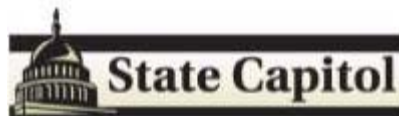


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# Bill requiring insurers to cover autism in the works

## Legislators hear experts' testimony



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**ATTORNEY:** Memo on WVNET's future violates state code. **Page 6-A.**

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**BY DAVID BEARD**

The Dominion Post

CHARLESTON — Legislators plan to once again discuss a bill to require health insurance companies to cover treatment for people with autism spectrum disorder (ASD).

Subcommittee members of the Joint Standing Committee on the Judiciary heard this week from a number of experts on the costs and benefits of covering ASD.

The problems are manifold, said Jeff Sell, vice president of the Autism Society. Among them, treatment for autism itself isn't covered because companies take advantage of legal loopholes.

direct and indirect medical and non-medical — for children who recover typical function at \$605,130. For children who receive no treatment, it's \$3.4 million. The lifetime per capita societal cost of autism is \$3.7 million.

The lifetime societal cost in West Virginia for all children with autism is \$1.15 billion, based on only 603 people who might be covered by insurance, he said.

That figure might be low. Nationally, the experts said, about 1 in 110 children born are diagnosed with ASD; in West Virginia it's 1 in 91 births, with ASD for boys more prevalent, at 1 in 30. About 200 West Virginia children per year may be diagnosed.

In 2009 alone, Klingberg had 245 ASD referrals, and

And often, for a person diagnosed with autism, insurers won't even cover treatment for conditions they would cover for other members.

For instance, Sell said, he has had to threaten lawsuits in order to get his insurer to cover his son's gastrointestinal problems. Parents who aren't experienced lawyers simply have to pay out of pocket or do without treatment for their loved ones.

"It's wrong to focus on just the costs when the benefit side is so high," he said. "Autism is a very treatable behavioral and medical condition. Our biggest problem is accessing the care these children so desperately need."

Four bills mandating coverage came before the Legislature last year — three in the House, one in the Senate. All died in their respective banking and insurance committees.

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**Autism is a very treatable behavioral and medical condition. Our biggest problem is accessing the care these children so desperately need.**

Jeff Sell  
Autism Society  
vice president

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Preston and 78 in Marion. Sixty percent are 18 or under.

Because autism isn't covered, services are rare in West Virginia, the experts said. Klingberg has a three-month waiting list. It can be two years at Marshall, which recently got some funding and trimmed its list from 300 to 150 families.

The 23 states that mandate coverage have far more care available, Becker-Cottrill said. Pennsylvania has 484 board certified behavior analysts; Florida has 1,308; New Jersey has 393.

West Virginia has 18.

After South Carolina passed a coverage law, the number of analysts jumped from 18 to 65.

"This creates a job market," she said.

132 were diagnosed, Poe said. The West Virginia Autism Training Center at Marshall University works with 1,918 families, said Executive Director Barbara Becker-Cottrill. Since 2004, it has registered anywhere from 150-200 new families per year. Its current clientele includes 93 in Monongalia County, 22 in

This time, said committee Co-chair Sen. Even Jenkins, D-Cabell, the question isn't whether there should be coverage, but how much.

There are four coverage variables to explore, he said:

- Age caps, if any.
- Annual or lifetime monetary caps, if any.
- Breadth of coverage.
- Authorized treatment providers.

### **Autism and its costs**

Dr. Susannah Poe, an autism specialist with WVU School of Medicine's Klingberg Center for Child Development, said ASD is a "complex neurobiological/behavioral disorder," not a mental health disorder. It ranges from mild to severe, and is characterized by problems with social interaction and communication, and is accompanied by unusual or repetitive behaviors.

The only proven treatment for ASD, she said, is Applied Behavior Analysis (ABA) — one-on-one behavior modification employing a number of techniques. Research shows, she said, that "any treatment other than intensive, one-on-one, individualized [ABA] has no scientific evidence to support its use." In fact, Poe said, patients often regress under other treatments.

Early intervention is key, she said — treatment should begin from ages 2-6, and 30-40 hours of treatment per week is essential.

Jennifer Saunders, health program policy associate for the National Conference of State Legislatures, said the Council for Affordable Health Insurance estimates health insurance premiums may rise 1 to 3 percent for autism coverage. In states that adopted coverage, premiums rose anywhere from 74 cents to \$15.12 per member per month, depending on the levels of coverage.

Delegate Ralph Rodighiero, D-Logan, not a committee member, shared his story. His son's ASD symptoms appeared at about 18 months. It was going to cost them \$50 an hour for four hours a day five days a week for in-home intervention. His wife quit her job to become a caregiver, and they mortgaged their home to pay for treatment. Their son is now 18, holds down a job and graduated 20th in

his high school class.

Members said one other factor to consider is Medicaid. Waivers are available for those families who don't meet income guidelines. Jenkins called for state Department of Health and Human Resources (DHHR) representatives to come before the committee and explain DHHR's potential role.

Subcommittee Co-chair Barbara Evans Fleischauer, D-Monongalia, said the presenters provided valuable information. There is solid cost-benefit information available now, not just estimates. And she expects more support for a bill next time.

"A lot of families out there have desperate problems," she said. "I think there will be a lot of pressure on legislators to do the right thing."

A West Virginia-based cost-benefit analysis provided by consulting economist Jon Hockenyos, Resources for Hope, shows that with early and intensive intervention, 47 percent of those with ASD recover typical function, 40 percent make significant improvement and 13 percent make little progress.

Studies, he said, calculate lifetime expenses —