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For Autism Programs, Revolving Issues

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AS school districts across the Island work on the budgets they will put before voters in May, they are facing a growing financial headache: the rapidly rising cost of educating autistic children.

New York State law requires specific education programs for children with autism, one of the few disorders covered by such a mandate, and the districts have no choice but to provide them, one way or another. The programs cost tens of thousands of dollars a year for each child, and \$100,000 a year or more in some of the best programs.

Case numbers are exploding, because autism is being diagnosed much more often and because families with autistic children are gravitating to school districts that are seen to provide the best services. And dwindling state aid to Long Island schools is saddling local property taxpayers with a greater share of the bill.

According to a 2005 study by the Centers for Disease Control and Prevention, autism has been diagnosed in 1 in every 166 people nationwide, triple the rate seen in 2000. Experts estimate that 18,000 cases of autism -- a developmental disability that can cause social isolation, repetitive behavior and difficulty in developing language skills -- currently exist on Long Island.

"The costs to educate an autistic child are very expensive," said Christopher Gallagher, superintendent of the Southold schools and president of the Suffolk County School Superintendents Association.

Noting that Albany's system for allocating state aid works heavily against Long Island districts, he said, "Just like everything else in public education, the state isn't shouldering their fair share of the burden, and instead is pushing the responsibility onto the taxpayer."

Some districts send their autistic children to programs run by one of the Island's three Boards of Cooperative Educational Services, known as Boces. Others hire a consultant to provide services in the district's own school buildings instead.

Dr. Gallagher said his district chose the in-house approach because busing its three autistic students (out of 1,000 students over all) to the nearest Boces center, 45 minutes away, would be more expensive. The difference in cost could have ranged from \$128,000 to \$188,000, with the state reimbursing 25 percent of the difference.

Either way, most autistic children are taught in settings separated from the main student population. There is a growing view among experts and parents that most autistic children do better if they stay in a mainstream classroom and the special services they need are performed there. But this approach is much more expensive.

Albany has identified five districts around the state as having especially high-quality programs. Two are on Long Island: Half Hollow Hills and Three Village. The two districts report that as a result, families are moving in from other parts of the Island specifically for autism services.

Enrollment figures show that the two districts now have unusually high numbers of autistic children: 87 in Three Village, which has 8,000 students in all, and more than 120 in Half Hollow Hills, with 10,000 students. The figures translate into rates of 1 in 80 and 1 in 90, roughly double the national average.

The state gave the two districts grants to develop elaborate programs of services, delivered in both the classroom and the home, as a model for other districts to emulate.

But Patrick Harrigan, assistant superintendent in Half Hollow Hills, said that reimbursements from the state had not kept up with the expanding costs of the program. And he and other administrators said they doubted whether more districts would follow suit.

"We have hosted many site visits, so that other districts can learn from what we offer," Dr. Harrigan said. "If they could offer it in their own district, then it would encourage parents not to move." But finding the staff, space and money needed to start such a program "may be too much of a struggle for some districts these days," he said.

Evelyn Ain, the mother of an autistic child and the publisher of Spectrum, a national magazine for parents of children with autism, said she warns parents to be careful about moving to a school district solely because of its autism services.

"These programs are not written in stone," said Ms. Ain, who is from Oyster Bay. "Administrations can change, teaching methods can change, and districts can cancel a program completely because of budget problems and opt for the Boces program instead. Then you will find yourself in a situation where you spent a huge amount of money to move, and the program you moved for fell apart."

Karen Loiacano moved to Massapequa two years ago specifically because the schools there had a well-regarded program, run by a nonprofit organization in Plainview called the Genesis School, that she thought would suit her autistic son's needs. Two months later, she learned that the district planned to drop the program and bus its autistic students to a Nassau Boces facility.

"I was livid," she said. "I've seen how Boces works, and I know it's not for him."

Parents in Massapequa successfully lobbied the district to choose another program akin to Genesis, known as the Eagle Program, rather than use the Nassau Boces.

"Not everyone can afford to live in a certain town, but every child should receive the same services," said Melanie Farris of Port Washington, whose autistic son is enrolled in an out-of-school program at the district's expense. "As parents, we try our best to go where the system does work for your child. But a child doesn't choose to be autistic, and there should be equal opportunity for everyone with this disorder."

Experts say that the quality of services for autistic children varies considerably from district to district, and that many of those who struggle most with the cost of services are in low-income areas. Even proper diagnosis of autism can be a problem in some districts because of cost.

"We certainly ask the question as to whether identifying kids is stronger in some districts than others," said Dr. John Pomeroy of the Cody Center for Autism at Stony Brook University. "You need the financial backing to access the services for diagnosis and early intervention. Those children from low-income communities may be falling through the cracks."

With so many districts struggling with budget cuts to other cherished programs, parents say the rising cost of autism programs is sometimes met with resentment, or a head-in-the-sand response.

"I have seen districts skirt around the issue, by questioning the services a child needs, because they would rather spend the money on new bleachers," Ms. Ain said. "The priorities in some of these districts are screwed up."