

ADVOCACY UPDATE

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AUTISM SPEAKS

If you keep up with the news even just a bit, odds are likely that you've seen a news report within the last six months related to insurance coverage of autism treatment. The TODAY Show, NPR, CNN's Dr. Sanjay Gupta, *The New York Times*, *The LA Times* and *The Boston Globe* have all highlighted families with children diagnosed with autism that are struggling to obtain evidence based treatment.

Autism Speaks, the world's largest autism non-profit, is addressing this struggle head-on. Co-founded by Bob Wright (former chairman of NBC Universal and Vice Chair of General Electric) and his wife Suzanne in 2005 after their grandson Christian was diagnosed with autism, the mission of Autism Speaks is to change the future for all who struggle with autism spectrum disorders. Part of their focus is to change state insurance laws to require private health insurance policies to cover the diagnosis and treatment of ASD's.

The sad reality is that most states do not require private insurance companies to cover even essential autism treatments and services. In the absence of coverage, families often pay as much as they can out-of-pocket for services that can cost upwards of \$50,000 per year. "Families across the country are going broke as they struggle to provide their children with the services they need and deserve," added Suzanne Wright. "A family should not have to choose between getting necessary therapies for their child and making their mortgage payments."

The insurance legislation supported by Autism Speaks specifically targets coverage of Applied Behavior Analysis (ABA) and other structured behavioral therapies, which

are the most effective forms of treatment and have the best outcomes, both in human costs and in long-term economic benefits.

Nationwide, few private insurance companies or other employee benefit plans cover Applied Behavior Analysis and other behavioral therapies. In fact, most insurance companies designate autism as a diagnostic exclusion, meaning that no autism-specific services are covered, even those that would be used to treat other conditions.

An August 2nd article in *The Washington Post* highlighted the Oldham family and their struggles to obtain treatment:

Having three young children -- the oldest son, Tristan, is 6 -- would be an ordeal for any family, but there is an acute sense of urgency in the way the Oldham family takes care of itself. Two of the three boys are autistic. And treating the illness that leaves Casandra Oldham's two youngest sons, Korlan, nearly 2, and Garath, 3, "locked behind a wall" cannot wait.

To get the best results in treating autism, children should be very young and therapy should run as close to around-the-clock as possible. But finding the money to pay for 40 hours of ABA therapy a week is overwhelming, said Casandra's husband Bill Oldham, then finding the therapists feels impossible, too.

"We just have to keep moving, though," Casandra Oldham said.

In trying to overcome this challenge, the Oldham's have lost their savings, their social lives and a sense of normalcy, they say.

Even to get the basic therapies, a recommended 40 hours of ABA therapy a week for each of her two sons would cost about \$14,000 a month. They compromise at 15-20 hours per child in the summer. During the year, they supplement with several area Special Education Programs in the Loudoun County Public Schools.

"I'm finding myself forced to pick and choose which therapies we are going to do," Casandra Oldham said. "Do I potty train my older kid or do I help my youngest learn how to speak?"

Due to the sheer number of children like Korlan and Garath that are receiving inadequate levels of treatment, poignant stories like the Oldham's are being heard over and over by state legislators. In the Oldham's home state of Virginia, Casandra Oldham recently testified at an emotional hearing before the Mandated Benefits Commission, sharing the excruciating decisions she has to make on behalf of her two little boys. The hearing was held to determine whether or not HB 1588 should be recommended for consideration by the General Assembly of Virginia. (HB 1588 would require private insurers to cover evidence based treatments like speech, occupational and ABA therapies.)

Not a single legislator on the commission voted against the measure.

Commission Chairman, Delegate Tim Hugo, had this to say about the compelling stories told by parents:

I was deeply stirred by the testimonies of parents across the state and from all walks of life. One testimony in particular was from a parent who pleaded for help because they no longer wanted their child to be 'condemned to the darkness of autism.' As a parent of four I could not deny any child the opportunity of a

normal life or any parents the chance of treatment for their kids.

Virginia is just one of many states where autism insurance reform is being taken up by state legislators. Following their successful efforts in Florida, Pennsylvania and Louisiana in 2008, Autism Speaks, via their Autism Votes initiative, is working in more than twenty states across the country to end discrimination against children with ASD's and provide access to much-needed treatments. Speaking in a November article done by the Associated Press, Elizabeth Emken, Autism Speaks' Vice President of Government Relations said that this issue is "the number one thing we hear from parents." Emken went on to say "What's more difficult than knowing there's an effective treatment for your child, but you can't afford to offer it to them because it's not covered by insurance?"

Seven states in total (Arizona, Florida, Indiana, Louisiana, Pennsylvania, South Carolina and Texas) currently have legislation requiring insurers to cover ABA. With the exception of Indiana, whose mandate has been in effect for several years, these states are now working to implement this groundbreaking legislation. The federal government is also recognizing the momentum of this movement. President-Elect Barack Obama has committed to bringing autism insurance reform to our entire nation in the form of a federal mandate. (A draft of this legislation can be found here.)

2009 will truly be a year of reform across the country, changing the face of autism treatment for both parents and providers. It is crucial that all stakeholders come together to accomplish these life-changing state and federal goals. To receive advocacy alerts or to become involved as a volunteer in the effort, please register at Autism Votes.

"It's time for insurance companies to step up and assume some of the financial burden now

shouldered by families and school districts,” said Bob Wright. “The autism community is mobilized and determined to go state-by-state state and knock on every legislator’s door until these unreasonable insurance laws are changed. It’s time to remove these barriers to care.”

To stay informed about movement on both a state and federal level, or to become involved in this effort, visit www.autismvotes.org. To contact Judith directly, please e-mail her at judith.ursitti@autismspeaks.org