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Fighting for their future

When 'special ed' becomes anything but special, how parents battle back

"Because of the information SPEDWatch gave us we decided to expand our story into five or six different pieces on special education." *Doreen Leggett, Managing Editor
The Cape Cod Voice*

Straight Talk: The September specialty

By Doreen Leggett, Cape Cod Voice

No matter how old you are, September evokes memories of going back to school, with all the trepidation and anticipation associated with freshly waxed hallways and lumbering yellow buses.

Lately there seems to be a lot more anxiety, from national worries about the quality of local services – drastic budget cuts, lack of taxpayer support, declining enrollment and growing pressure on teachers to act as social workers.

All these concerns are worthy of journalistic investigation, but this September we chose yet another focus; special education, because it challenges all our schools, because the people involved are so compelling, and because the issue is at the very heart of our society's most important promise – to give every child the education he or she deserves.

Just as school was starting last September, Boston's Channel 5 TV ran a two-part series on how special education was bankrupting the state's public school systems.

Ellen Chambers remembers watching scenes of mentally retarded students in wheelchairs, intercut with sound bites from superintendents saying the high cost of educating them takes money away from "typical" students. The "investigative" report concluded that special education will continue to cannibalize the mainstream because federal and state laws give those with special needs priority over all others.

To Chambers, executive director of a recently formed advocacy group called SPED Watch, the journalism was appalling, in large part because it perpetuated myths.

"Most people, when they hear 'special ed' go right to wheelchair retarded," Chambers says. Their next thought is, 'What's the point of educating them? They won't be contributing members of society.'"

This misperception goes beyond ugly prejudice to embrace a broad misunderstanding. "Special needs" students are not "all mentally retarded in wheelchairs," she says.

About 90 percent of special needs kids are not cognitively impaired and can do as well as their peers, given the right services, she argues. The

remaining 10 percent can become valued members of the community.

As a culture, at least on paper, we have come a long way from the days when “handicapped” students were shut away, given lobotomies and shock treatment to deal with behavior issues. Massachusetts has been a leader in this progress, creating groundbreaking legislation that demands all schools provide students with disabilities a free and appropriate education in the least restrictive environment possible.

But Chambers says those laws are broken every day, in schools across Cape Cod and the state, for reasons that include both money and attitude.

MCAS exams dramatize the shortfall: only 26.1 percent of special ed students scored “proficient or above” in English language arts; for math the number was 15.5 percent. This reflects poor education, not poor students, Chambers says.

Chambers’ battle for equality started several years ago when she launched SPED Watch out of her Pepperell home. She became an advocate for special needs students after nearly losing her autistic daughter to suicide. Now her daughter is a successful senior heading for college, no longer trapped in a system that made no allowances for her, Chambers says.

Cape parents profiled in this issue also see their children struggling, unhappy and failing within the confines of public school.

Susan Danton was driven to start her own school for autistic children. She could no longer stand seeing her son Joe forgotten in favor of Barnstable’s bottom line – the district’s stubbornness and reluctance to provide services, as she saw it, prompted her to pull him out.

Educators know there are flaws. But they believe they are doing the best they can. We visit one classroom teacher proud of the work he does, and the accomplishments of his students. We visit with a creative, engaged family who feels they have gotten passionate care and commitment in the public schools.

Educators point out funding for special education legislation has never risen above 20 percent of what it takes to make all those programs real, and mostly it hovers around 15. That, they argue, is a recipe for failure.

Oftentimes, teachers advocate testing students they see as needing help, but are stymied by administrators who don’t want to add expense; once a student is shown to have special needs, by law the school must address them.

Finances aside, special education advocates say there is a pervasive underestimation of what students can accomplish, that schools are reactive rather than proactive, that accountability is lacking, and that inadequate training makes it difficult to break out of a cookie-cutter atmosphere.

Support groups are springing up among parents who could not get schools to acknowledge their children’s disabilities. And even if a good plan is created, sometimes parents have to fight tooth and nail to make sure it’s followed.

Brian Wasser says his son is stumbling backwards because Barnstable school officials refuse to follow a mandated education plan. He’s now in the uncomfortable position of considering a lawsuit against his hometown.

Other parents have become advocates for more than their own children. Toni Saunders is one; she hopes others won’t have to live with the kind of memories she carries, like when she was asked if her daughter, who has cerebral palsy, would be better off “with her own kind.”

She has seen frustrated and lost children who flunk out of school unnecessarily, and then wander down a bad path. “The school to prison pipeline,” she calls it.

Sometimes educators are so busy with multiple demands, and too little funding, that they don’t have time to find out why children are struggling, let alone provide special attention that can be something simple, or surprising; a hearing device for an auditory disorder, or help with deadlines and organization for what’s called “executive

dysfunction disorder” that causes a child with an IQ of 120 to fail.

Other times the need is more pronounced, demanding one-on-one attention outside the classroom. Here too there are countless examples of state-mandated plans not being followed, school districts denying a disability to avoid onerous and expensive work.

The Cape is by no means alone; advocates say school systems across the Commonwealth are failing special education students in profound ways. The irony, Chambers adds, is Massachusetts is excelling compared to many other states, a reality she says doesn’t bode well for the nation.

If local pressure produces change, it won’t be the first time Cape parents have been successful in improving services.

In 1994, Abbie Bowden, then nine years old and in the Barnstable schools, was physically restrained 14 times in one day for refusing to blow her nose, not going to the “time out” area when asked, and other “noncompliant” behavior, her mom, Jean, says. Abbie has autism and her mom says she has the mind of a three-year-old.

Teachers used what is called a floor restraint; the child is pushed face down on the floor; hands pressed against her back with a teacher sitting on the child.

The Bowdens settled a lawsuit against Barnstable in 2004, and the case convinced Beacon Hill legislators to pass a bill banning the use of floor restraints except when students are a danger to themselves or others. Similar restraints reportedly have resulted in children’s deaths.

“The only reason it got passed here is because they saw it on video,” Jean says, adding that Abbie is now in an out-of-district placement set up by the school, and the family is satisfied with the help they’ve gotten from Barnstable.

The use of restraints is seen as a civil rights issue because the tactic is not allowed on people without disabilities. Chambers extends the analogy: School districts continue to violate the

rights of special education students, much like black people and women were denied basic rights.

“If things are not going well, you need to stand up and put your hand up and say, ‘I don’t like what is going on,’” says Chambers.

In this issue, there’s plenty of that.

When pushing for special education feels like stepping in quicksand

By Doreen Leggett, Cape Cod Voice

Brian Wasser moves the red and white pills from beside the toy school bus on the kitchen table and plunks them on the counter.

“My son’s vitamins,” he says, adding it’s unusual for Sam not to have taken them.

Wasser’s son is autistic and has compulsive behaviors, which can be handy, the father adds with a grin; the six-year-old never has to be asked to brush his teeth and always wants to go to school, even if he’s sick.

Sam, who goes to Hyannis West Elementary School, is high functioning, Wasser says. “We’re lucky.”

That’s not only a proud parent’s view. Multiple specialists, he reports, have said, “Given the right services, our kid can get off the spectrum.”

But his son isn’t getting those services, Wasser adds. He’s sliding backward, while the father has gotten more and more frustrated.

Sam’s Individual Education Plan, the legal blueprint for his schooling, said he should get one-on-one attention and should be in the mainstream

Special Education Director Jane Jezard says the school should be able to address questions about each child’s education in a timely fashion, and the agreed-upon plan should be carried out.

But “should” is different than “is”; sometimes plans are ignored.

“I’m not going to say that it doesn’t happen,” she says. “But it shouldn’t.”

classroom 40 percent of the time.

He has never gotten one-on-one care, Wasser charges; his learning environment has ranged from six students per teacher to two students per teacher. And Sam is in the conventional classroom virtually full-time. Wasser says he can't even get a straight answer on who is working with Sam, and when he tries to figure out what is happening, he gets the hairy eyeball.

Like the time his wife decided to march in before the "scheduled observation time." She did so because the scheduled time "was nap time and lunch," Wasser says, rolling his eyes – tough to judge Sam's educators when his boy is eating or sleeping.

The Wasser family spent countless hours and tens of thousands of dollars having specialists in Braintree and Boston evaluate Sam, and it's important to them that the expert's recommendations actually happen.

But, Wasser says, when the time comes for the school to implement the plan, it doesn't. The staff isn't qualified, Wasser believes: "They hire the cheapest people they can find. [School officials] say it's important he receives services, but they are just running out the clock. The kid is going to be 40 years old before [they] get services for him."

Wasser apologizes for his sarcasm, but he is fed up with a system he feels doesn't care about his son – so much so he is thinking of suing the school.

He is trying one last route to avoid legal action, he says, because "property values go down. It looks bad for the school. I feel very loyal to my town and community."

But Wasser also suspects he might represent other parents at odds with the district. "I doubt we are the first people who have complained," he says. About that, at the very least, he is right.

What Rose Rogan has gone through with her son Christopher convinced her to become a family advocate. She's completed training and is now getting the counseling hours she needs to be certified.

Rogan says her son, who is eight, is hard of hearing and has a learning disability. Getting an Individual Education Plan for his time at Marstons Mills East wasn't an issue, she says; living up to it has been.

Christopher has an FM system the school pays for, a little box hooked into a microphone the teacher wears which helps Christopher hear. It was hard to get, Rogan says, and unfortunately breaks down regularly.

At one point he was without it for a week. Then it broke again and week after week after week went by – while school officials said they had a temporary measure in place.

One day her son said he felt like "the worst kid in the world." Rogan, an assistant at Marstons Mills East, walked into the classroom and, to her horror, saw they had outfitted him with a karaoke machine.

She put a stop to that, and continued to press for the FM machine. Rogan was told it was in California. She asked if they could get one locally and was told the district didn't have a relationship with local vendors.

After two months, she wrote a rather pointed letter, showed it to school administrators, and said she was going to drop off a copy at the superintendent's office. Coincidentally enough, the machine appeared that afternoon.

"They'll tell you they'll do anything but then nothing happens," she says; only hassling gets results.

Rogan then began advocating for a new, more effective machine that Christopher's doctor recommended. School officials told her it hadn't been brought to market yet, but when she e-mailed the company she was told it has been out for two years. Christopher still hasn't received it.

Being a school employee makes the whole situation that much stickier; Rogan got some attitude from co-workers.

"I don't care," she says. "My son comes first, before any job."

Linda Kelly took a slightly different route when her high school age son accumulated six

weeks of suspensions for what she terms “class clownish” behavior. Kelly and her husband were able to reduce that, but any extended time out of school for a teenager with a learning isn’t the smartest move.

Her belief her son’s education plan wasn’t being followed, now subject of a federal investigation, prompted her to start a support group for parents.

Kelly learned parents can have a voice in the district’s special education programs through a Special Education Parent Advisory Council mandated by state law.

“No one knew anything about it,” she says; the support group morphed into the more formal council.

Frustrations with the district vary from family to family, she says. Many involve stonewalling, or not providing services. She believes her son got in trouble after she pushed for a stronger education plan. And when asked she asked why he was disciplined, suddenly the tactic became verbal reprimands with no specifics.

That said, Kelly emphasizes that the council’s concerns shouldn’t serve as “sweeping” condemnation; a lot of people are doing a “wonderful” job, she adds.

Barnstable Director of Special Education Jane Jezard’s office is in the corner of the brick administration building behind town hall in downtown Hyannis. Trying to meet the needs of 800 special education students (some attending out-of-district placements like the Cardinal Cushing School), stay versed on the law, deal with a complex network of services, and grapple with a tight budget, makes for long, intense days.

Jezard says the school should be able to address questions about each child’s education in a timely fashion, and the agreed-upon plan should be carried out.

But “should” is different than “is”; sometimes plans are ignored.

“I’m not going to say that it doesn’t happen,” she says. “But it shouldn’t.”

Jezard, a low-key woman who worked for 10 years at Barnstable High School with emotionally disturbed students before becoming director, says she is proud of her staff, despite parental complaints.

“I think the students in Barnstable with disabilities are getting their educational needs met,” she says.

Jezard explains she’s in a Catch-22; specifics of each student’s plan are what matter rather than general concerns, but she can’t and won’t comment on specific students.

She did attempt to explain why parents feel their children aren’t getting services.

If the Individual Education Plan “team,” which includes parents, decides a student requires special help to access the general education curriculum, then in is “incumbent” upon the district to provide it. Yet some parents feel their child needs more services than the district proposes.

Others are pleased with the process, and the outcome, Jezard points out.

For example, Toni Zugle’s son, seven-year-old Harry, went to the same pre-school program as Sam Wasser, a program that Zugle describes as “fantastic.”

She uses the same word to describe the aide who works with Harry every day.

“We have always had a good team to work out what he needed to have better success,” she says. The town is working very hard. [Staff members] have the best interest of students at heart.”

Zugle readily admits the experience hasn’t been nirvana; transition from pre-school to kindergarten was sketchy. But those problems have been solved, she says, and she thinks her child is getting what he needs right where he is.

Part of the problem, at least when it comes to children on the autism spectrum, is the district has had to redo its program. There are bound to be problems when that happens, explains Zugle.

Harry is “classically autistic” non-verbal she says. His program has been around for years;

however, there has been an increase in students on the high-functioning end of the spectrum.

Those students, she says, don't fit well in the special education classroom or the mainstream class.

"I think the town is still struggling" with how to serve them best, she says.

Jezaard admits classroom teachers aren't trained to deal with every disability, but then again they shouldn't be:

"We need to meet the needs of a diverse population. That's why we bring in consultants."

"There are no decisions in special ed that should be made because of funding," Jezaard adds, pointing out that out-of-district placements can cost \$200,000 per child, per year.

But even teachers admit that money, or lack thereof, plays a role.

"You can't have a classroom for every kid," says Jon Watson, a teacher at the high school. "There is no money chest."

Clean cut, engaging and seemingly unruffleable, Watson is generally lauded for his work. He grins and says some parents love him.

"They know I respect their kid," he says; he communicates with parents every day.

And he thinks highly of his students, who stay with him from age 15 through graduation at 22.

"I get to know them very well, which is why it's so great," he says, sitting in his classroom near a banner that reads "Fair means everyone gets what they need."

He introduces three students, making sure each shakes hands and says hello. The teacher's assistants, Lori Ciran and Debbie Bearse, are quick to congratulate all three and move on to the next task.

Josh Norman fashions a place setting, and then puts everything away. He can use sign language and pictures to describe what he wants or needs; some of his peers can't communicate at that level.

Others, like J. P. Kennedy and Matt Wroe, have a wider range of skills. The two soon

arrive from a special education class up the hall. "They're a couple of characters," Watson says, coming for help in English and math. With three classrooms for different achievement levels, some students spend time in all of them. Watson says six of the eight students in the transition classroom have jobs in the community, which they'll keep when the graduate,

"That's success in my book," he says.

Watson is leery of reflecting on what goes on in other parts of the district.

"I would be stupid to think that every kid has every single thing that they need," Watson says. "Do I think my students have everything that they need? Yes. I wouldn't be doing my job if my students weren't getting what they need."

He heard criticisms of his program before he arrived.

"It was a revolving door of teachers," he acknowledges.

Josh's mom, who Watson describes as very able to advocate for her son, took Josh out of the program in middle school and sent him to Cardinal Cushing, at the district's expense. She brought Josh back when she saw Watson's efforts, and he's doing well.

Other teachers handled behavior problems differently, Watson knows. For instance, some used potato chips to lure recalcitrant students back into the classroom.

Watson makes one thing clear: He doesn't do that.

Brian Wasser, Sam's dad, sympathizes with the challenges teachers face, saying some do a good job but don't have the tools to do right by Sam; for one stretch of several months, his son's speech therapy class was in a hallway, then in the cafeteria. That shouldn't happen, he says.

Wasser is a lawyer, so his background helps him marshal arguments. Sitting at his computer, he moves the mouse to double click in various letters and reams of documentation he needs to stay on top of his son's education.

"It's difficult because it's a bizarre and foreign field and they are speaking their own language," he says. "The parent is at a huge

disadvantage. It takes up a lot of time, energy, money and the schools know it.”

“No matter how clear you are, the school will always impose loose language with lots of loopholes.”

And if you push for something, he continues, they can scuttle the whole deal. An old IEP will remain in place until a new one is approved; if parents don’t compromise they may lose all the improvements made:

“They sort of blackmail you into accepting.”

The Wassers recently contacted the Massachusetts Department of Elementary and Secondary Education’s Program Quality Assurance Service, one of myriad departments that checks whether schools are complying with special education law.

The state contacted Barnstable about Wasser’s concerns and the district’s response, says Wasser, convinced the state to open its own investigation.

School officials readily admit that they aren’t following Sam’s IEP, he says, claiming the program they have is in the best interest of the child – an opinion Wasser stridently disagrees with.

This time he got some satisfaction from the state, which said the school violated several aspects of Sam’s plan, including “failure to provide complete program, required services and the proper learning environment – a classroom.”

Wasser is “grateful” for the state’s assessment. But, he says, the department goes “too easy” on schools. Still, he sees the report as ammunition when he voices concerns.

“[School officials] always deny everything and say everything is wonderful,” Wasser says. Now they can’t do that, at least not as readily.

The Wassers are again at loggerheads with the school about what is best for Sam, and what the school is willing to provide. Wasser has hired specialists to map out goals.

“When an expert looks at the schools, they usually roll their eyes; for parents it doesn’t inspire much confidence,” he says.

If the school and the Wassers can’t agree by the beginning of the school year, the state will step in again.

Wasser says so far the district’s response hasn’t convinced him to abandon thoughts of a lawsuit, but he is hopeful the state’s report will help Sam and other special education students.

“It’s sort of a warning shot,” he says.

Using every detail to advantage and to advocate

By Rose Connors, Cape Cod Voice

“I’m a crazed advocate,” says Toni Saunders.

She doesn’t look crazed. She’s relaxed and smiling in her Sandwich home office, surrounded by filing cabinets “full of kids,” where she runs Associated Advocacy Center-Visions for the Future, Inc.

Saunders does, however, sound like an advocate. Her passion is palpable, her mantra simple: “Save the children. Heal the earth.”

She started with one of her own.

Her family lived in Brockton when daughter Cassandra, who has cerebral palsy and uses a wheelchair, started school. “It was a daily fight to keep her in regular education classes,” Saunders says. The school wanted to segregate her.

School personnel seemed to regard special needs kids as “less than,” Saunders says. At a transition-to-high-school meeting, she was told her daughter should be in classes with “people of her own kind.”

She shakes her head hard, like someone sloughing off a bad dream. “Can you imagine?”

Saunders stuck to her guns, telling teachers and administrators, “You have to educate her for real.”

As a result, “Cassandra never was in a special needs classroom.”

From an adjoining office, Cassandra laughs.

“Except for one month,” Saunders says, fighting back her own laughter.

“All of a sudden, she didn’t have any homework. None. Each night, I’d ask and she’d say, ‘No, no homework tonight.’ I thought maybe it was because it was around the holidays.”

The laughter next door kicks up a notch.

“She didn’t mind,” Saunders says.

Finally, after a month, Cassandra ‘fessed up.’ She was “not still in the same classes.”

“I went into the school that minute,” Saunders says, demanding to know why.

The school didn’t have an aide, she was told.

“I said, ‘You don’t have to have an aide. It’s the law. Now we’ve lost a whole month. What are you going to do about it?’”

After a “team meeting,” the school coughed up funding for an aide and agreed to provide summer tutoring.

The family moved to the Cape in 1997 and Cassandra, now 25 and working as a web site designer, graduated from Sandwich High in 2001.

That’s when Saunders began advocating for other people’s children.

Some parents “don’t fight because they don’t know they can or they don’t know how to,” she says. That’s when she steps in.

She works with teachers, parents, and doctors “to help children succeed in school.” Some of the children she champions are special needs students, some not. Then again, she adds, “all children are special. Every kid has special needs.”

The students she works with are “having a hard time accessing the curriculum,” she says. “I help them figure out why.”

She starts with a comprehensive records assessment. “I read everything,” she says. Test results, teachers’ evaluations, doctors’ notes – she knows “everything about the student” before she meets with administrators, teachers, and parents about a student’s independent education plan.

Having all the facts at her fingertips is key, she says, because “no one else does. Everything

I know I learned from them, so they could know everything too. They just don’t do it.”

If school officials “don’t know what the disability is and how it presents,” she says, then “they don’t know what the child needs.”

“You go in [to a meeting about an education plan] with more information than anyone else and you win,” she says. “It’s that simple.”

“We are talking about money here,” she acknowledges, but for her, money is not the stumbling block.

“We have the money to educate our children…”

“Most of what these children need can be remediated with appropriate identification of services, accommodations, and modifications. These, for the most part, are already budgeted for.

“Districts get more funding for children with disabilities than without … Where is the money going?”

Saunders has worked more than 1500 cases across the state, charging between \$50 and \$100 per hour “depending on the unique circumstances of each family.” She uses a “sliding scale” to adjust fees downward and at times offers her services free.

When she finishes her assessment and makes recommendations, “usually the school is happy, the parents are happy, everybody’s happy. The student graduates and life goes on.”

Since she began seven years ago, Saunders says, “I’ve only raised my voice twice.”

“Once in Mashpee, I had to end a meeting because the principal was yelling, even at his own teachers. He was telling them to be quiet, to stop answering my questions.

“He said, ‘This is my school.’”

“I said, ‘Excuse me, but it’s the taxpayers’ school.’”

If a student’s difficulties can’t be resolved by working directly with school staff, Saunders petitions the Department of Education in Malden for an administrative hearing.

“I do take people to hearings,” she says, “It’s not something I enjoy. In fact, I hate it.”

Part of the problem, she says, is that some schools identify learning disabilities based solely on their own testing. “School teams try to diagnose,” she says, “but they don’t have the expertise. Doctors diagnose.”

Saunders doesn’t diagnose either. “I listen to the child’s symptoms, and I’ll tell the parent, ‘When you put them altogether, it sounds like autism. But I can’t give you a diagnosis; you need to go find out.’”

She recalls the case of a 10-year-old boy who’d been acting out in class. School authorities wanted to put him on lithium, but her investigation revealed that the problems surfaced when the child’s parents divorced.

“That’s not bipolar,” she told the school. “That’s post-traumatic stress. He doesn’t need lithium, he needs counseling.”

It’s not just that schools don’t require a full work-up, she says. “They don’t want you to get one,” she contends.

“All they do is give parents test scores, with no explanations. Parents don’t know what [school personnel] are talking about. The schools aren’t telling [parents] what they need to know to make an informed decision. And that’s part of the law – informed consent.”

She pauses for a breath. “I really love what I do.”

With proper testing, she continues, “I can find out why a child brought a gun to school.” Some parents come to her after drawing their own conclusions, wanting to place their child in a particular program.

“If I don’t think that’s appropriate, I’ll tell them. Sometimes they’re not happy about that; they say ‘thank you very much’ and go away. And that’s okay.”

When she started in 2001, Sanders recalls, special education directors put specific, written recommendations into students’ education plans. Now they don’t. “And they all stopped at the same time,” she says.

“I asked, ‘Why all of a sudden?’

“They said, ‘Because we found out that parents will hold us to what’s put in writing.’” She does that shaking-off-a-bad-dream thing again.

Saunders advocates for a number of children who suffer from Williams Syndrome, a condition akin to autism. Williams kids share specific facial features, close-set eyes and puffy cheeks. They also share an uncanny affinity for music.

“These children have great strengths,” Saunders says. “We can teach them with music. If we say the alphabet to them, they won’t get it. If we sing it, they learn ...

“But try to get music therapy into a program for a kid with Williams. It doesn’t happen.”

So what becomes of the Williams kids?

Saunders sighs. School systems routinely put them in “life skills” programs, she says, and then “pretty much throw away the key.”

Another diagnosis that shows up frequently in Saunders’ caseload is auditory processing disorder, a condition experts believe affects five percent of school-age children. These students have normal hearing, but the ear and brain are out of sync; the kids can’t process words the way others can.

With APD, Saunders says, schools tend to find children at fault for having a special need.

“Pretty much every meeting I go to, they blame the kid. I keep telling them, ‘You can’t do that. If he spells phonetically, there’s a reason for that.’”

Schools have a “major bias” against these students, she adds. “It’s so sad. So many of these kids could be graduating with a diploma.”

She plucks an engraved invitation from the shelf above her desk. “This is my first kid graduating from college,” she announces. “He’s getting a degree in criminal justice.”

And he’s only one success story.

“Toni fights hard for all her kids,” says Gwen Haddad of Falmouth. “There are a lot of things she just won’t let the school get away with.”

Saunders has been an advocate for three of Haddad’s six children: 19-year-old Terrence has

been diagnosed with attention deficit disorder; 14-year-old Christopher with auditory processing disorder; and 6-year-old Eli with Williams Syndrome.

Saunders got involved with the family when Terrence was in 10th grade. "He wanted to quit," his mother recalls. "High school can be very tough." The fact that certain teachers seemed hostile made matters worse.

Saunders went with Haddad to meet with teachers and administrators and "questioned why," Haddad says. In the end, she got Terrence transferred into different classes, where "other teachers were willing to work with him." In 2007, Terrence graduated from Falmouth High.

For Christopher, Haddad says, Saunders' efforts led to his having just completed his "first full year of regular education classes." He starts high school this fall.

School authorities wanted to place six-year-old Eli in a "special program" at Mullen Hall, but Saunders lobbied for a repeat year of regular kindergarten instead.

"They just didn't know how to teach him," Haddad says.

Now paired with a kindergarten teacher "who really wants to work with him," Eli is "doing his numbers, letters, and shapes," his mother reports.

"When you have a child with disabilities," she adds, "it brings out the best in you. It's an honor to be the parent of a child who's doing his best. He doesn't have to be Einstein to have a productive life.

"Toni taught me that ... I call her Superwoman."

But Saunders says educating our children doesn't require superpowers. "All you need are the right tools."

She estimates she carries between 70 and 130 active cases. "There are no lulls in my business," she says. She does assessments throughout the summer, then "hits the pavement running" in September.

"Because these kids should not be thrown away."

A new school emerges - with only one student so far

By **DOREEN LEGGETT**, Cape Cod Voice

Susan Danton sits down at a table in her new school, smiles and makes a confession:

"You know what? I don't hate anyone anymore."

She no longer feels the ugly urge to run someone down with her car – not that she ever would, of course. But her feelings for her son, Joe, run very deep and he was suffering.

"He was so angry and disruptive, he was so very unhappy," she says.

Danton and her husband, Tom Bober, felt trapped in the Barnstable public schools, like a bad episode from "Groundhog Day," the film about the same day repeating over and over again. Doing the same thing again, expecting a different result: Isn't that the definition of insanity?

So they took Joe out of school and opened the Manor School for autistic children in a building they own on Route 134 in Dennis, downstairs from Susan's business, Dynamic Listening Center of Cape Cod, where she works with children and adults who have learning disabilities.

"This is student number one," she says, inclining her head toward Joe. "Necessity is the mother of invention. If I could do it for him, why not other kids?"

There are no other kids yet; she still has a number of obstacles to overcome. She pays about \$80,000 a year to give her son the services he needs; she also has a legal tab of at least that much, run up trying to get the Barnstable schools to provide similar services. She is trying to recoup both costs.

"We've been hemorrhaging money," she says matter-of-factly.

Danton is applying for approval so school districts will pay for children who attend the Manor House. Other parents are interested in her school, but an out-of-pocket cost of \$2400 a week isn't feasible.

She had hoped to take a big step forward this summer. If the Dennis-Yarmouth school committee agreed that she had the proper curriculum, policies and procedures in place, she would join the list of accepted, reimbursed placements.

But the school committee postponed the meeting, a huge disappointment for Danton, who has more than 100 pages of information waiting to buttress her case.

If Danton's home district finally signs off, Manor House will be one of a small handful of approved schools started by parents. Most parents unhappy with public schools lobby to get their children into established private schools.

Danton argues there are no nearby schools that provide the services available at Manor House. One sign that she might be right is down the road from her, on Telegraph Hill, where another mother feels the same way about the school she is opening, Tandem Academy.

Mary Gallante has so little faith in public schools that she isn't trying to win the district's approval. She is starting her school for kids with Down Syndrome strictly as a private pay facility. She doesn't want her two boys, Joseph, 9 and Thomas 4, to be buffeted by problems she says plague the traditional system.

"I want them to just go to school – no politics, no money problems; just teach these children what they need to know to go out into the community," she says.

Danton doesn't want to go that route; she wants a partnership with public schools.

"Will it work?" she asks. "Yes, absolutely, without a doubt."

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"Joe, 7, runs from a swing to a pile of blocks to a maze-like tunnel. He looks like any kid having fun, but every action has a purpose; getting Joe to listen, comprehend, and perhaps most importantly, ask for things by name.

Danton watches her son work with his teachers, and reply to requests. Sometimes they're one-word answers, but for a child who

was non-verbal a short time ago, one word is music to Danton.

He needs a room filled with motivating things, she says, "because we want them to ask for stuff." The coveted items are usually just out of reach.

"They have to be motivated to talk, because they don't want to talk," she says. "And then, oh boy, do they talk."

Joe's classroom in the public elementary school had no toys in it, Danton, says, nothing to motivate him.

Here, with two teachers trailing behind, Joe walks into a more structured room and sits quietly at a desk. He practices hundreds of tasks, including demonstrating the word "across." When it comes up on a note card he runs a toy truck across the table and is congratulated by his teachers.

Joe seems content accomplishing his tasks; he already knows how to do 80 percent of them, so he doesn't get discouraged or overwhelmed.

Danton argues that her son, and many other autistic students, are as capable as most children in a mainstream classroom.

"They have no cognitive disability, just behaviors that can be shaped. There is no reason why they can't make it. If they get the right interventions they can be the originators of wonderful things in the future."

Flailing arm movements often associated with autism are stopped – "blocking" is the clinical term – by the teacher who holds Joe's hands down, asks him to stop, and redirects his energy to a pile of Play-Doh.

Danton says those movements, or "stims," were out of control before Joe's teachers took up the verbal behavior approach of Applied Behavior Analysis, so much so that he was deemed "unteachable." As those movements were reduced he learned more language, which further reduced them and other "problem behaviors."

Danton says many people, including police, are concerned about outbursts of autistic people. A child may start punching a police officer, but

with extensive effort those damaging behaviors can be stopped.

But they won't stop if a child is just punished. The behavior needs to be dealt with so the child can learn.

"Joe doesn't have those hideous aggressive behaviors anymore," she says.

"He is verbal now," she says. "He has a repertoire of words. He listens so beautifully.

"It's been a long time since I've seen miracles."

Danton speaks unashamedly. It's a lot of work to have any kid in the house, she says, and with a child like Joe the difference is exponential. No doubt she loves him, would give her life for him, she says, but she used to think, *Where is my life?*

Now, she says, she asks Joe if he is done eating and he puts his plate in the sink. She says it's time for bed and he goes and brushes his teeth.

She says, "Joe, give me a hug," and he scurries over and gives her one.

Tears well in her eyes.

"We are giggling at home. We are laughing," she says, eager to share all Joe has accomplished in such a short time.

"He understands that water is in a cup, comes from the sky, is in a puddle, that he takes a shower in it," she says. "No way he would be like that if he was in Barnstable."

"They may be very nice people," she says, "but they are not trained."

Jane Jezard, Barnstable's special education director, won't comment on Danton or her new school, because Barnstable faces a lawsuit from Danton about the district's treatment of Joe.

But one thing is certain: If he was in Barnstable, the district would be paying for specialists who cost Danton \$60 an hour.

Danton hopes that by "providing a specialized program, one-on-one approach," students will improve so much that they won't have to stay in private placement. If services are provided early, students could succeed in mainstream

classrooms – and cost much less money to public schools in the long run.

"My philosophy," Danton adds, "is if they aren't cutting it in these public schools, could it be they need an intensive environment first?"

She feels the Manor House, named for English gathering halls where everyone was treated equally, is just the beginning. Danton wants the school to grow into a research center with clinical services, to work with and improve the public schools.

And as much as her fledgling school has helped her son, it's helped her too.

"I don't have a cold pit in my stomach anymore," she says.

The civil rights role model, with the same goal

By Jeffrey S. Davidson, Cape Cod Voice

In 1957, nine black students tried to enter an all-white school in Little Rock, Arkansas. White students and parents protested; the governor blocked Central High's doors. Finally, President Eisenhower sent the U.S. Army's 101st Airborne Division to escort them in. That didn't solve the problems, but it defined a civil rights movement, and gave face to the Supreme Court's resolve to desegregate public schools.

Maybe that kind of escort is what Massachusetts children with disabilities and their parents need. According to Ellen Chambers, SPEDWatch's founder and executive director, it's the same battle for civil rights, being waged by a group facing similar discrimination.

SPEDWatch formed in 2006 with one goal: To demand "that children with special needs in Massachusetts be given the education they are legally entitled to."

The group calls itself a "grassroots nonprofit social change movement" working "within the context of a civil rights movement," trying to

bring about change through dialogue or, if necessary, direct action.

At Dennis-Yarmouth, for example, only 14 percent of special needs students suffer “significant cognitive impairment.” MCAS scores for the rest of the special needs population should mirror those of non-disabled students, but don’t. According to SPEDWatch, less than 14 percent scored proficient or better in 2007.

“It’s fundamentally wrong,” she argues. “It’s child abuse.”

Chambers traveled from Pepperell to Yarmouth earlier this year to highlight problems with Cape schools. She chose the South Yarmouth library to unveil her organization’s report, “Broken Promises: Special Education in Massachusetts,” because SPEDWatch gave the D-Y system a “D” grade for its compliance with special education laws.

Chambers told a small group that D-Y isn’t alone; schools across the state consistently fail children with special needs. She blames the system, not the district.

Oftentimes the fix is not expensive, but takes time and effort to figure out, Chambers says.

Those comments prompted an Upper Cape mom to tell a story familiar to others in the room. Her bright, elementary-school-age daughter wasn’t doing well academically, and that was affecting her outlook on life. The mom had pressured the schools to diagnose the problem but was stymied until a specialist in the system tester her child for Irlen Syndrome, which causes people to have problems reading black type on a white page.

Outfitted with pink-tinted glasses, the child is now successful, her mom said, but the questions remain: Why aren’t specialists available in every school? Why aren’t children tested before they suffer for years? Or worse yet, what if her child had been in another district where a specialist wasn’t available.

On paper, Massachusetts promises much to special needs students, thanks to a law that’s been on the books for 34 years. It’s stronger,

more detailed than the federal equivalent it inspired. But “schools can break the law with impunity, without consequences,” Chambers says.

Violations need only be corrected within a year to retain federal funding. A year is an eternity for a young student, and “nothing [in the law] requires improvement,” she argues. The money keeps coming even when the same violations occur several times a year over several years.

Cape schools are about on par with other regions, Chambers says. Some are not doing badly, others “horribly, horribly, just about as bad as they could get.”

Most frequently violated are laws that require the development and implementation of Individualized Education Plans, annual reviews, and evaluations. For example, as recently as 2006 in Barnstable, “they were not evaluating students with disabilities properly, which means you’re dead in the water.”

Several Cape schools are “not doing the appropriate outreach to find students in need,” meaning students are being neglected. Many schools have failed to properly report on student progress or to “document and justify why students are removed from the mainstream.”

Chambers blames funding, not teachers.

“The federal government has never properly funded special education,” she says, and neither has the state. Special needs students put schools under strains that administrators don’t want to deal with:

“Their job is to prevent as many children as possible from being found eligible for special education, and for those children that are found eligible, to minimize as much as possible the amount of attention each child receives. And that is without regard for what the child needs and has legal right to.

“It’s educational neglect. When parents do it, they lose their children. When schools do it, they get a pat on the back for staying within budget.”

Chambers understands financial hardships, but “the answer to not having enough money is not to deny students the help they need.” SPEDWatch is pushing the state to up its commitment, but so far, says Chambers, it’s been a dead end.

State Special Education Director Marcia Mittnacht and Interim Education Commissioner Jeffrey Nellhaus have responded by detailing what is already being done, suggesting other possibilities for later, but committing to nothing.

The June release of Governor Deval Patrick’s Readiness Project report on education also failed to address special needs students. “The report is very broad and very vague,” Chambers says. “It’s heavily weighted toward putting support and resources in for students who are low income or face other socioeconomic factors.” But there’s “no recognition at all that we have a rampant noncompliance issue,” she says.

“It’s all very lovely, pretty words,” she says. “I’m going to have to bring a crying mother into his office.”

Chambers also met with newly-appointed Commissioner of Education Mitchell Chester in June. She didn’t bring an agenda, rather an introduction to SPEDWatch.

Chester asked if she thought increased compliance would really have a positive effect. Her answer, of course, was yes.

“He just didn’t seem very concerned,” she says.

Chambers distills the official position as follows: “Sorry kids. We have a pervasive lack of commitment to do anything to help.”

SPEDWatch has turned to direct action, demonstrating at the department of education, pushing to have a special education director in central Massachusetts fired. Now the group is tracking that woman’s job search; wherever she interviews, the group tells local parents about her past:

“I call it an intervention. The message is clear: there are people watching,” Chambers

says. “You can’t just breeze through your career.”

Tactics like those are controversial; many educators believe children would be better off if SPEDWatch fought for money to help them meet their goals, instead of working against them.

Chambers isn’t deterred, however, and sees public perception as another target for the grassroots approach.

The public still “devalues people with disabilities,” she says. And so people ask why a school on a limited budget “has to give all this money to kids that aren’t going to give anything back.” She thinks that perception can be changed by education, and informing parents of their rights. SPEDWatch offers a way to “get together and speak with a unified voice.”

Civil rights progress highlights the problem – and gives Chambers hope.

“How many black parents have to hire an advocate so that their children can go to school with their white peers?” she asks. The answer today is next to none; she would like that to become the case for parents of kids with special needs.

Instead, parents are burnt out battling with their school districts, she says. They have to find advocacy if they can afford it, or start a legal battle, and watch their children suffer.

“We don’t expect things to change overnight. We’ve already been waiting over 30 years. How much longer do you want to wait? I’m done waiting. Schools would still be segregated if the black population had said, ‘We don’t want to push too hard.’

“We’re taking a tried and true strategy and applying it to this problem,” she says. “Make people aware so people will be interested.” Then she figures, lawmakers will have to comply.

With any luck, intervention by the 101st Airborne won’t be necessary.

Getting There

By SETH ROLBEIN, Cape Cod Voice

Max Macort is ready to start the second grade, a big moment in any young life. But for Max – extraordinary, smart, idiosyncratic, charismatic in his unique way, but also grappling with the difficulties of Asperger’s Syndrome – that’s a bigger leap than most kids have to make.

Max is making his way in the Orleans public school system with a lot of love and support from home, and a lot of compassion, flexibility, and personal attention at school. It hasn’t been easy, and won’t be; neither has it been anything close to a “by the book” approach to helping a student with “special needs.” But Max’s story is a compelling account of how a family, and a school system, try to help an unusual child – while understanding that he is not the only unusual child in the world, that the school cannot take on full responsibility for his life and growth.

We’ll let Libby Macort, Max’s mom, a Cape Cod native (who worked for several years here at the *Voice*) pick up the tale:

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“We knew he was really bright from the get-go,” Libby remembers, but when he started pre-school in Brewster, the staff kept offering ideas to “make things easier” for Max.

“Well, why?” Libby remembers wondering with her husband Tim. “Why does Max need that? Is he different?”

For some reason, call it parental instinct, they delayed getting Max his “MMR” (measles, mumps, rubella) vaccine until he was three – some studies now suggest the vaccine can trigger the onset of the syndrome. A month later, the school called to ask for a meeting.

“We have a strong suspicion that Max has Asperger’s Syndrome,” they told the Macorts.

“What?” was Libby’s response. “I’d never even heard of that. Basically I stood up, walked

out of the meeting, and started making phone calls.”

Asperger’s, Libby found out, is a form of autism, but with striking characteristics. Children often reveal extraordinary verbal skills and high intelligence, but have serious trouble with social interactions. They can’t deal well with change, have a hard time reading “body language,” often become obsessive or preoccupied, need a set routine, panic when surprised.

“It was all so bittersweet,” she remembers. “We were finding there were labels to what we were seeing with Max. And there was a kind of grieving – I could see that we were going to have to work hard to help this kid.”

That work started right away, with an occupational therapist, speech therapist, behavioral advisors, so by the time Max was ready for kindergarten two years ago, and a group meeting was pulled together in August, Libby had a good idea of what she was hoping to see in the school.

“I went into that meeting thinking we were going to create an IEP,” she remembers, an individual education plan that would outline how Max should be educated. She knew some of the things that would help; preferred seating on the left-hand side of the room, a visual schedule, warning if something dramatic like a fire drill was about to happen.

Instead of an “IEP,” she heard school officials talking about a “504,” which turned out to be a federal version, similar but different.

“Our state is stronger than the federal requirement,” she says. “The 504 thing is a handshake – we’ll try to do our best. The IEP is mandated. It’s not like, ‘We’ll try,’ it’s more like, ‘This has to be.’”

Advocates for special needs kids know the distinction very well, push for parents to insist on IEPs, and say schools are reluctant to write them because of the money and commitment they represent. But Libby was more concerned with the personalities, relationships, and real goal – a good situation for Max.

“You really have to be an advocate, no doubt,” she says, “but you don’t have to be a real jerk. If I’d gone in there double-barreled, in their face all the time, what kind of relationship is that for Max, for all of us? We all should be on the same team, trying to help this kid live. So who’s going to benefit from an adversarial relationship?”

It was a different kind of approach than the hardball many parents feel they have to play. The question was whether it would work.



The first week of kindergarten was a little honeymoon, but in retrospect, Libby thinks Max was “so anxious he was kind of paralyzed.” Before long, some classic Asperger’s reactions began to surface, one of the most troubling being that Max would jump up and bolt, run out of the building at stressful moments.

“It’s fight or flight,” Libby says. “Something, anything, a smell, a taste, someone saying something mean, can trigger it. And it’s been drilled into him that fighting is not acceptable, so flight is the only option. Trying to stop him is like telling someone halfway through a sneeze not to sneeze.”

School staff members were soon chasing Max through the parking lot. “At this point I think they realized, ‘Oops, this is more serious than we anticipated,’” says Libby. “But the cogs turned so slowly, just trying to get this kid under control.”

Frustrated by that, but overjoyed at “the incredible bond” Max was making with his kindergarten teacher Judy Suchecki, the Macorts kept working on ways to get Max help. He was being pulled out of regular class for one-on-one attention like speech therapy, and he had calmed down a bit but still became very anxious at unexpected moments. Libby theorized that “fine motor skills” might be a big part of the problem, that he became frustrated when he couldn’t do specific things well. She got a referral to RHCI, the Cape’s rehabilitation center, to get special help for speech and motor

skills, driving to Sandwich many times a week for six months.

And the family got extra creative, finding people who train “assistance dogs,” almost like seeing eye dogs, raising enough money among friends and family to bring “Coco” into the house. Sure enough, the dog senses when Max is on the verge of a panic, calms him and keeps him from bolting – or at least finds him right away.

All of this needed to dovetail with progress at school, and that was slow in coming. When Max reached first grade last fall, Libby remembers, “he kind of blew a gasket” with the big changes and once again became very difficult to handle. “At that point the school really had to take it all seriously, and finally started getting the net in place,” she says. “It wasn’t because they were mandated by some law. It was because they could see that otherwise, this kid would fall to pieces.”

Working with a team including his teacher, aides and school psychologist, simple but crucial tactics evolved: When Max started feeling tense about something, he was told to touch his nose – right at the outset. A teacher would be alert to the signal, come to help. “The whole idea is to head things off at the pass, so he doesn’t get to the point where he runs away, or throws a desk,” says Libby.

Max got a clear reward for coping rather than bolting: a game of catch and some quiet time with a teacher he especially liked. In anticipation of his move into second grade this fall, the school invited Max over to play cards in the new classroom, so he can get used to it in advance and not feel overwhelmed. He’s celebrated for his interest in Indiana Jones, for wearing an Indie hat like his hero, for his successes.

All this is happening without an “IEP,” and without the legal teeth that process can bare. The Macorts have decided not to push beyond the “504” they have in place, understanding full well that this is a less muscular document from an enforcement point of view.

“The care and warmth and support the school is offering Max now is so fantastic. I don’t want to ruin it worrying about which three letters or numbers are on top of the page,” Libby says. And so it’s about trust (after all, the school has her kid in its care) but also about an understanding on the Macort’s part that public schools are under stress, and that Max sometimes adds to that stress because he needs special attention – which can become very expensive.

“They never imply that, but I think about it,” she says. “So there’s a limit to what I ask for, because I can make up for a lot at home. I don’t think the school’s job is to raise our children for us.”

And so this unusual family, with an unusual kid, is navigating in creative, unique ways, trying to find the line between advocacy and cooperation, wanting everything good for Max but not believing this should (or could) come only after becoming an adversary to the schools.

It’s not a path every family can take, it has its dangers just like every other way. But for now, Max is looking forward to the second grade, and his mom is looking forward to the future:

“I’m told kids like Max really thrive when they hit college, and that kind of environment,” Libby says. “I really want to see him get there.”

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