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**MEMORANDUM**

DATE: April 25, 2011

TO: All Members of the Delaware State Senate  
and House of Representatives

FROM: Ms. Daniese McMullin-Powell, *DMP/KH* Chairperson  
State Council for Persons with Disabilities

RE: S.B. 22 (Autism Spectrum Disorders Insurance Coverage)

The State Council for Persons with Disabilities (SCPD) has reviewed S.B. 22 which would provide insurance coverage for the diagnosis and treatment of autism spectrum disorders. As background, the bill is part of a national initiative of Autism Speaks. Consistent with the attachments, twenty-four (24) states have adopted autism insurance reform legislation. The bill would require health insurers regulated by the Delaware Insurance Commissioner to cover costs of screening, diagnosis, and treatment of individuals less than 21 years old with autism spectrum disorders. Insurer outlays would be subject to a \$36,000 annual cap. The current bill is similar to legislation (S.B. 204) introduced in the 145<sup>th</sup> General Assembly which the SCPD endorsed. However, the current bill differs from its predecessor in several respects. The most prominent difference is that the proposed annual cap of insurer outlays regarding applied behavior analysis services is reduced from \$50,000 to \$36,000. A related change is automatic indexing of the cap based on the Consumer Price Index (lines 15-19, 112-116). The bill also covers "screening and diagnosis" instead of just "diagnosis" of autism spectrum disorders (lines 4, 41, 101, and 138).

SCPD endorses the proposed legislation since, consistent with the attachments, the advantages of early identification and intervention for persons with autism spectrum disorders are well documented. In addition, the April 6, 2010 News Journal article addresses advances in diagnosis and treatment of children with autism spectrum disorders.

Thank you for your consideration and please contact SCPD if you have any questions regarding our position or observations on the proposed legislation.

cc: The Honorable Jack A. Markell  
Mr. Brian Hartman, Esq.  
Governor's Advisory Council for Exceptional Citizens  
Developmental Disabilities Council



# Cost of treatment a 'double whammy'

## Parents of children with autism struggle to pay out of pocket for needed therapy

By KELLY BOTHUM • The News Journal • April 6, 2010

After years of frugal living and careful saving, Mark and Susan Johnston finally got the place of their dreams: a four-bedroom house in a new development where their kids, Conner and Madeleine, have room to roam.

But two years after moving in, the walls are still white. Only one window has curtains. Though the couple would like to paint, add new furniture and spruce up the backyard, those plans are on hold, along with regular family vacations. After paying \$1,300 a month for one-on-one therapy for Conner, who has autism, there's little money left for splurges.

The therapy, known as applied behavioral analysis, or ABA, uses repetition and reward to help people with autism develop skills they can build upon. Conner works six days a week for three hours a day practicing words and sounds with University of Delaware students. In a year and a half, the 5-year-old has gone from having no vocabulary to more than 100 words. Recently, he's started pointing and telling his parents he wants juice when they offer him milk.

"This wouldn't be a big deal for most families, but this is huge for us," said Conner's father, Mark Johnston.

Though ABA is considered a standard therapy for children with autism, it isn't covered by most private insurance or Medicaid in Delaware. That means families often have to pay out of pocket for ABA and additional speech, occupational and physical therapies they believe help draw their children out socially and emotionally. In some cases, parents are able to have extra services covered, but only after spending hours on the phone with medical and insurance personnel and haggling over diagnostic codes that would qualify their children for treatment.

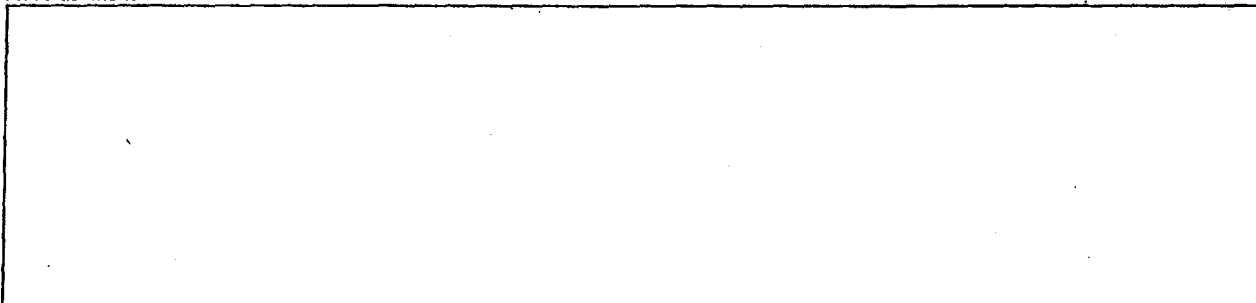
A bill introduced last month by state Sen. Liane Sorenson, R-Hockessin, aims to help families burdened by the cost of paying out of pocket for autism-related services. Senate Bill 204 would require private insurance companies to cover the cost of services related to the diagnosis and treatment of autism disorders up to age 21, including up to \$50,000 a year for ABA alone. The legislation was drafted by Autism Delaware, a statewide advocacy organization, and the office of Delaware Insurance Commissioner Karen Weldin Stewart.

Mandating insurance coverage for these services can not only save families money, it also increases the odds that children with autism will grow up being able to communicate and participate in the world around them, said Susan Jenette, investigative supervisor for life and health insurance with Weldin Stewart's office. Fifteen other states, including Pennsylvania and New Jersey, already have private insurance mandates for autism.

For many parents, it's also a matter of fairness.

"If your child had any other sickness, they would

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get the help they need," said Johnston, who believes the financial sacrifice his family makes is well worth it based on Conner's success since starting one-on-one ABA. "You have this double whammy of getting the diagnosis and then finding out the only treatment that's been proven successful, you have to pay out of pocket for it."

### A promising therapy

Autism is a complex neurological disorder that affects about one in 110 children born in the United States, according to the Centers for Disease Control and Prevention. Boys are four times as likely to be diagnosed as girls. Most experts believe a number of genetic, environmental and other factors play a role.

Social dysfunction is considered to be the hallmark of autism spectrum disorders.

That can take several forms, including a desire to escape from social environments or avoiding eye contact with other people. Many with autism have limited verbal communication, relying on only a few words and pointing to picture cards or using assistive technology to convey what they want. Repetitive gestures and a narrow, almost obsessive focus on items of personal interest are other symptoms.

Although there is no cure, the ABA method is considered one of the more effective means to coax social, verbal and behavioral improvements from people with autism. The method works by asking children to engage in a particular behavior, such as saying "mom," then rewarding them if they comply. If they don't, the behavior is requested again.

Children with autism also may need speech and occupational therapies to learn new sounds, how to dress themselves and to encourage more social behavior. They may require weekly physical therapy to improve low muscle tone – common in autistic children – and better control their body movements. Prescription medication can help anxiety, sleep and other issues.

The challenge for families is how to pay for it all. Because autism is not covered by most private insurances, parents either have to pay out of their own pocket or work with their physician to see if the

therapies can fit under another, accepted diagnosis that qualifies for coverage. Even when private insurance covers physical or occupational therapies, it often caps the number of visits annually, Jennette said. Children with developmental disabilities often exceed those visits before the year is over.

### The insurance labyrinth

Stacey O'Rourke, who has three daughters on the autism spectrum, said she has learned the importance of letters of medical necessity, prior authorization and knowing which diagnostic codes will help her eldest daughter, Katelyn, who has a severe form of autism, get the treatment she needs. Doctors are often sympathetic, choosing to write physical therapy prescriptions for hypotonia, known as low muscle tone, rather than autism.

"There is a high demand to do speech therapy, occupational therapy and physical therapy with kids who have autism, but if that diagnostic code or symptoms on the bill say 'autism,' most insurance companies will say it's an exclusion," said O'Rourke, of Wilmington, who spends what little free time she has calling physician offices and her insurance company about her daughters' care.

"First there's the heartbreak associated with autism. And then it's like, 'I have to play the insurance game?'" O'Rourke said.

Some families rely on Medicaid to help with coverage even when they have private insurance.

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The Children's Community Alternative Disability program provides Medicaid coverage to severely disabled children, including those with developmental issues, said Dave Michalik, spokesman for the state Division of Medicaid & Medical Assistance. Children who qualify for this coverage can get developmental and nutritional assessments, speech and other therapies and nursing services, but ABA services are not covered.

Johnston said Conner went on Medicaid after being denied private insurance coverage. O'Rourke's children are covered through private insurance and Medicaid. When children have other health insurance, Medicaid pays only after private insurance has issued payment, Michalik said.

### A push for legal mandate

Two years ago, officials at Autism Delaware began working on insurance mandate legislation after hearing horror stories of families whose savings and retirement funds were decimated to pay for autism therapies, said Kim Siegel, director of development for the organization. Proponents teamed up with Weldin Stewart's office.

With 15 states already mandating that private insurance cover autism services, more than two dozen others, including Delaware, are considering similar legislation, according to Autism Speaks, a national advocacy organization.

In general, insurers are opposed to mandates because they ultimately raise the cost of coverage and make it less likely employers can afford it, said Susan Pisano, vice president of communications for America's Health Insurance Plans, which represents nearly 1,300 companies.

Therapies for autism are complicated by the fact that some are classified as medical services by pediatricians, while others are considered educational. With more states and school districts facing funding crises, some of those therapies are being eliminated, she said.

But O'Rourke said without needed interventions, children with autism will become adults who can't function on their own or without expensive supports. Because of ABA-based drills, her 5-year-old daughter can pull her pants down on her own,

though she still wears a diaper.

"If we would mandate insurance companies to pay, it would save money and get the services we need," said O'Rourke, who has spoken at Legislative Hall on behalf of early intervention programs. "If we can make them more productive, in the long run, that's less cost on the state."

### Value of one-on-one

More than 900 children in Delaware have autism, Sorenson said. Many attend school through the Delaware Autism Program, the only statewide educational program in the country for children with autism. Some students may meet the medical criteria for autism but not the educational standard, so they don't receive school-based services.

While ABA instruction is a big part of the curriculum for students in DAP, it isn't always on a one-to-one basis, said John Dewey, principal of the Brennen School, which provides educational services for New Castle County students in the program. A child's instruction is based on what skills they already have, so if a child is learning something new, the student may get one-on-one time with an educator while doing a set of drills. Later, the student may work in small groups with an instructor and two or three other students to better generalize the skill, Dewey said.

Many parents, including the Johnstons, want their kids to spend more time in one-on-one instruction b

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ecause that's where they see the most improvement. During the school day, Conner attends a class at Wesleyan Church of Newark that's run by DAP.

But for families whose children aren't in DAP, who haven't been given an educational diagnosis of autism or who are considered higher-functioning, it can be a challenge to make sure they are getting the services they need to build their vocabulary and interact with the world around them, said Theda Ellis, executive director of Autism Delaware. With a mandate in place, parents could supplement services for their children without worrying about whether their insurance will cover the cost.

While families such as the O'Rourkes and Johnstons are hopeful the legislation will pass and ultimately be signed by the governor, it won't change their plans to provide additional therapies for their children, only how the bills are paid.

"We never knew when Conner was hungry, when he was thirsty or wet. Everything was a guessing game," Johnston said. "His progress has been slow, but it's real."

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# Autism study confirms benefit of early therapy

## Children gain IQ, language skills in intense program

Associated Press

CHICAGO — The first rigorous study of behavior treatment in autistic children as young as 18 months found two years of therapy can vastly improve symptoms, often resulting in a milder diagnosis.

The study was small — just 48 children evaluated at the University of Washington — but the results were so encouraging it has been expanded to several other sites, said Geraldine Dawson, chief science officer of the advocacy group Autism Speaks. Dawson, a former University of Washington professor, led the research team.

Early autism treatment has been getting more attention, but it remains controversial because there's scant evidence showing it really works. The study is thus "a landmark of great import," said Tony Charman, an autism education specialist at the Institute of Education in London.

There's also a growing emphasis on diagnosing autism at the earliest possible age, and the study shows that can pay off with early, effective treatment, said Laura Schreibman, an autism researcher at the University of California at San Diego.

The National Institute of Mental Health funded the study, which was published online today in *Pediatrics*.

Children ages 18 months to 30

months were randomly assigned to receive behavior treatment called the Early Start Denver model from therapists and parents, or they were referred to others for less comprehensive care.

The therapy is similar to other types of autism behavior treatment. It focused on social interaction and communication — which are both difficult for many autistic children. For example, therapists or parents would repeatedly hold a toy near a child's face to encourage the child to have eye contact — a common problem in autism. Or they would reward children when they used words to ask for toys.

Children in the specialized group had four hours of therapist-led treatment five days a week, plus at least five hours weekly from parents.

After two years, IQ increased an average of almost 18 points in the specialized group, versus seven points in the others. Language skills also improved more in the specialized group. Almost 30 percent in the specialized group were re-diagnosed with a less severe form of autism after two years, versus 5 percent of the others. No children were considered "cured."

The treatment is expensive; participants didn't pay, but it can cost \$50,000 a year, Dawson said. Some states require insurers to cover such costs, and Autism Speaks is working to expand those laws.

# Kids can recover from autism, research shows

## Skeptics question 10 percent range

Associated Press

CHICAGO — Leo Lytel was diagnosed with autism as a toddler. But by age 9, he had overcome the disorder.

His progress is part of a growing body of research that suggests at least 10 percent of children with autism can "recover" from it — most of them after undergoing years of intensive behavioral therapy.

Skeptics question the phenomenon, but University of Connecticut psychology professor Deborah Fein is among those convinced it's real.

She presented research this week at an autism conference in Chicago that included 20 chil-



Leo Lytel, 9, has "recovered" from autism, his mother and a researcher say. A study says at least 10 percent can be considered no longer autistic after intensive therapy.

dren who, according to rigorous analysis, got a correct diagnosis but years later were no longer considered autistic.

Among them was Leo, a boy in Washington, D.C., who once made no eye contact, who echoed words said to him and often spun around in circles — all classic autism symptoms. Now he is an articulate, social third-grader. His mother, Jayne Lytel, says his teachers call Leo a leader.

The study, funded by the National Institute of Mental Health,

involves children ages 9 to 18.

Autism researcher Geraldine Dawson, chief science officer of the advocacy group Autism Speaks, called Fein's research a breakthrough.

"Even though a number of us out in the clinical field have seen kids who appear to recover," it has never been documented as thoroughly as Fein's work, Dawson said.

"We're at a very early stage in terms of understanding" the phenomenon, Dawson said.

Previous studies have suggested between 3 percent and 25 percent of autistic kids recover. Fein says her studies have shown the range is 10 percent to 20 percent.

But even after lots of therapy — often carefully designed educational and social activities with rewards — most autistic children remain autistic.

Recovery is "not a realistic

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expectation for the majority of kids," but parents should know it can happen, Fein said.

Doubters say "either they really weren't autistic to begin with ... or they're still socially odd and obsessive, but they don't exactly meet criteria" for autism, she said.

Fein said the children in her study "really were" autistic and now they're "really not."

University of Michigan autism expert Catherine Lord said she also has seen autistic patients who recover. Most had parents who spent long hours working with them on behavior improvement.

But, Lord added, "I don't

think we can predict who this will happen for." And she does not think it's possible to make it happen.

The children in Fein's study, which is still ongoing, were diagnosed by an autism specialist before age 5 but no longer meet diagnostic criteria for autism. The initial diagnoses were verified through early medical records.

Because the phenomenon is so rare, Fein is still seeking children to help bolster evidence on what traits formerly autistic kids may have in common. Her team is also comparing these children with autistic and non-autistic kids.

So far, the "recovered" kids "are turning out very normal" on neuropsychological exams and verbal and nonverbal tests, she said.

## Parent Information Center of Delaware

We help parents of children with disabilities become effective partners in their children's education.

POSTED 1/11/2010

### Brain Scan Could Allow Autism Diagnosis In Infancy

#### Initial Research Findings

Brain scans detecting a sound processing delay common in children with autism could lead to earlier diagnosis of the developmental disorder, researchers said Friday.

In a study of children with and without autism, researchers monitored brain activity while the children listened to various sounds. They found that it took children with autism an average of 11 milliseconds longer for their brains to respond, researchers report online Friday in the journal *Autism Research*.

"This delayed response suggests that the auditory system may be slower to develop and mature in children with ASDs," said study leader Timothy Roberts of Children's Hospital of Philadelphia. "An 11-millisecond delay is brief, but it means, for instance, that a child with ASD, on hearing the word 'elephant' is still processing the 'el' sound while other children have moved on."

The finding is significant because it could lead to a single, measurable tool for diagnosing autism as early as infancy, researchers say. Currently autism is diagnosed using clinical observation and the disorder can take years to manifest. If diagnosed at younger ages, experts say treatment could be more effective.

"More work needs to be done before this can become a standard tool, but this pattern of delayed brain response may be refined into the first imaging biomarker for autism," Roberts said.

<http://www.disabilityscoop.com/2010/01/08/brain-scan-autism/6615/>

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Teen's family transformed after autism intervention

STORY HIGHLIGHTS

- The Bilson family was at wits' end with the behavior of autistic teen daughter
- A behavioral therapist conducted a weeklong intervention at the Bilsons'
- Behavior modification techniques helped Marissa Bilson control her outbursts
- Autism treatments are expensive; often not covered by insurance

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READ VIDEO INTERACTIVE

By Linda Saether CNN

10/17/2008

(CNN) — Until recently, the Bilson household was under siege. Thirteen-year-old daughter Marissa, who has autism, ruled the roost, screaming shrilly until she got her way and enjoying special privileges that didn't extend to her siblings, Brittany, 15, and Brendan, 6.



Behavioral therapist Rick Schroeder prepares Marissa for a walk through a store.

The family couldn't go out in public because of Marissa's tantrums, and they couldn't take her into stores because she'd shoplift what she wanted, or just scream until she got it.

But that was before. Watch Marissa "before" »

Today, the Bilsons' family life is a lot calmer and quieter. That's because Marissa and her parents, John and Mary, are following the rules that were made during a five-day intervention. The intervention was provided to them free by the group Autism Partnership, or AP. Usually this type of treatment costs about \$20,000 a week, and it's not covered by insurance, but because CNN was allowed to videotape the entire process, AP waived the fee for the Bilsons.

The intensive, one-on-one, in-home therapy was meted out by behavioral therapist Rick Schroeder, who used a technique of behavior modification

known as "applied behavior analysis" or ABA. ABA essentially breaks down behavior patterns in order to reward good behavior and not reward bad behavior. Essentially, it's all about laying down the rules and sticking to them in a way that Marissa can understand. Watch the therapist work with Marissa »

Marissa — who before the therapy was, in Schroeder's words, "out of control" — now has rules to follow, something she didn't have before.

Marissa's mother also learned some lessons about her daughter that week. "I learned that Marissa is smart," Mary Bilson said. "Smarter than I thought."

These days inside the Bilsons' cozy house, there is a lot less screaming and more boundaries are in place. The balance of power is flipping back into the hands of the parents and away from Marissa and her tantrums.

Did the therapy work? Watch life for the Bilsons "after" »

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But there is still work to be done; the only difference is that now the Bilsons — not Schroeder — will be in charge.

The theory remains the same: "It's all about the teaching," Schroeder explains. "With a child like Marissa, we can't sit down and discuss it with her — she's just not going to get that. So we have to take it in small steps. Make them understandable and move on, one step at a time."

That's just what the Bilsons are doing: One step at a time. They have increased the amount of time that Marissa has to practice her new behavior, from a starting time of 20 minutes a day toward a goal of 60 minutes. Learn more about raising a child with autism »

In a recent e-mail, Mary Bilson wrote that the initial rewards that Schroeder had used with Marissa have had



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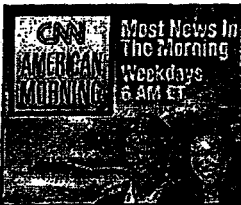
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their appeal, and Marissa wasn't interested in working for them anymore. However, Bilson added, she has discovered other rewards the teen is eager to work toward.

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- MayoClinic.com: Asperger's syndrome



As a result, said Mary Bilson, her once unruly teen has continued to follow the rules that were put in place during that weeklong intervention: Marissa no longer goes into sister Brittany's room, she no longer monopolizes the family computer, and her once-frequent screaming fits have all but stopped.

Possibly best of all, Marissa can now go out in public without creating a scene — a goal Mary Bilson was eager to achieve, because before, the Bilsons "could never go out together as a normal family."

In other words, one week of intervention therapy has done more than simply give Marissa some rules to follow and the household some much needed quiet. It has brought this once-divided family back together. [E-mail to a friend](#) | [Mix it](#) | [Share](#)

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▼ **Sound Off:** Your opinions and comments

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 Bill - once Autism is diagnosed many insurance providers do not cover anything, especially if a company is self-insured. (here's a CNN story from April 2008 with good news for South Carolina: [more](#)
- Mary**  
 updated Wed  
 February 4, 2009  
 I have 2 sons with autism, ages 14 and 11. Since Wisconsin has programs in place to pay for ABA therapy, our sons both received this in home therapy at young ages, when it's most effective. My husband is a teacher a ...[more](#)
- Sharon Akalwa**  
 updated Wed  
 February 4, 2009  
 I have a 20 yrs. old daughter with Autism, she similar to Messisa, out of control. I am 59 yrs. parent that need help. My daughter was put into a Autism treatment center two year's ago, she act's but not the same. B ...[more](#)

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