



Autism

A father's response

By Susan K. Wittstock

Jon Peterson leads the fight to increase state funding for the severe disorder that affects his 11-year-old daughter. It doesn't hurt that he carries more clout than other parents: He's a member of the Ohio House of Representatives.

Jon and Hannah Peterson at their Delaware home.

Hannah Peterson was 18 months old when she was diagnosed with autism. For her parents, Jon and Melissa Peterson, the devastating news meant that a child who they thought was healthy would instead struggle every day with some of the most basic skills in life—talking, sharing, listening, touching. They went from dreaming of a future for their daughter that included college and marriage to wondering if she would be able to live independently.

"From the very beginning, I went through a grieving process. They say you do almost like the loss of a child. You expect the child to be so-called normal," Melissa Peterson says. "I had a hard time for about a year, but Jon was just gung-ho. The more he read, the more interested he became. The more I read, the more upset I became. He was more positive."

Over time, it became clear that Hannah's autism was not as severe as her parents first feared. She's been diagnosed as high-functioning, and with therapy and a lot of support she's enjoyed a much more normal childhood than many children with autism experience. Hannah is now an active 11-year-old who enjoys swimming, reading and soccer; she's learning to play the flute.

Her father, meanwhile, is fronting the charge to get

more state support for autism-related services. Peterson's efforts at the Ohio Statehouse pack more punch than the average parent: He's in his fourth term as a member of the Ohio House of Representatives.

The Delaware Republican's efforts have led to results, including the creation of the Ohio Autism Task Force in 2003. In March, after the task force's 22 members released 43 recommendations, Peterson helped get four of them into a tight budget for fiscal years 2006 and 2007. "Passion is how you do it," he says. "You can get a great deal done within the legislature if you are focused, if you do your homework, if you make a good case to your peers."

"It speaks very well of the respect Representative Peterson has and his ability to influence decision makers," says task force member Mike Armstrong, director of the Office for Exceptional Children in the Ohio Department of Education. "He has made them aware of the presence of autism in this state,"

Peterson has found his fellow legislators—Republicans and Democrats—can agree that autism is a pressing issue. "I don't think there's any one of my colleagues in the House or the Senate who have not had constituents come to them asking for improved services for autism. They understand the need," Peterson says. "But they



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have issues that are more important to them and that they're focused on, so it took, I think, someone in the legislature who had a direct connection to really get the hall rolling."

The Peterson family's experience with autism is becoming a more common occurrence. Depending on who is counting, as many as one in every 116 or 250 children in the United States is born with the developmental disorder. According to the Ohio Department of Education, the number of Ohioans ages 3 to 21 diagnosed with autism has risen by 22 percent in the last year.



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"We're not sure if it is an increase in actual cases or in diagnosis, although in general there is some understanding that there is an increase in prevalence," says psychologist Jacquie Wynn, head of the Comprehensive Autism Center at Children's Hospital.

Autism is a severe developmental disorder, Wynn says, because it affects so many areas of functionality. Symptoms of autism include avoidance of eye contact, aversion to sensory stimulation, nonimaginative play and refusal to participate in family activities. "On top of having difficulty in language and social skills, there also is the presence of repetitive behavior, rigid practices which can make the challenge of everyday life overwhelming," she says.

The cause of autism isn't known, nor is it understood why some individuals with the disorder are high functioning, as in Hannah's case, while others are drastically affected. Researchers are studying possible genetic and environmental factors, including the effects of mercury contained in vaccines. But Wynn says no one has yet discovered conclusive evidence proving any one factor as the cause.

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It's also a difficult disorder to diagnose. Roughly 50 percent of autistic children appear to be developing normally until about age 1, when they may begin to lose skills. "There's no genetic test or blood test. You have to meet with the child and talk with the family about the child's history and look for a clustering of me symptoms," Wynn says.

There is no cure, but Wynn says intensive and structured therapy, preferably reinforced at school, home and anywhere else the child spends time, can affect positively the autistic child's productivity and happiness. "Intensive behavioral intervention is very effective. Establishing clear expectations, a predictable pattern of events, clear consequences to behavior, lots of feedback and step-by-step instruction are all good strategies," says Wynn, who notes that individuals with autism are intelligent and have good visual and spatial skills. "You tailor what you do to each child's needs. We get a range of outcomes, but we're able to see advancement for each child."

The earlier the intervention, the better. "We are very blessed in Delaware County," Peterson says of Hannah's educational opportunities. "We had her immediately enrolled in Hickory Knoll school, which is a school for those with developmental disabilities. At the age of 21 months she was engaged in the process of receiving behavioral intervention. It's hard to quantify how much of her success is attributed to that, but those in the field say they think that early diagnosis, and then acting on that diagnosis, is critically important."

After two years at Hickory Knoll, Hannah entered regular kindergarten and has since been mainstreamed in the Delaware City Schools' special-education program. Her proficiency test scores show she's still a bit less than proficient in reading and writing, he says, but in math and science she tested well above average. "She's doing very well," he says.

Peterson recognizes that many parents in Ohio aren't so lucky.

There really is a difference between services that are offered in different parts of the state," he says. "The quality of services shouldn't be dictated by the county you are born in."

Although many people in Ohio realized that autism was becoming more prevalent, it wasn't until the Ohio Autism Task Force was formed that anyone sought to analyze the disorder as a statewide issue.

The committee—consisting of legislators, parents, educators, autism experts and professionals, and an autistic adult—initially started with monthly meetings in Columbus. "We were receiving some very mean-

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ingful input, but something was missing," Peterson says. "And what was missing was the input from those who live with this disability daily. So we decided to have eight regional forums that would complement, not displace, our monthly meetings."

About Asperger's

A disorder classified within the autism spectrum is Asperger's Syndrome, a milder form of autism that doesn't tend to present itself until a child is in elementary school. "They've probably gone to kindergarten and done well academically and are able to speak," says Jacquie Wynn of Children's Hospital. "But they're not able to make friends. They may appear odd. They don't share interests with other kids."

Like children with autism, kids with Asperger's exhibit social deficits and engage in repetitive and ritualistic behaviors. "But they have fewer impairments in language and cognitive and adaptive skills," Wynn says.

Children with Asperger's also often form an obsession with a particular interest—say, dinosaurs—to the exclusion of anything else. It takes time to sort out whether a child has a normal intense interest in a subject, or the extreme interest of a child with Asperger's.

"It might seem like a personality quirk at first!" Wynn says. Typical children tend to share their interest with other people, but a child with Asperger's will not. "If you interfere, they might have a meltdown," Wynn says.

Language skills, while less impaired than with autism, also are affected. "As the kids get older, problems come up. They don't understand idioms or figures of speech. There can be an adult quality to their speech," she says.

It can be tough to diagnose. "Some kids with Asperger's have enough behavioral problems to get upset and throw tantrums, but others just slip by," Wynn says. "It all starts with the pediatrician giving a good screening to determine if there is a developmental problem."

If a pediatrician feels (here is cause, the child can be referred for additional tests to a team of experts, including speech pathologists, developmental pediatricians and psychologists.

The 43 final recommendations call for a wide scope of services, including creating standardized methods for screening and diagnosis of autism; a confidential statewide registry of Ohio individuals with autism, and a higher education-level teaching credential for autism. It also urged preventing insurers from excluding coverage to individuals with autism, and that state and federal government fully fund special-education programs and services.

The four task force recommendations that made it into the Ohio budget include changes involving Medicaid; the creation of the Ohio Center for Autism and Low Incidence (OCALI); an increase from about \$15 million to \$19 million for state funding for catastrophic special-education costs, and a hike in the autism scholarship, from \$15,000 to \$20,000, that helps parents get their child into a private school for special services.

Peterson thinks OCALI may be the most important recommendation the task force introduced. Located on the campus of the Ohio State School for the Blind, it's

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staffed by experts in autism who will help parents and professionals make informed decisions. "We think it would be very advantageous to have one central place where individuals will be referred when there's a diagnosis," he says. "Statewide, no matter where you are, they will refer you to services in your area."

When Hannah was first diagnosed, Peterson says it was hard to find assistance. "You get mad because you feel impotent to seek services because you don't know where they are," he says. And professionals will benefit since the center will gather information on local and national best-practices for the treatment of autism.

"I am hopeful that in the decades to come it will fulfill what our vision was and it becomes a central storehouse for knowledge regarding services available to individuals in Ohio with autism," Peterson says.

Meanwhile, Peterson is working with the Autism Society of Ohio to establish priorities and a timeline for tackling the remaining recommendations, some of which carry a big price tag. "We know that this is a 10-year process at a minimum," he says. "To do it right we are doing it thoughtfully, thoroughly, addressing it in a comprehensive way. Ultimately, it will all be done, but it will take some time."

Peterson has had a lot of help in push-

ing the recommendations through the legislative channels. He credits one of his constituents in particular: Westerville resident Doug Krinsky, who first contacted Peterson in 2002, shortly after his 3-year-old son was diagnosed with autism. Krinsky repeatedly encouraged Peterson to move forward on autism issues.

In fact, Krinsky and Peterson came up with the idea for the task force. "I was extremely motivated because nothing was going on in the state," Krinsky says. "He was looking for someone outside of politics to work with him."

"You need to develop relationships with your legislators," says Peterson. "It shouldn't just be a one-time thing. That's how it happened with Doug Krinsky. I can't overestimate just how important he was, because I had the passion, but he kept me focused, kept me harnessed to the plow."

"Jon is a member of the ruling Republican party, he's ranked pretty high in the House and can get things done. He's a doer, not a talker," Krinsky says. "He's the pied piper, leading us and giving us direction and, so far, it's been terrific."

In the past, constituents in the society's nine chapters across the state approached legislators individually, "When Jon Peterson came on the scene and people knew he had a daughter, everybody approached

him, but all with different messages," Autism Society of Ohio president Barb Yavorcik says, "We met with him and were told, Talk with one voice."

Yavorcik, who estimates there may be upward of 10,000 individuals in the state who are tapped into the autism network, is ready for the challenge. "If we could get even 1 percent of them to contact their legislators, that's powerful," she says. "Let's face it. Peterson] can't do it all. He can't introduce every piece of legislation and he's term-limited."

Assuming he is reelected next year, Peterson will be forced to leave the Ohio House in 2008. To prepare for his post-political career, he is taking classes at the Methodist Theological School in Ohio in Delaware. "I'm gravitating toward a master's in special ministries, so I can continue my work with special-needs children," he says.

He relies on the gospel for inspiration. "I think it's pretty clear what we're commanded to do," he says. "We're not requested. We're not asked. We're demanded to help the least among us, and when I had this very, very special child in my life, it was only natural that is where my passion would be." •

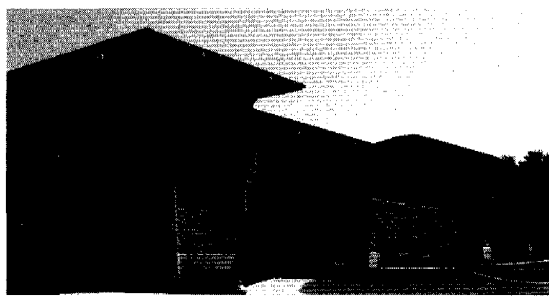
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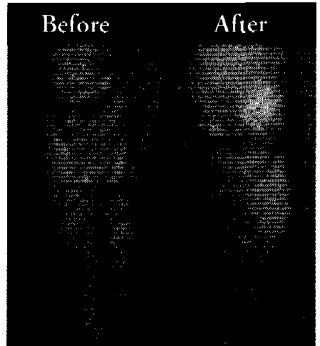
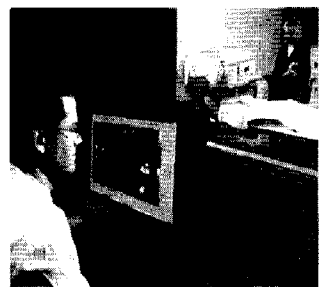
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