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Eli's Choice: A Teenager Rejects the Mainstream

His parents fought for boy with Down syndrome to be in the mainstream. As a teenager, he just wanted to be with his friends.

By Amy Dockser Marcus

For years, Eli Lewis was the only student in his class with Down syndrome.

The genetic condition, which causes a range of cognitive and physical impairments, made it harder for him to do his school work. But his parents felt strongly that he could succeed. They hired a reading tutor. An aide worked with his teachers to modify tests and lessons so that he could be in the same classroom as everyone else. He participated in his middle school's award-winning chorus and was treated as a valued member.

But when all the other kids in his class were making plans to go to the local high school this fall, Eli, 14 years old, said he didn't want to go. He wanted to be in a small class with other students like him. "I don't want to get lost in a big crowd," Eli says.

Eli's declaration surprised his parents. Then his mother recalled the many times she stopped by the school to check on her son, only to find him eating by himself. Once, when she came to pick him up from a dinner that chorus members attended, she says she found Eli sitting with his aide, while the students sat at a different table.

"The kids liked him, they knew him, they spoke to him," says his mother, Mary Ann Dawedeit. "They just didn't think of him as a peer." Eli, she says, was tired of "being the only kid who was different."

Federal law mandated in the 1970s that children with disabilities be offered a "free and appropriate public education" in the "least restrictive environment," rather than being separated only in special schools or institutions. Over the years, advocacy and additional laws resulted in efforts to get children with disabilities placed in regular classrooms, with proper support, whenever possible. The process, called "inclusion" or "mainstreaming," has largely been an academic success.

Studies have shown benefits for all children, not only those with disabilities, who study together. Many researchers argue this is one reason why people with Down syndrome have made such remarkable progress in recent decades. People with Down syndrome who learn in regular classrooms do much better academically, research has found. They also have significantly higher rates of employment after they graduate and earn more money than peers who studied mainly in self-contained classes.

And yet, Eli Lewis's experience poses a difficult dilemma, one that is only now starting to be recognized and addressed. With help, he had succeeded academically in a regular classroom. But he felt isolated. In a book to be published next year, researchers at the Center for Social Development and Education at the University of Massachusetts in Boston say that although people with intellectual disabilities made enormous gains academically due to inclusion, their social integration at school "remains stagnant."

In a survey of 5,600 seventh- and eighth-grade students from 70 schools across the country, more than half of the youths said they were willing to interact with students with intellectual disabilities at school. But only one-third said they would be willing to invite such students to their house or go to the movies with them, according to the survey done by the University of Massachusetts center and the Washington-based opinion firm, ORC Macro. "Student attitudes continue to remain the most formidable barrier to inclusion," the researchers concluded.

At first, Ms. Dawedeit and her husband, Howard Lewis, thought Eli might change his mind. The couple—who have two other sons who don't have Down syndrome—felt there were many advantages to Eli staying in a regular classroom, including greater independence and more interaction with the general student body. But eventually, Mr. Lewis says he began to recognize that having Eli in a regular classroom might not be "as important to Eli as it is to me."

Ms. Dawedeit remained reluctant. She talked with a friend who had a son with Down syndrome, who was also learning in a regular classroom. "I felt like I had let her down," Ms. Dawedeit says. "I had preached a mantra for so long to so many."

In May, at the science exposition at Eli's middle school, her feelings changed. The eighth-graders took over the school hallway and parents were invited to visit. Some students demonstrated elaborate experiments they had been working on. Eli worked with his aide to do research online about the chemical properties of silver. He learned where to find it on the periodic table. For the exposition, he printed out some of the documents he had found.

When his mother came to see his project, Eli again raised the subject of where he was going to high school. For Ms. Dawedeit, the contrast was sharp. Here was Eli, successfully participating in a science exposition with peers who didn't have disabilities—but still talking about wanting to be with other people with Down syndrome.

She says she realized she needed to try to accommodate her son's desire for a social group. "I really had to step back from my personal beliefs," she says.

In the fall, Eli enrolled in the ninth grade at Bethesda's Walter Johnson High School, a sprawling building of over 2,000 students. He is in a special program with 20 other students who have disabilities, including one who gets around in a wheelchair and has difficulty talking. Six of the students in the class have Down syndrome. Eli already knew some of the kids from various extracurricular activities, such as drama class and Special Olympics, where he participated in soccer, basketball, swimming and bowling.

Getting out of the mainstream has meant trade-offs. His school is about 10 miles from Eli's house, farther than the local high school that his older brother attends (The local high school doesn't have a separate special-education program). A special-education bus now comes each day to pick up Eli, along with other students with disabilities.

"This was one of our big compromises," says his mother. In middle school, Eli walked to a bus stop and rode a regular school bus. "Other kids knew him," says Ms. Dawedeit. "now he's a special-ed kid on a bus."

One evening in November, after a dinner of chicken burritos and salad, Eli helped his brothers, ages 12 and 17, clear the dishes. Then his parents watched him, as he started making his way through his homework a work sheet to practice using nouns and verbs. Since Eli was born, they had fought to have him included in regular classrooms. Now it sometimes felt as if Eli might end up outside the world they had tried so hard to keep him in. All along, they shared a similar goal: for their son to be able to live independently. But Mr. Lewis, a lawyer, began to worry that the academic gap between Eli and other classmates was getting wider in the regular classroom as he grew older, and might be too difficult to bridge in high school. "I'm not married to inclusion at the expense of Eli's getting the skills he needs," he says.

Ms. Dawedeit, a manager at a retail store, was less certain. She knew how much Eli, like all kids his age, wanted to belong. But without spending significant amounts of time in regular classrooms, how would he ever learn the skills he needed to reach the goal of living on his own? "The truth is he has to go out and get a job," she says. "If he's educated with his regular peers, then maybe a regular peer will hire him."

Eli finished his English worksheet, and got up to take a break. He came over and gave his father a hug. "Are you meeting any new kids at school, Eli?" his dad asked. "Not just yet, Dad," Eli answered. "Why are you hanging out only with the kids in your class?" his father queried. "Because I know them," Eli answered, and went into the kitchen to get some cookies.

At his new school, the Parent Teacher Student Association has put the issue of how to promote the inclusion of students with disabilities in extra-curricular activities on the agenda for its January meeting. A student group that pairs students with disabilities with a buddy without disabilities has already scheduled several activities for the coming months, including ice skating and bowling.

Still, for most of his school day, Eli is now in a separate classroom from the general school population. Last month, ninth-graders in the general-education classes were reading the novel, "To Kill a Mockingbird." In the special-education classroom, the teacher was going over worksheets that had been adapted from the book, with some related questions.

Eli was signed up for a regular physical-education class, but asked his parents if he could switch to one with only special-education students. His mother was reluctant to change, because it was one of his only chances to meet kids in the general-student population. She offered a compromise: He could switch to the special-education gym class with his friends, if next semester he took weight training as part of the regular class. Eli agreed.

Janan Slough, the assistant principal who oversees the special-education department at Eli's school, says the school has difficulty finding certified special-education teachers because of a national shortage.

The school tries to foster as many opportunities as possible for those with disabilities to be in general classrooms, she says. Still, she adds, "I feel caught" between juggling the need for socializing with the need to teach basic, crucial tasks, such as handling money. On one field trip, the special-education kids went to a grocery store; they were supposed to buy something their family might use at home, pay for it, and make sure they got correct change.

Most of the kids with disabilities need to focus on independent-living and job skills, rather than college preparation. "I'm charged with thinking about where they are going to be at 21," she says. "I don't want parents to come back and say, 'It's nice they were socially included and had parallel instruction, but you didn't prepare them for the world of work.'"

For now, Eli has only one class – ceramics - that he attends with the general school population. On a recent morning, Eli sat next to a boy assigned to help him. The students were designing tiles, and from time to time his peer assistant would look at what he was doing, or go with him to get more clay. For much of the class, the boy bantered with one of his friends, who had pulled up a chair next to him and was regaling him with a story. From time to time, Eli made a joke and the boys all laughed together. But when they walked Eli back to the special-education classroom, there was no suggestion that they meet up again that day. When Eli was asked if he enjoyed spending time with his assigned partner, he shrugged and said, "It's OK."

Eli has a lot of ideas about what he wants to do after high school. In middle school, he took a media class and worked in the school's TV studio. Along with the other kids in the class, he was given a homework assignment to make a public service announcement. Eli made one about the Special Olympics. "I want to be a director," he said, when asked about his plans after high school.

"Eli has serious career aspirations for himself that may not have anything to do with what the rest of the world sees for him after high school," said his mother, one afternoon last month, while waiting for him at a drama class he takes outside of school. The class, made up of students with and without disabilities, was planning a variety show, and Eli was excited about performing. Every night, he went to his room to work on a dance routine he had created to accompany a song from the soundtrack of the movie, "Holes."

His girlfriend, whom he met in elementary school and also has Down syndrome, had invited him to be her date to the upcoming Winter Ball at her private school. Next month, Eli will turn 15 and is planning a big party. The only kids he plans to invite also have disabilities, his mother says.

While she's glad he has found a social circle, she still wonders about what he's missing by going to special-education classes instead of staying in regular classes. "I go back and forth on it all the time," she says. For instance, his school has a state-of-the-art TV studio with editing facilities and a control room, where a class is given. Eli's parents wanted him to be in that class, but it's not possible right now, because he needs to attend the special-education math class, which is held during the same period.

On a recent morning at school, Eli weaved around the teenagers lining the hallway. Some sprawled on the floor, catching up on homework. Others joked with each other by their lockers, or rushed to get to their next class. Eli didn't talk to any of the students. He walked with purpose, heading to the special-education room.

When he got there, his face brightened when he saw one of his friends. "This is my best friend," he said, throwing his arm around the other boy, who also has Down syndrome. He pressed his face close to his friend's until their cheeks almost touched. Eli smiled. "What table are you sitting at lunch today?" he said as they walked together down the hall. "Come on, make sure you sit with me."