise health-insurance costs for everyone.

Others raised concerns that the coverage for autistic children came at the expense of coverage for other groups.

A bill to require insurers to cover mental-health treatment at the same rate as other medical treatments has failed to go anywhere for more than a decade.

"This is nothing more than a mandate," Rep. Andy Tobin, R- Phoenix, said when the bill was approved in the House. "One group has won out over many others."