

CURRENT

75¢ Vol. 32, No. 16

In the Community, With the Community, For the Community

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Jason Madore

Taking control

Apple Valley family makes education system work for them

ERICA CHRISTOFFER • SUN NEWSPAPERS

In third grade Jason Madore took his education into his own hands. "I told mom when I came home from school one day I wanted to not be of special ed," says Jason. He wasn't satisfied with the structure of his school day, so he started attending his own Individualized Education Plan (IEP) meetings. "Self advocacy is big in our house," says Jason's mother, Shelley Madore, a resident of Apple Valley who also serves as representative for House District 37A in the Minnesota Legislature. "He's spending seven hours a day at school. It's got to be productive and it's got to have an outcome that he's happy with." Jason, now 14, is autistic. But that label hasn't been and will never be smelly education that holds him back from living his life to the fullest and getting

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Annamarie Nerka, an occupational therapist at Lincoln Center Elementary in South St. Paul, made an art project in the autism classes. (For more photos, visit our online Photo Gallery at www.mnSun.com.)

EDUCATING A PHENOMENON

Taking a look at ASD in the classroom

ERICA CHRISTOFFER • SUN NEWSPAPERS

Gluing and pasting fluffy balls and googly eyes, children in Annamarie Nerka's class work on an art project at Lincoln Center Elementary in South St. Paul. A drip of glue falls from one boy's hand. He immediately wants to wipe it off because he doesn't like the feeling.

"Can you pass the sticks, please," he asks his classmate across the table. "Yes," the other boy answers. The exchange is made without eye contact. These students fall under the umbrella of Autism Spectrum Disorder (ASD). Nerka of Inver Grove Heights is an occupational therapist helping the children work on sensory issues. In the world of education, the number of ASD cases has grown in the last decade.

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This week of our Sun Newspapers Special Report "Portraits of the Spectrum," we will examine the educational opportunities for children with ASD. We welcome your comments on our stories. You may contact us online at www.mnSun.com or e-mail us at sun-currentsouth@sunpapers.com.

Madore

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everything he can from his education, says Madore. Ten years since his diagnosis, Jason works in his education team at Apple Valley Middle School, telling them what works and what doesn't, and providing feedback on how his teachers help him. "I think, given the high dropout rate for special education, he's going to go to be one of those statisticians," says Madore. Three special education students for every one general education student drops out of school in Minnesota. Most of Jason's time is in general education classes. A creature of habit, Jason gets up on time everyday, has breakfast and heads to school. If he's having trouble with a class or having sensory issues, Jason has an option to work with special education staff who cater to autistic students. When he comes home, he needs some down time. Once a week a behavioralist from the Courage Center visits the Madore home to work with Jason. "She helps him to debrief and teaches him some coping strategies," says Madore. "I like it because they come to the house and frankly, we all deal with autism in this house."

The beginning

Madore and her husband, Paul, first realized something was amiss with Jason in his speech, or lack thereof. "He had a lot of difficulty talking," Madore says. He understood what things were around him, but when it came to giving those things a name, problems arose. He came up with the same word for every object, posing a tough quest for Madore to figure out exactly what her son meant. "You could see it on his face, that I want to tell you something and I can't express this," says Madore. As opposed to Madore's elder daughter, Erica, who was singing songs at 14 months, Jason still was not talking at 2 years of age. Frequent trips were made to the doctor's office in search of an answer. At the time, Madore was attending Early Childhood Parent Education (ECEPE) classes through District 196 Community Education. She learned Jason could receive a free evaluation at 30 months. "At 30 months and one day I took him and had the referral done," Madore says. Jason was diagnosed with significant speech delay. "That was how it got started," she says. "He had the cognitive skills of a 4-year-old, but he had the verbal skills of a 3-month-old."

Early childhood classes helped bring Jason's speech skills up to his age level, but he still had difficulty interacting with other children. January 1968 brought the Madore family answers from Jason's diagnosis: Asperger's Syndrome. Jason's lack of eye contact, his trouble processing verbal instructions, his tendency to point rather than use his words and how he typically played independently suddenly made sense. He was 4 years old at the time, and Madore says the early diagnosis made all the difference. Immediately he was offered supplemental services for children with autism in his early childhood classes and then in school.



Jason Madore, 14, realized a music cylinder onto an Edison Standard Phonograph in his Apple Valley home. Jason, who was diagnosed with Asperger's Syndrome in 1998, shares a love of music with his father. The two collect albums and vintage phonographs. (For more photos, visit our online Photo Gallery at www.mnSun.com.)

autism portraits of the spectrum disorder

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"What's unique is that it permeates itself in totally different ways," says Madore about Autism Spectrum Disorder (ASD). "Some kids have full sensory issues, in that light, sound, touch are enough to set them off. Yet they can last all day in an environment they're comfortable in." For Jason, transitions are a challenge, as is time management and organization. But his mind is like a steel trap when it comes to music and collectibles. "He and his dad collect antique photographs and records," Madore says. "He can tell you filmmakers, artists, costs, the whole nine yards."

Finding what works With autism comes a learning curve. Because people with ASD can be very literal thinkers, sometimes traditional methods of communication don't work. For example, when Jason was in daycare, the caretaker called Madore one day to tell her Jason was sitting too close to the television. The provider told Jason it would hurt his eyes. "But it doesn't hurt my eyes," he'd say. Madore found that telling Jason that TV was only watched from a mat on the floor (a reasonable distance from the screen) did the trick. ASD and every disorder that falls under its umbrella, needs to be addressed

through all aspects of life, not just in the education setting, Madore says. "In the autism community, we've been very frustrated that there have been no national studies on this," says Madore. "Where are the increases [in diagnosis] coming from? Is this a mercury poisoning? Is it environmental? Is it neurological based? That there's a brain chemical issue? What is it in the first 28 days of life where the brain and spinal column are being formed that has a mismatch? Or maybe it's fully genetic and it's just the way it is. I don't know."

In the end, success

Jason is a two-time Eagle Award winner, given to high achieving students at Valley Middle. He's taking Spanish because he wants to. Through his ups and downs, Jason has found success in school. Speaking up and taking control of his education in third grade was the right thing to do, he says. For the last five years Madore has helped run the District 196 parent support group, explaining to parents their rights in the education system. "This whole system is driven by everybody's best intentions," she says. "At the end of the day everyone's good intentions don't mean anything if we can't keep a kid engaged."

One day Jason and his fellow autistic students will go on to college and the workforce, where they won't have a teaching specialist assisting them. "He needs to be able to graduate from high school successfully; he needs to be able to be gainfully employed as an adult," says Madore. Employable outcomes, Madore says, skills that get young people ready for the workforce are just as relevant in her son's education as is focus. "I think what we do too often is focus on the nice mouth cycle, but then you've forgotten what the goal of that school year was," Madore says. "It wasn't just to learn new verbs, but it was also the things that make you a valuable employee." How to stand in line, eat lunch with others, compromise, set goals and meet them are just a few of the traits employers look for when hiring. But are special education students being taught those skills as well? Madore, as a legislator, plans to take up the issue this summer and next year, setting up meetings with the Department of Employment and Economic Development (DEED) and talking to educators to see what can be done to ensure all students are being taught employable outcomes. "The world is moving fast and the expectation of our youth is so different than it was 20-30 years ago," says Madore. "This is about Jason's life." (You are invited to comment about this story on our website at www.mnSun.com and/or write a letter to the editor at sun-currentsouth@sunpapers.com.)

Education

FROM PAGE 1A

Just this year, South St. Paul added another autism specialist position, with two now at the elementary level and two in the secondary schools. In 1999, Rosemount District 196 served 92 ASD students. This year there are 538.

Meeting the need

South St. Paul and the Rosemount-Apple Valley-Egan school districts are one of the smallest and one of the largest districts in Dakota County. Yet they both are facing similar issues when it comes to ASD. "The trend, it's just phenomenal," said Mary Kreger, director of special education in District 196. "Look at the huge learning curve this puts districts in." Students with ASD fall into three general categories: academic, Communication and Interaction Disorder (CID), Communication and Interaction Program (CIP), and general education learners who need extra support. The education team works with ASD fall under the latter category, and are supplied with a variety of services as recommended in their Individualized Education Plan (IEP). Most work with an autism specialist to help structure their day or support them in their mainstream classrooms. CID includes the most severe cases of autism, where students need special education services throughout the entire day. CIP falls in the middle, with a broad range of students who spend part of their day in special education, with some time in general education. Madore made up of a special education teacher, a general education teacher, a school psychologist, a school administrator, and the parents determine what services will be most successful for the student. Because of the size of District 196, there is the opportunity for more students with similar profiles. Each category of ASD has nearly all the 18 elementary schools, six middle schools and four main high schools. "Our size helps us because we have a lot of people who can bring their areas of expertise to us," Kreger said.

For South St. Paul District 19, a relatively small district, individualized services are the key. "We do what all districts do, but we give more individual support to meet the students' needs," said Linda Gardner, director of special education in South St. Paul. A formal diagnosis of ASD must come from a medical professional. However, the state of Minnesota does not require a medical evaluation to receive a school evaluation. School districts are required to try intervention methods first, such as extra academic support and social support or moving the child's seat in class. If that doesn't work, the district will request that an initial assessment be conducted. If the student's parent agrees to an assessment, a specialist will present the child with play tests, using toys to judge the quality and level of interaction and whether it's appropriate for their age level. The student might also have speech/language and IQ tests. "Teachers and staff then work with parents to develop an IEP. Depending on

Two county organizations provide alternatives to students with ASD

Aside from what public school districts offer for children with ASD, there are also a couple of other organizations in Dakota County that provide supplemental training to students. Both were founded by parents of children with disabilities seeking to provide parents with more treatment options.

Partners in Excellence (PIE) is based in Burnsville, but also has an office in North St. Paul. PIE is open to students ages 1-13 and focuses on Applied Behavior Analysis (ABA) on teaching students with ASD. Director Deb Thomas, who has a 13-year-old with a physical disability, founded PIE in the beginning of 2001 with the intention of eventually integrating students into conventional schools. "PIE is more like a springboard," said Thomas. "We want to help the kids and get them into their home districts as soon as we can." At PIE, which is a for-profit organization, students are organized by ability and age, where they spend a part of the day learning in small groups and part of it receiving one-on-one time with therapists. About 100 therapists with various backgrounds work with about 75 students.

Parents also communicate with teachers on a daily basis through information sheets and in person. "Communication is very, very important to us," said Thomas. Students have the option of attending morning or afternoon sessions, or going to school for the whole day, throughout the whole year. The school also serves students with other disabilities, such as cerebral palsy and other neurological and neuromuscular impairments. For more information about PIE,

visit www.pieofmn.com or call 952-748-6300.

Boost! Learning Enrichment Program was founded by Sara Tinklenberg, who is the mother of a son with special needs resulting in social difficulties. Boost!, based in Burnsville, opened in January and provides weekly hour-long sessions where children ages 2 through sixth grade spend time with a small group and a therapist practicing different social skills. "It's small-group, constructed play time where they really work on a specific skill," said Tinklenberg, who worked as a special education teacher in the Lakeville School District 194.

"Social skills aren't really meant to be rote taught, but they kind of need to be taught that way [to children with social difficulties]. It's a place where they can be safe and not different than anybody else." Tinklenberg said the classes are also meant to be a platform where students can meet new friends. The classes are designed to be a supplement to a child's regular education classes, not a replacement. Boost! also acts as a consultant for daycare providers looking to help preschool students with special needs. Tinklenberg said her organization is also working on designing summer camps for students, as well as other programs.

For more information, visit www.boostlearningenrichment.com or call 952-907-1091. -Compiled by Grant Boelter

the age of the child, they too, may be included in planning the IEP. "Autism is so fascinating because it's a spectrum," said Kreger. Jason's education team at Apple Valley Middle School includes a special education autism teacher in District 196, said there are currently 84 early childhood youngsters that fall under ASD. When in high school, Jason was assigned to be a supplement to a child's regular education classes, not a replacement. Boost! also acts as a consultant for daycare providers looking to help preschool students with special needs. Tinklenberg said her organization is also working on designing summer camps for students, as well as other programs. For more information, visit www.boostlearningenrichment.com or call 952-907-1091. -Compiled by Grant Boelter

find what works, said Amy Johnson of Inver Grove Heights. Johnson is a CIP autism teacher at the elementary level in District 6 and works with about a dozen students a day. Some come to her room for 30 minutes, while others are with her all day, depending on their IEP. Finding a balance between direct instruction and time with their general education peers can be a challenge, she said. "Every student is very different," Johnson said. "I have to try lots of different things to connect with them." Right when the pieces fall together, it's all the more rewarding. "I get to laugh everyday at work," said Johnson. "And to see them achieve something they couldn't do on their own is rewarding." Cavanaugh said District 196 early childhood special education has been providing additional training to regular early childhood staff because they are seeing increases in their classrooms. She also works to provide more information to parents, such as intervention strategies.

ASD in the community

When Emily McGinn was a teenager, she took a job in the nursery of her church. It was there that she met a young boy with autism.

"It was something I wanted to learn more about," said McGinn of Cottage Grove. She was fascinated by his inverted nature and lack of eye contact, setting him apart from the other children in the congregation. Today, McGinn is an autism specialist at Northview Elementary School in Egan, where she works with 10 children who need support for ASD. "The amount of time spent with each really depends on the kid," McGinn said. There are 28 children with three teachers in the CIP program at Northview. "The idea that autism is a disease, I think is really misleading for people," said Holly Schmidt, a K-12 autism resource specialist. "They really have a processing difference. They all can learn; they can gain skills. It's not a disease they need to be cured of." McGinn pointed out that the public should be aware of the sensory issues that go along with ASD. "Different things we don't experience as painful: flickering of fluorescent lights, loud noises - are painful for them." According to Schmidt, who has experience teaching in New York and Virginia, Minnesota is at the top of its game. "Minnesota was really at the forefront in identifying ASD as a special education category," she said. And, Minnesota will provide services to children identified with ASD, regardless of a medical diagnosis. Not all states do that.

Full funding

Training for teachers, hiring more specialists, finding classroom space - this all costs money. As the cases of ASD continue to climb, so do the dollars needed to pay for services. For the 2007-07 school year, the gap between special education costs in District 196 and the funding received from the state and federal government was \$21 million. The district, along with many others throughout the state, had to foot that bill through their general fund budgets. By law, special education is required to be funded - no matter what. The Individuals with Disabilities Education Act promised to fund 40 percent of special education mandates for school districts. Currently, 17 percent is being funded by federal dollars. "The costs continue to rise and the number of kids continues to rise," Kreger said. Students often need different specialists to meet their needs, such as a speech, adapted physical education or occupational therapy. If special education were funded to the 40 percent mark, the students who would benefit the most are those in general education classrooms, said McGinn. "If we increase the special education funding, it would decrease the amount we need from the general education fund," she said. "We're obligated by law and ethics to meet the needs of these kids."

Community editors Grant Boelter, Megan Anderson, Erica Christoffer, Joseph Palmersheim and Heather Voorhes; design editor Jason Walker; photographer Scott Thesen; and managing editor Bonnie Bolberg contributed to this series "Portraits of the Spectrum."