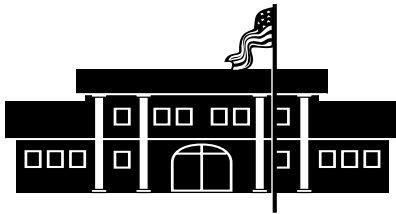


American Dreaming: The Importance of School

May, 1999



Dreams of Inclusion

The opportunities for freedom, status, participation, belonging and growth afforded by public school were a major theme of the conversations with individuals who have disabilities and parents. School, as a universal experience in our society, represents a launching pad for citizenship and community life. Many families began to dream about inclusive schooling when they made a connection with others' experiences, or with their other children's experiences.

"When Trevor was in intensive care right after he was born, I can remember thinking I just couldn't bear the thought of him going to the segregated school. I think instinctively I knew I didn't want him to be separated. Probably the biggest motivator was the video tape, 'Regular Lives.' When I saw that video, I knew, that's it. I don't think I would have come to it on my own if I hadn't seen it."

– Diane Hannum

"Ryan has been included in typical classroom settings in school since kindergarten. Inclusion was not an issue that my wife and I ever talked about or knew about. We just felt that Ryan should have the same educational process that his sister had, so we did the same thing with Ryan as we did with Melanie."

– Bob Mathews

"At age 5 Tom started to school at our local school district in a regular kindergarten like everyone else. In our little rural community the school personnel thought, because he was a kid, he could go to school, which I thought, too. He learned a lot from his brothers and sisters. I would have never made it if he had been the oldest, because I wouldn't have had any models."

– Margaret Burley

"Kevin has lived the continuum of special education, from home-bound studies to institutions, to segregated school, segregated classroom, and full inclusion. I feel he has prospered in the community at large more than he has ever prospered in any segregated setting. Before, he was out there in nowhere land. Jessica had a brother that nobody knew. People know that she has a brother now, because he's in her school."

"When I saw the setting my daughter was in, versus the setting my son was in, it dawned on me that she had many more advantages. The environment was more normal, more upbeat, with more things going on. When I saw the differences, I realized that separate is not equal. I realized that Jessica was reaping benefits that Kevin had no access to. I felt that he deserved the same opportunities."

– Meg Kane

When I saw the differences,
I realized separate is not equal.

Special education

The very system of special education designed to open the doors of education to all students has, for some, had the unintended result of leading to more exclusion. Some families have found that the special education system has stood in the way of their dreams.

"I see special education, in some cases, hurting kids more than helping kids. One time when her brother was in elementary school with her, Jessica was bringing children from her class into his classroom, and she was told to stop, because it was disrupting their class time. I thought this was appalling."

– Meg Kane

"In kindergarten they put Tom in the smallest class with no IEP, no aide. The school folks were pretty resourceful. They didn't say, 'We can't do this,' they said 'How can we do this?'" The teacher was wonderful, innovative, creative. Tom was beginning to be successful because of a lot of people's efforts.

"This was going along very well, until the experts got involved. The rude awakening came when the school called to say that the state Department of Education had visited the school. They were told that they were supposed to have tested Tom, because he had a handicap, to see if he was able to learn. The mere fact that he was learning in kindergarten was inconsequential, because there were these procedures.

"They said that Tom would have to not come to kindergarten anymore. He left school in October, and his turn to be tested didn't come up until the following February. It was a real setback emotionally for him and for us."

– Margaret Burley

"Cara wasn't identified as a student with a disability until she was 12 years old. She went through preschool, through 5th grade, as a typical kid with no IEP. It was wonderful, far better than after we got an IEP. Teachers automatically did accommodations. To me, that was a sense of freedom. She was just a kid. They knew she had some difficulties, but it was no big deal. I wasn't Attila the Mom.

"It all fell apart when she became eligible for special education. She had an IEP, and it was the beginning of the end. We went from her being totally included as 'one of the kids' to a segregated classroom. You want to talk about not feeling free, really feeling trapped, watching her behavior deteriorate, watching her academic skills go. She lost things that she has never regained, because the expectations were so much lower. That was our biggest experience with whatever is on the other end of the spectrum from freedom. She was absolutely a victim of the system.

"In high school they were very nice to Cara, they liked her, and at least they let her be in regular classrooms. Did they teach her anything? Not on your life. And were they accountable for anything? No. So there was that bubbling anger that I always had.

"With my son's graduation from high school I had this real sense of loss. He was moving on, all of his friends were going away. Three days later, Cara walked across the stage in her graduation, and it was a real sense of relief. I was thrilled to get out of high school. It was a very, very different emotion, that this was over and I didn't have to fight with these people anymore."

– Cathy Heizman

Negotiating with schools

Avoiding exclusion and creating opportunities within schools requires intense, active negotiation on behalf of a student. Families have often had to change “the rules of the game” for negotiations to succeed.

“I guess I am a little cynical. When Trevor was going to his old school, they put all the kids with disabilities in regular classrooms and they didn’t have any separate class. Then we moved to a new district, and the old district went right back to segregated classrooms the year after he left. They had changed the whole system around, and they all talked about how well it was working and how wonderful it was, but when he left, everything went back to the way it was. Over at the new school there are three kids with Down Syndrome who are getting a pretty good education in regular classrooms. People like them, they are having a good time. Everybody else is in a segregated classroom.”

“I try to take my older son Eric to all the school meetings, and I talk to Eric about advocating for Trevor. I have tried to train him about meetings. Eric’s response is, ‘You want me to do what?’ I said, ‘Trevor’s whole life he’s going to have to be negotiating for services of some type or another. Somebody needs to be able to go to those meetings to make sure somebody is paying attention to Trevor’s needs being met. If you don’t do that, who is going to do that, Eric?’ He just kind of shakes his head. It’s not like I am asking him to live with Trevor. It’s just that somebody’s got to keep track of this.”

– Diane Hannum

His whole life he’s going to have to be negotiating for services of some type or another.

“We became involved in the school system and PTA. We made a commitment that one of us at all times would be involved with school, community, local organizations, whatever, because we felt that people needed to know who we were. Many of the administrators and teachers in the school system are involved with community activities and community organizations. It’s hard for someone to say no to Bob and Karen, but it’s easy for a school system to say no to Mr. and Mrs. Mathews. We knew the people we were interacting with in different situations, not totally school-related but also community related. We were viewed in a different manner. That has helped in many, many ways.”

– Bob Mathews

“At five or six years old they just told me to take my daughter home, ‘We don’t have any schooling for her.’ I went looking for programs and found nursery schools. I just told them that she was immature.”

“At that point we moved to a state that was a little farther ahead. They had kids in the school system, but they didn’t have anybody labeled anything but LD, so she became LD, and she went into the school system.”

“My husband and I were totally sure that she wouldn’t make it in the world unless people liked her and unless she could be polite, and so we changed the goals in school. They wanted us to write math goals and spelling goals, and we kept writing social goals. How was she ever going to make it in society, if she didn’t know how to do those things? We said, ‘If you get to the math and spelling, fine.’”

– Lynn Doll

“When we were making the move from MR/DD to public school, Adam was in junior high. One thing we learned was we had to talk about it with everybody, first of all to convince ourselves, second of all to convince everybody else. When we went to the junior high, they said, ‘This has never worked for anyone coming from MR/DD. They’ve always had to go back to MR/DD, and we don’t think he belongs here.’ We had to tell everybody, so that we had a support system, because we were doing something that we thought was in his best interest, but nobody else thought so.”

– Linda Hasecke

We had to talk about it, to convince ourselves and everybody else.

Transition to middle school

Moving from elementary school to middle school is a turning point for many families. It is often a time when schools have trouble figuring out how to include children. For families, it may feel like “the bottom drops out” of what was a reasonably successful situation.

“Going from elementary to middle school we were optimistic. Things had progressed throughout elementary school. Amber was going to go to her home middle school. It seemed like it was set up to be inclusive, and it was disaster from day one. It was awful.

“We had a lot of negative behaviors from Amber in response to the way she was being treated. I was getting called every day, it was that bad. Every time the phone would ring, it was like an electric shock.

“When we hit eighth grade, the Principal put out a note to see who would be interested in having Amber in class. It was worded like, ‘If I were you, I wouldn’t do this.

“One eighth grade teacher said, ‘I want Amber in my class.’ She was the teacher you would least expect to do that. She was quiet, never made any waves, an English and French teacher. It looked like she might possibly only be teaching French, and she said, ‘Amber can be in my French class, then.’ Okay, she’ll take French. This teacher was really wonderful.

“Her science teacher didn’t take Amber into his class in the beginning, because he didn’t think it was right, but she ended up having him for two years. In the second year he started saying things like, ‘I never want to teach again without having kids who have disabilities.’ He even said, ‘I turned around 180 degrees.’ He became an advocate for inclusive education.

“The special education teacher encouraged the other teachers and helped them adapt things. We ended up with the best team we have ever, ever had. It was rejuvenating. There are middle school teachers that I would do anything for. If they wanted me to jump off a tall building, I would say, ‘Which building?’ They allowed themselves to be open enough to try some things, learn from them and grow.

“For example, one teacher who initially was very negative about having Amber in the building eventually had her in class and was wonderful. I think it was because she saw that things were working out and saw growth in Amber. The point is that even though people are not directly involved at first, if they are around, they see how other people are interacting and responding and supporting. It will rub off. I believe that happens, at least for people who allow themselves to be open to letting that happen.

“When we got to high school we didn’t want Amber to stay in the self-contained special education class. We had a lot of people spend a lot of time trying to talk us out of it, running down the whole litany of why not. I love the safety issue, ‘We are concerned for her safety,’ as if we’re not, which is the way they make you feel. If you don’t agree with them, then you must be bad parents who don’t care about your kid.

“The higher the grade level, the tougher the fight is and the more resistance there is. They see these kids need to have their credits, they need to get their academics, and they don’t see inclusion as something that is compatible with that. People dig in more. We fought it hard all through middle school. At high school level, we basically settled for compromise. A fight might mean we would get there about the time Amber is done with school.”
– Linda Griffin

Opportunities in school

As difficult as negotiations for services may be, they can open the doors of public schools, where opportunities abound. Many of these opportunities create new possibilities for the future.

“School was very difficult for me. Four of the first six years I had to go to a so-called ‘handicapped’ school. By the time I got to 7th grade I got to go to a regular school, finally, for crying out loud. That’s where I started getting involved in things. I was the manager for the junior high football team. I was in FFA for two years. I learned how to be a leader in FFA. Let me tell you this much right now: If I wasn’t in FFA, I would not know how to speak what’s on my mind and say, ‘Hey, give me a chance to prove myself.’ I learned a lot of leadership skills there.
– Clyde Yoder

“First I graduated from public school, then I graduated from the MR/DD school two years later. In public school I took law, writing, home economics and animal science. I wish we could take them at the MR/DD school. I was in the Honor Society in public school. We had meetings once a week in the library and talked about helping other students succeed.”
– Sarina Winner

“When Ryan was in 5th grade and it was time to become involved in band, he wanted to learn to play an instrument. We didn’t think he would be able to because of his limited range of motion. We were trying to discourage him. Like every parent, we didn’t want to see him be disappointed and try something and fail.

“Ryan has been very persistent all his life at trying and trying and trying, until he is able to do something. He expressed to the music teacher that he wanted to learn to play an instrument but wasn’t sure he would be able to. The music teacher told her husband, the band director, and when he came to the building the next time, he brought a trumpet and had Ryan make a sound with it. He came home from school that day with a note from the band director. Ryan said, ‘You need to call him to talk about me learning to play an instrument.’

“My wife and I were being unrealistic, putting a limit on Ryan, because we didn’t want him to get hurt. From that point forward, my focus in work and personal life has been not looking at a barrier as something that can’t be overcome, but trying to find ways to accomplish the goal or task at hand. I use that as a guidepost, so we don’t fall back in that trap, because Ryan showed us.”
– Bob Mathews

Now you don't need to talk for him.
Now he speaks on his own behalf.

"Mario was involved in MR/DD school from preschool all the way through junior high. Then he was mainstreamed. He just progressed and kept doing better academically.

"They didn't think he was college material, because of his cerebral palsy and his cognitive delay, but he passed the necessary test to go to college. Rehab denied him funding for a four-year school, because no one thought that he was a worthwhile investment. I said, 'Keep your money. He's going to a four-year school. We'll find funding someplace else.' That's what I did.

"He went to college and did well. Then I went back to Rehab with his grades. They funded him from that point on, paid for everything. It was all about proving that he was capable of academics.

"When Mario was in grade school and was asked what he wanted to be when he grew up, he said he wanted to teach the public about disabilities, because his hardest years were in school, with the kids mocking him and making fun of him. Now that's what he does. He goes to grade schools, junior highs and high schools to speak. The kids love him. Now you don't need to talk for him. Now he speaks on his own behalf."

– Deb Armstead

What opportunities do, or did, I have in school to increase my learning, status and belonging (or what opportunities did my son or daughter have)?

What can I do now to make school a place where all students experience learning, status, belonging and opportunity?

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