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Woodstock Times - Featured News

11/26/2003

In good company

New school at Onteora for teens on the autism spectrum may be a model for a revolutionary approach



Two ASPIE students enjoy some free time. [Dion Ogust]

School's over, the buses will arrive in about 20 minutes, and the boys are having free time. Their teacher, Michelle DeFelice, distributes Monopoly money they've earned during the day with which they can buy time to do things they enjoy. A couple of kids lean over a game boy. One is designing traffic grids on his laptop. One is showing another a large piece of lava rock he brought back from vacation in Hawaii. They move about the few small rooms of their new school, joke and jostle one another, their camaraderie expressing the strong bonds among them. DeFelice is easygoing, firm, matter of fact, compassionate, funny, and respectful of her charges. The mutuality of that respect and affection is palpable. The boys seem happy to be in this place and in one another's company.

The atmosphere is in many ways what you might expect to find in any well-conceived, well-run private school. But something unique is happening here.

The school for Autistic Strength, Purpose and Independence in Education, known as ASPIE, is the creation of Valerie Paradiz, whose son Elijah was diagnosed with Asperger's syndrome 10 years ago. Rejecting the view that Elijah was afflicted with a disability that would inevitably and profoundly limit the quality of his experience and that would probably be best managed in a residential setting far from home - at 12, he graduated out of Kingston's Children's Annex - Paradiz and Elijah chose to embrace the culture of the autism spectrum, designing approaches to learning that would capitalize on her boy's considerable gifts.

After working with Judy UpJohn in the Indie program at the Onteora schools - UpJohn's special media-centric curriculum serving kids that, for a variety of reasons, are not thriving in the conventional classroom setting - Paradiz observed that many of the strategies employed at Indie might be suitable for students like Elijah. Paradiz told UpJohn that she wanted to start a school for middle and high school students with Asperger's, autism and related syndromes. "Judy said, 'Go for it.'" They decided that ASPIE and Indie would share the building UpJohn uses, next door to the Onteora Middle and High School on Route 28. ASPIE became official in July 2003 and filled up immediately.

Eight students, 7th graders and 9th graders, are enrolled. ASPIE has recently been recognized by the New York State Department of Education, so kids from districts as far north as Catskill and south to Highland attend at no cost. State funding follows the students. Through partnership with Barbara Boyce, director of pupil personnel services at Onteora, ASPIE is well staffed. The eight boys (males outnumber females on the autism spectrum roughly four to one, though Paradiz says they are likely to have girls in the program next year) work with DeFelice and classroom aide Pam Free - the two have been a team for years, in special education at the Phoenicia elementary school. Also on staff are Irene Brody, clinical psychologist and social skills teacher; John Miller, science, technology and physical education; MaryAnn Fraser, speech pathologist; Paula Wade,

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physical therapist; Michele Darling, occupational therapist; Elizabethanne Beaugard, visual artist in residence; Taima Smith, digital media curriculum developer and artist-in-residence, and David Nelson-Epstein, who also works with the digital media curriculum and is an artist-in-residence.

■ **Check It Out****Marlboro Paradiso**

ASPIE offers the Regents curriculum, on the assumption that these students, all of whom are highly intelligent, will complete high school and are likely to go on to college. The Markertek Fund, that also supplies equipment for Indie, donated the Macintosh computers that support the learning process. "Computers are a very important tool for students on the spectrum," says Paradiz, "they love the logic of that world; computers become their pals." And Paradiz explains that her students write much more fluently using a computer. In the studio shared by ASPIE and Indie, 20 or so laptops blink silently in a cabinet as they recharge. "So the kids can use them anywhere," says Paradiz.

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ASPIE students all have diagnoses of high-functioning autism, Asperger's syndrome, or they present significant social and communications differences similar to those of autism. There are few options for students at middle and high school level. Families must choose a distant residential program, home schooling, or mainstreaming in a regular classroom in either a private or public school. But Paradiz says that students on the autism spectrum "don't do well in the mainstream." Often they are placed in classrooms with students with a range of disabilities, many of whom may be cognitively compromised. "They become very bored, and that can exacerbate difficult behaviors," says Paradiz. "Their lives tend to fall apart."

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In addition to insufficient and inappropriate stimulation, mainstreaming has another very serious drawback, Paradiz explains. "These children seem to be targeted more swiftly than any other group for intense, visceral, rejection." The response to a kid who doesn't manifest physical symptoms of a recognizable disability (like Down's syndrome) but is clearly different can be violent. "One of our boys was once beaten unconscious," says Paradiz. Suicidal ideation is common. "At best, they are just coping," she says of their experience in the conventional classroom. "They are in survival mode," agrees DeFelice, not a state conducive to learning or to developing social skills, and many keep the hallmarks of post-traumatic stress syndrome for some time afterward.

But the boys of ASPIE are engaging and ebullient; the transition marking the end of the school day does not appear to be causing anyone stress. The kids' progress excites everyone involved. Pam Free speaks of one student's family member who was told by a neighbor that the boy had come a long way. "The neighbor said, 'that's not the same kid,' and he's not. He's not hiding under the table any more."

"They feel safe here," says DeFelice.

She describes a gym class during which the students were asked one by one to do an exercise using a specific set of motor skills. One boy - "he hates gym" - was very apprehensive and said he'd only do it if no one looked at him. Without discussion, the other members of the class turned around and faced in the opposite direction. The boy completed the exercise and when he was done, says DeFelice, "the class turned back around and everyone applauded him."

But safety from abuse is only a small part of the story. Paradiz is very involved with advocacy for people on the autism spectrum; she is on the boards of several organizations that are part of what she's identified as a movement. "It's a fight for their civil rights." The legacy of society's ideas of how to deal with people with autism has included some extreme responses, says Paradiz, "mercy killing, sterilization, institutionalization." She says that when people on the spectrum do speak out, making it clear they are not content with simply being passive recipients of treatment, or isolation, "hackles are raised."

To address this, Paradiz has made self-advocacy an important part of the program at ASPIE. "We watched a tape of a 60 Minutes segment dedicated to autism and it was full of sensationalist sound bites: 'tragic,' 'frightening.' The boys were very angry; they were insulted. And I told them, 'these people are representing you.'" The self-advocacy skills Paradiz and her staff teach offer language with which these young people will be able to represent themselves.

This shift in perspective is not easily accomplished. Many of the students came into the program only recently having learned of their diagnosis, and having weathered the worst of the larger community's behavior toward difference. "It's very stressful to learn you're autistic before you have any real understanding of what that means," says Paradiz. She tells of a student, very gifted, who had learned of his diagnosis a few weeks before school started and on the second or third day experienced "a meltdown." The ASPIE space includes a "crash room," equipped with all sorts of comfort aides - a weighted blanket (when it's pulled around you, it feels like an enveloping shield), a swing, a futon couch. "He was in there, just screaming, 'I don't want to cooperate with any of you! I prefer being with computers! I like machines better than people! I don't want to be cured!'" Paradiz said to him, "This isn't a place that aims to 'cure' you, but tell me why you feel you don't want to be cured."

"I'd lose my intelligence," the boy told Paradiz.

Paradiz says this young man has moved through his fear and anger and become increasingly interested in self-advocacy. The boy had, since learning of his diagnosis, read volumes of literature written by people who are not autistic, "experts" in the field, largely psychiatrists. "Now he understands that this is only one perspective. There's the academic perspective, the psychiatric perspective and the autistic perspective," says Paradiz. "Through the self advocacy curriculum, they'll become their own best experts."

The empathy displayed by the students in the gym class that DeFelice described is a social skill that, along

with other behaviors most of us might take for granted, must be learned the way others learn math, or to play an instrument. The appropriate behaviors must be broken down into their component parts, and cause and effect explored. DeFelice illustrates a sample inner monologue: "Val just kicked me. What I'd really like to do is kick her back, hard, but that wouldn't be a good idea. It would escalate into a fight and disrupt the classroom. One or both of us might get hurt. I should, instead, ask her why she did that, and..." The work on social skills is integrated into the academic curriculum. "For example, when we're talking about the arrival of Europeans to this hemisphere," says DeFelice, "we ask them to imagine how the Native Americans must have felt about it, and they have another opportunity to use empathy." The kids feel pride in owning this behavior. "One of the boys bashed his finger and another kid ran up to him saying, 'I'm feeling very empathetic toward you,'" says DeFelice.

Recognizing that they feel emotions is an accomplishment for students on the spectrum, says Paradiz, and many have great difficulty articulating their feelings. "Their vocabularies tend to be very sophisticated, but they need practice using language to describe internal states. Pragmatic speech does not come easily for them." As most are visual thinkers, says Paradiz, the class employs "emotion charts" that use cartoon representations of a range of rather complex emotional states - different for each student - which are marked daily and kept so that progress and trends can be charted. The boys' performance in this area is one way they can earn the Monopoly money distributed at the end of the day.

Traveling to promote the book Paradiz wrote about her journey of discovery with Elijah, *Elijah's Cup* (Free Press 2002), Paradiz saw her family's trials reflected everywhere. "It's a national crisis," she says. "The situation is reaching critical mass. Incidence of Asperger's and autism is increasing, and the services available - especially for middle and high school students - is nowhere near keeping pace. There's a great gulf here," she says, indicating with her hands an emptiness that she believes her program could fill.

How to proceed is a subject of constant conversation for Paradiz and her staff. The school may double in size next year. "We're trying to decide when to expand and how," says Paradiz, "without burning out." And without compromising the quality of the experience. "This could be a model for programs all over the country," she observes, but Paradiz, DeFelice and Free state with strong emphasis that they intend always to keep their commitment to each individual student foremost. They give a great deal to their students. "And we get it all back," says Free.

As the kids are putting on their backpacks and walking out to the buses, Paradiz greets a student who's on the futon in the crash room - not crashing, but looking at maps on his laptop. "She had a great idea," he says, pointing to Paradiz, "I thank her for it. She's my hero."

"It's mutual," Paradiz answers, "You're my hero."++

For more information about ASPIE, including enrollment procedures and an application, visit the school's website: www.aspieschool.org. Or call 845 657-7201.



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