

Public schools open their doors to autism

New classes driven by savings and desire to keep children in the community



DANIELLE P. RICHARDS/STAFF PHOTOGRAPHER

At the Stepping Stones program in Fair Lawn, from left, instructors Lucia Pascua, Heidi Nicholas and Janine Reccione with pupils Vinny Gimmelli, Daniel Dubin and Caitlin Doherty. Officials say openings there are "very rare" in a program that cost \$49,000 per child last year.

By **KATHLEEN CARROLL**
STAFF WRITER

The growing number of children identified as autistic – and the steep cost of educating them – is fueling a boom in public school programs.

In Bergenfield, a dozen pre-school students are attending the inaugural class of the TriValley Academy, a collaborative effort with New Milford and Dumont. Districts including Leonia and West Paterson also opened new autism classrooms this month.

Existing programs are growing quickly. Hawthorne, Paterson and Teaneck have added classes. A two-year-old program for teenagers run by the Bergen County Special Services School District grew 50 percent this fall.

Public awareness of the disorder is at an all-time high, and more children are being classified as autistic under special-education rules. Plus, the state's stellar reputation for autism programs has attracted fam-

ilies from all over the country, creating demand for more services.

Last year, there were 7,400 students throughout the state – a jaw-dropping 30-fold increase since 1991. There were 2,150 students in Bergen, Passaic, Morris and Hudson counties.

"We know a lot more about autism than we did a decade ago," said acting Education Commissioner Lucille E. Davy. "People are focused on, the sooner you in-

tervene, the more likely it is that you can really bring about positive change for these young students."

That means the pressure is on the public education system, which is responsible for those students from age 3 through 21.

Enormous bills

Every school district in North Jersey includes at least one autistic student. Some – such as Tenafly, Ramsey, Oakland and Mahwah – have dozens. Wayne

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In autism's grip

Six-part special report

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More districts open doors

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has 67. Teaneck has 59. North Bergen has 36.

Educating autistic students, who need intensive instruction and customized speech and occupational therapies, is a complicated and expensive job.

Services for 2,755 students last year — the neediest autistic students, whose bills exceeded \$40,000 each — cost taxpayers \$170 million. Sending a single child to a separate school for the disabled can cost over \$100,000 per year.

School districts are responsible for the bulk of those bills. And they haven't been getting much help.

A state aid program intended to help has been frozen for four years — last year, districts received 30 cents for every eligible dollar they spent. So most special-education costs — \$3 billion for all students last year — are showing up on property tax bills.

This month, lawmakers examining ways to reform New Jersey's sky-high property taxes heard testimony on the state's escalating special-education costs. Barbara Gantwerk, an acting assistant commissioner and former special-education director at the state Department of Education, described separate programs as expensive

options that can cost twice as much as a regular class.

She said that although some severely disabled students may be well-served in separate settings, an "over-reliance" on such programs has been costly. New Jersey sends 9 percent of its special-needs children to separate schools — by far the highest percentage in the country, and triple the national average.

"I would hope that [districts] think, if I'm spending this much to send students out, how can I use that money to develop services and the ability to serve them in-district?" Gantwerk said in an interview. "A student should not be sent out of district just as a result of a lack of programs. If that's the reason, you can develop the programs."

With this financial pressure, and new encouragement from the state to include special-education students in regular schools, districts are building the in-house programs.

Statewide, 29 school districts had autism-only classrooms in 1995. Ten years later, there were 139 — including Pequannock, Ridgefield, Haledon and Hasbrouck Heights. Most are based on Applied Behavior Analysis, or ABA, an individualized, highly structured therapy that teaches



DANIELLE P. RICHARDS/STAFF PHOTOGRAPHER

Job coach Anik Ostrowski shadowing Corey Freeman, 17, as he worked at a natural-foods store in Northvale. The job training is part of New Bridges, a program of the Bergen County Special Services district.

skills one at a time and includes frequent rewards.

Towns that a decade ago had two or three autistic students now have enough to fill a class. Small districts are working together to develop shared local programs. The TriValley program is expected to save taxpayers in Bergenfield, Dumont and New Milford \$300,000 this year. Administrators in Teaneck, which started an autism program last year that now serves 16 students, estimated it has trimmed costs for those children by more than \$500,000.

The new programs have cut the percentage of autistic students attending out-of-district schools to 40 percent, down from 60 percent,

said Gantwerk. That trend is in line with federal special-education law, which requires that students be served in the "least restrictive environment" possible. Sending children to special schools limits their chances to interact with typical kids and be included in regular school activities.

"We are preventing [some of] them from going out of district now," said Renee Archer, director of elementary special-education instruction in Paterson, which has hired experts and expanded its autism classrooms to serve 48 students this year. "We are working toward the most integration possible."

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Resources

For information about services, contact your school district's office of special services or your county superintendent:

Bergen: 201-336-6875
Passaic: 973-569-2110
Morris: 973-285-8332
Hudson: 201-319-3850

Parent groups

■ Bergen County: Meets in Ridgewood. Gary Lahm, 201-503-9476.
 ■ Bergen/Passaic Asperger's group: Meets in Glen Rock. Susan Nierenberg and Claudia Reitmeyer, 201-391-0758.

■ Hudson County Spanish-language group: Susana Albisu, 201-864-7262.

■ Morris/Sussex/Warren: Meets in Hackettstown. Jodi Pimentel, 973-663-2505.

Research and advocacy groups

■ NJCOSAC: 800-4-AUTISM (800-428-8476) or njcosac.org — Statewide advocacy group with information on research, support groups, legislation and school programs.

■ Autism Society of America: 800-3-AUTISM (800-328-8476) or autism-society.org — Nationwide group with information about research, treatment and legislation.

■ Autism Speaks: 212-252-

8584 or autismspeaks.org — Non-profit agency that promotes autism awareness.

■ ASPENNJ: 732-321-0880 or aspennj.org — N.J. headquarters of the national Asperger Syndrome Education Network.

■ National Institute of Mental Health: nimh.nih.gov/healthinformation — Research and information.

■ Autism Research Institute: autismwebsite.com/ari — Nutritional treatment for autism known as the DAN protocol.

■ Center for the Study of Autism: autism.org — Links to research.

■ Statewide Parent Advocacy Network, or SPAN: 800-654-SPAN (800-654-7726)

or spannj.org — Trains parents to advocate for their children.

■ New Jersey Department of Education: 609-292-0147 or nj.gov/njded/specialed — Information on services.

■ U.S. Department of Education: ed.gov/parents — Links to basic information for families.

■ Families and Advocates Partnership for Education: fape.org — Nationwide group about special-education law.

■ health.groups.yahoo.com/group/Mosaic-List: Listserv for Bergen County parents

■ The Daniel Jordan Fiddle Foundation:

djiddlefoundation.org — provides grants for programs for autistic adults and adolescents.

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In 2004, the Education Department issued its first-ever “best practices” guide for autism education. This year, at Governor Corzine’s urging, the state Legislature set aside \$15 million in grants to help districts launch autism classrooms. The money will be distributed later this year.

“Encouraging expansion of services in-district is partly geared toward the financial side,” said Davy, “but also geared toward the fact of having kids served in their local communities, like their neighbors are.”

Satisfied — and not

On a brilliant September morning, Lilian Drago sighed with relief as she watched her curly-haired daughters’ first few moments in school. Olivia and Alessandra, 3-year-old fraternal twins, played with blocks while their teachers readied the day’s lessons.

Her girls have autism, as does their 11-year-old brother, Angelo. But despite their exceptional needs, all three children are attending public schools this fall within walking distance of the family’s home in Dumont.

Olivia and Alessandra are part of the first preschool class at the TriValley Academy. Drago is thrilled that her young daughters won’t spend hours on a school bus every day.

During a recent lesson, the twins sat around a table with their classmates. Adult aides perched behind each child, helping them through the activity and gently guiding their bodies back into tiny chairs when they started to wander or engage in autistic behaviors, such as flapping their hands.

The aides held up two pieces of paper in front of each child’s face, one green and one red, and asked them to pick the red one. Some children knew the colors and were exuberantly congratulated for a job well done. Others needed help, so the aides guided the students’ hands to the red paper and praised them for “picking red.”

They repeated the drill over and over, gathering enough red paper to make a classic piece of kid art: a paper apple, perfect for hanging on a refrigerator door.

The program, housed in Bergenfield, is what Gantwerk calls a “perfect example” of the innovation required to develop adequate autism programs. Plans call for it to



DANIELLE P. RICHARDS/STAFF PHOTOGRAPHER

Lunchtime for twins Olivia, left, and Alessandra Drago, 3. They attend preschool at the TriValley Academy, a program for autistic children from Bergenfield, Dumont and New Milford.

expand every year as these first students grow up and a new class of preschoolers enters. TriValley includes some sought-after features: an aide for every student and a full-time behaviorist.

The services are still expensive: \$62,000 per student, compared with about \$12,000 for the average student. But that’s still less than tuition at a private or separate public school, and the districts will save on busing costs, said Bergenfield Business Administrator Tom Egan.

The program’s success relies on getting families onboard. But coaxing parents to sign on for a brand-new public class can be tricky.

Families usually rely on observations to determine what’s best for their children and may be reluctant to accept services they cannot see ahead of time. And so most new programs start by modeling themselves after a successful program. TriValley went on the charm offensive this summer, with home visits by the school’s director and letters that highlighted its collaborative relationship with existing programs.

Still, not everyone was happy. Carlos and Claudia Pinzon of New Milford had expected their youngest son would go to a private school or a public school for disabled children when he turned 3. Instead, this month they sent Daniel to TriValley.

“We didn’t want it,” said Carlos Pinzon. “It was too new.”

He called the placement a nec-

essary compromise. Federal law gives parents an equal voice with their school’s child-study team in deciding how to meet their child’s special needs. All parties must sign a contract that they agree on the child’s placement every year.

“We don’t have anything against the program. It has tremendous potential,” Pinzon said. “We just didn’t want to provide our kid as the first class. ... I’m a scientist, a chemist. I have problems piloting something new. Doing something for the first time has a lot of risks.”

Both of the Pinzons’ sons have autism. The Pinzons said they initially wanted both children to attend a school dedicated to autism, but eventually signed off on Daniel’s in-district placement — in part because officials agreed to send their 5-year-old, Sevastian, out of district to an established school of their choice dedicated to disabled students.

The negotiations left a bitter taste in Pinzon’s mouth.

“If I was a wealthy individual, I would eliminate all of this ... and just pay for my kids,” said Pinzon. “[But] at the end of the day, it’s like a marriage, the schools and the parents. You have to get along with them because it’s for the long haul.”

Is separate better?

Some parents are skeptical that a regular public school can re-create the personalized treatment offered by programs dedicated sole-

ly to autistic students.

Barbara Strate of Palisades Park, whose daughter has autism, runs the popular Mosaic Internet listserv for Bergen County families of autistic children. She said that well-researched parents may be loath to accept public school placements.

The state’s guidelines for these programs require a teacher for every three children and a maximum class size of six — though many districts offer much lower teacher-student ratios. At a top-flight private school, such as the Alpine Learning Group in Paramus, teachers and students work one-on-one.

Strate, like all parents interviewed by The Record, noted there were exceptions to every rule and that every child’s needs are distinct. That’s why, she said, she’s proud that New Jersey school districts send children to specialized schools in such high numbers.

“I see that as completely positive,” she said. “It means that New Jersey is looking at every child, and not just shoving them into a classroom just because it’s a block away from their house.”

Her 10-year-old daughter attends the private EPIC school, or the Educational Partnership for Instructing Children, in Paramus. Strate said her daughter needs the intensive attention she feels EPIC can provide.

“I would prefer her to walk down the street and go to school

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with her brother," she said. "But our school district cannot accommodate her the way that EPIC can."

Other families are clamoring to get into the most popular public programs.

In Fair Lawn, which has offered a reputable program for autistic students for seven years, officials field two phone calls a week from school districts that want to send their autistic students there. But openings are "very rare" in the Stepping Stones program, which cost \$49,000 per child last year, said Joyce Beam, director of special services. Local kids filled all but four of the program's 36 spots this year.

The program offers one-on-one instruction, and teachers work hard to ensure that lessons link to the curriculum studied by typical students. By the time students reach second grade, many transition into regular classrooms, escorted by an aide, said Beam.

"I know that one-to-one sounds exorbitant, and yet we know that the most growth a child with autism will make is in early years," she said. "We really believe that to be carried out effectively, the children need the one-to-one. That's been a very big commitment for Fair Lawn to make."

During a recent morning exercise in a class for 6- and 7-year-olds, the five students sang songs while practicing math and money-counting skills. When discussing the date, students put a number on the wall, grabbed a handful of straws that equaled the number, counted coins that added up to that number and sang it aloud.

Then, each child was escorted by an aide to a corner of the classroom, and they worked on basic skills one-on-one. One pair practiced shapes and colors. At another table, a boy named Daniel and aide Heidi Nicholas practiced giving appropriate responses in casual conversation.

"My hair is blond," the aide said.

"My hair is brown," Daniel said.

"Good! I like to eat spaghetti," the aide continued.

"I like to eat pretzels," Daniel replied.

The activities were timed, with electronic beeps reminding the students when to move on to the next lesson. The classroom was also equipped to offer multi-sen-

sory experiences to fulfill students' occupational therapy programs, with trampolines, a wrap-around nylon body sock, heavy wagons to push and plenty of room to jump around.

The in-district program is clearly saving some money – though it's impossible to calculate exactly how much, said Business Administrator Joanne Wilson, because each student needs a different menu of services.

"Without a doubt, they would be incurring increased transportation costs," she said. "The alternate placements would be to private schools, and there's a range of tuition that we would be charged."

Keeping students close to home has other benefits, equally hard to measure, said Beam.

"Fair Lawn has had a philosophy long before me that our children really should be educated in Fair Lawn if at all possible," she said. "We want students to be comfortable in the town that they are going to live in."

Too well-known

Districts must walk a fine line between making parents happy and becoming famous for it far beyond their borders. Families often pick up and move to a certain community – or even a certain neighborhood – to follow a reputation for outstanding special-education services.

"You can't say it's wrong, but it does dilute the services for the people who are already here," said Strate, of the Mosaic listserv. "There's just so much money to go around."

Every other year, a comprehensive guide to public and private programs is published by the popular autism advocacy group New Jersey COSAC – the Center for Outreach and Services in the Autism Community.

And every time, school administrators actually request they *not* be included in the guide, said Kimberly Edwards, outreach coordinator for COSAC.

"We have had a number of families who have moved in or tried to move in to our district for this school," said Irene Cook, autism coordinator for the Ringwood and Pompton Lakes school districts, which for seven years have had a joint autism program that is listed in the COSAC guide. "One thing I'll say to out-of-district parents when they say I want to move, I say talk

to your district. If they don't have a program, they have to send you somewhere. But sometimes they still end up moving here."

Gantwerk, of the state Department of Education, acknowledged the complication.

"If they have a great program for students with autism, parents will move in," she said. "Then, all of a sudden, they have lots of kids. So we have to figure out a way to do it regionally."

Existing regional programs are ballooning; enrollment at the Bergen County Special Services district has grown by a third in the past five years.

The public school district, which runs standalone programs throughout the county to serve special-education students, now has 210 autistic students, said Maureen Kearne, a district director of instruction who oversees autism programs.

The district's latest challenge is building new programs for older students – especially because most school districts are starting programs for preschoolers, not teenagers. One program, New Bridges at Rockleigh, just started its third year this month, having grown from 36 to 48 students. The students sample a variety of jobs and are trained in real-world situations.

"The whole idea is that these kids have a presence in the community," said Kearne. "We want the kids to grow up together, so they are accepting. So when I go out and talk to an employer about hiring a kid with autism, he wouldn't look at me like I'm crazy."

The district also has helped a half-dozen local school districts open their own autism classrooms in the past few years, she said.

"That's how you want it to be," she said. "You want the districts to have the capacity to do this. You want to keep the kids in their home communities."

A core group of parents agree. They want their children to attend neighborhood schools, and they do their research. Lorrie Lengyel and her family moved from South Hackensack to Wayne six years ago, after a home therapist for her son Tyler recommended programs in the Wayne school system.

Lengyel was determined to find a public school that was right for Tyler, who is now 11, to ensure he would be a part of his communi-

ty. She was set on ending Tyler's home therapy and putting him in school, to force him to interact with other children.

"He'd like to be by himself. That would make him happy, and I knew that was a bad thing," she said. "You hear about things years ago, people hiding their children. He has to be out there. People have to meet him and see him."

Echoing the thoughts of many parents, Lengyel stressed that individual school programs are as unique as her child, making objective proclamations hollow.

"It's one thing for me to be happy – the next person who moves into Wayne may hate the program," she said. "Just because somebody is happy with a private school or a district doesn't mean it's right for every child."

Keeping it secret

Like some school districts, many parents are reluctant to publicize where they live or identify which towns are considered "autism friendly." They're fearful of diluting resources by attracting more special-needs families, angering local Board of Education members and school administrators, or drawing attention to the high cost of services that their own children receive.

"Most people won't discuss it – they are worried about letting the cat out of the bag," said Dave, a Bergen County parent of an autistic child who requested that his last name and hometown not be used.

His family recently left one North Jersey town for another they thought would be more cooperative in serving their child, a preschooler who now receives 38 hours of expensive home therapy each week, he said.

"Most families that fight hard to receive appropriate services are hesitant about letting others know where they live," he said. "There's a fear that if people flood into a town, the level of services will decline, the available funds will decline and the town will be overwhelmed by families with special needs."

But this is a regional phenomenon. New Jersey overall – and especially Bergen County – has a strong reputation as an excellent place for public education in general – and autism education in particular.

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“People call me from all over the world that want to move here,” said Edwards, of COSAC. “People move here from all over the country and all over the world. That creates too much demand.”

Gary Lahm, who coordinates a Bergen County parents support group, is a common first phone call for families interested in moving to New Jersey.

This month alone, he has heard from families in Alabama and South Carolina.

“I have a list of 100 parents – I’m sure 50 moved here,” he said. “Everybody’s heard that Bergen County has exceptional services in the state, and the state is better than all other states, especially for services after age 3.”

That’s what brought Carol Rieske and her three autistic sons to Elmwood Park from Orem, Utah, six years ago. She was so desperate for services that she quit her government job after 18 years, packed up her children and drove to New Jersey after hearing about Bergen County from a special-education attorney she met on the Internet.

Back in Utah, local officials had suggested that she home-school her children.

Rieske created a home therapy program by hiring a consultant from New Jersey and training local college students. But it was exhausting and devastatingly expensive, and as divorce loomed, it would have been impossible to continue.

“I got on the Internet, onto an autism site, and talked with a few people and asked what services were like,” she said. “I picked Elmwood Park because it was the cheapest place in Bergen County. I went from a \$1,300-a-month payment for a 4,000-square-foot house to \$1,800 for an 800-square-foot apartment.”

Rieske, who also has three children without autism, is glad she made the move.

She has had difficulties in getting what she considers appropriate services for her children, she said, but today, the local school district has seen they are taken care of.

Ten-year-old Brent, who cannot communicate and has bouts of violence, lives in a caring institution. Her teenage sons Ken and Darren are thriving in good private

Enrollment by district

Public school district enrollment, ages 3-21

District	Total enrollment	Students with autism	District	Total enrollment	Students with autism
Bergen			Ramapo Indian Hills HS	2,278	13
Allendale	1,076	14	Ramsey	3,109	28
Alpine	134	2	Ridgefield	2,174	10
Bergenfield	3,914	47	Ridgefield Park	2,028	20
Bogota	1,154	9	Ridgewood	5,617	38
Carlstadt	536	3	River Dell HS	1,471	9
Becton HS	550	3	River Edge	1,123	9
Cliffside Park	2,673	10	River Vale	1,369	5
Closter	1,224	12	Rochelle Park	471	6
Cresskill	1,628	13	Rutherford	2,443	13
Demarest	721	6	Saddle Brook	1,700	15
Dumont	2,693	21	Saddle River	207	1
East Rutherford	756	5	South Hackensack	239	2
Edgewater	421	4	Teaneck	4,308	59
Elmwood Park	2,158	13	Tenafly	3,289	24
Emerson	1,170	15	Upper Saddle River	1,344	12
Englewood	2,824	17	Waldwick	1,598	1
Englewood Cliffs	456	4	Wallington	1,177	10
Fair Lawn	4,652	47	Westwood	2,709	19
Fairview	1,013	8	Woodcliff Lake	865	4
Fort Lee	3,512	14	Wood-Ridge	1,148	8
Franklin Lakes	1,741	4	Wyckoff	2,644	19
Garfield	4,559	18	Hudson		
Glen Rock	2,502	18	North Bergen	7,546	36
Hackensack	5,136	19	Secaucus	1,945	10
Harrington Park	700	2	Morris		
Hasbrouck Heights	1,686	15	Butler	1,147	2
Haworth	545	1	Kinnelon	2,157	13
Hillsdale	1,473	5	Lincoln Park	946	8
Ho-Ho-Kus	656	6	Pequannock	2,555	11
Leonia	1,733	15	Riverdale	266	2
Little Ferry	953	5	Passaic		
Lodi	3,127	22	Blomingdale	645	5
Lyndhurst	2,261	12	Clifton	10,526	48
Mahwah	3,451	31	Haledon	987	7
Maywood	813	8	Hawthorne	2,386	14
Midland Park	1,101	14	Lakeland HS	1,146	2
Montvale	1,039	8	Little Falls	862	8
Moonachie	291	3	Manchester HS	767	2
New Milford	2,006	17	North Haledon	676	3
North Arlington	1,555	6	Passaic	12,532	62
Northern Highlands	1,308	2	Passaic Valley HS	1,266	8
Northern Valley	2,429	12	Paterson	25,587	103
Northvale	577	4	Pompton Lakes	1,827	13
Norwood	650	6	Prospect Park	836	8
Oakland	1,729	26	Ringwood	1,433	8
Old Tappan	881	5	Totowa	956	3
Oradell	754	5	Wanaque	1,038	3
Palisades Park	1,436	11	Wayne	8,930	67
Paramus	4,632	25	West Milford	5,154	30
Park Ridge	1,338	13	West Paterson	965	5
Pascack Valley HS	1,757	6	Source: New Jersey Department of Education		

schools. And two of her three other children are in college.

“I drive into my driveway and I just thank God that I have this

wonderful place to be,” she said. “People talk about single moms and how sometimes the kids don’t quite make it to the level they

could. I say mine have way surpassed.”

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