

Who's In Control? One family's story

By Pat Amos

The most powerful problem-solving strategy in my advocacy work is easy to state: if you don't like the answers you're getting, re-think the questions. The lists of problem behaviors and demands for compliance that crop up in many IEPs pose questions about how to control a child. They presume a child has acquired an excess of power, and ask how to take it away. Johnny and his mother taught me how misguided such questions can be.

I first heard of Johnny when he was diagnosed with Pervasive Developmental Disorder at age four. His mother sought information from our fledgling autism organization, and by the time Johnny began school she was actively advocating for a child who puzzled or exasperated many of his teachers. A big guy with a gentle nature, intense curiosity, and a deep love of music, Johnny was also coping with a hair-trigger nervous system and sensory hypersensitivities that often left him exhausted and confused.

Johnny was assigned to a separate special education class in his local public school. Despite success in Cub Scouts, the geography bee, and fifth grade chorus, Johnny's strengths and interests remained largely untapped - and his agitation grew - as he passed the days in remedial tedium. His mother dared to hope that middle school would offer a fresh start among more hospitable educators.

As Johnny approached sixth grade, however, the welcome mat was whisked away and replaced with a detour sign. "We have no program for him here," explained the special education director, announcing that Johnny's recommended assignment was a label-based, segregated school. "But we promise we'll bring him back as soon as he's stable." Johnny's mother, alarmed by the chill in the air, decided to swallow her misgivings and picture the segregated school as a temporary respite in a warmer climate. Maybe it was global warming, but the climate in Johnny's new school heated up faster than anyone foresaw. A strict diet of rewards and contingencies, a constant focus on behavioral "do's" and "don'ts," physical restraint, and days in the time-out room led to volcanic reactions. Johnny became increasingly anxious, angry, and depressed.

His mother and I scurried to meeting after meeting, waving new behavior support plans and invoking special education law. Johnny had a more practical solution, and did his best to stay in the safety of his bed. As Johnny's third year began, the school ran up the white flag: they could not get Johnny under control, his case was too complex, and they wanted permission to request police intervention. Failing that, they resorted to tranquilizers.

One day Johnny could not be wakened for the bus home, and his mother was called. It was time, she was told, to surrender him to a residential placement. Johnny's mother looked long and hard at the slippery slope stretching in front of her son, and recognized that it was bottomless. Then we looked at each other in complete agreement, and did an about face. Maybe Johnny was not the powerful, manipulative, noncompliant child he

was now reputed to be, and maybe he didn't need to have control taken away. Maybe the opposite was true: Johnny was powerless, helpless, and afraid, and needed to have more control over his life.

Instead of marching toward residential placement, she was going to escort him back to the local middle school. Johnny spent three months in recovery, taught by a homebound instructor. In February, we held our breath as an eager but nervous Johnny entered eighth grade. It was another segregated classroom, however, and in June the district presented two discouraging options: retain Johnny in eighth grade or send him to vocational-technical school. Johnny and his mother had the courage to insist that he was high school bound, and would be included with his peers at last.

Anyone who has trekked back from segregation to inclusion will tell you it's no stroll in the park. Johnny had become sensitized to the slightest whiff of rejection, and in high school he reacted accordingly. After the barrage of coercive interventions in the segregated school, he had become hypervigilant in an environment he now perceived as threatening. When Johnny's stress levels rose he often became physically stuck, unable to take the next step in an activity or assignment - a condition easily misinterpreted as refusal, laziness, or inability. Johnny's mother and I observed that many of his high school teachers were struggling with the baggage of segregation, too. Lacking knowledge and experience of diversity, they inadvertently stoked Johnny's fears with their own. Their primary stumbling block was the same as Johnny's: they too feared the loss of dignity and control. With this insight in mind we were able to encourage Johnny's teachers to work with him rather than on him.

Johnny would be allowed to leave the classroom for a needed break, to modify assignments to suit his learning style, to take a reduced course load and finish high school in five years. And no one would say, "How irresponsible to let him have his own way!" The new mantra would be "Follow his lead." To some this approach was counter-intuitive, but others readily embraced it. The more they helped Johnny have control over his life, the less anxiety-driven he became, the more he blossomed, and the more powerful they became as teachers.

By his second inclusive year of high school, Johnny had the confidence to dismiss his school aide. He overcame his fear of fiction and learned to love Shakespeare. He volunteered for the school literary magazine. He discovered the joys of chemistry. He founded a bowling club and made friends. At graduation Johnny received the Class of 2003 Challenge Award, bestowed on any student who has demonstrated "perseverance under adversity." In college, Johnny's confidence continues to grow. He recently won an award for Outstanding Achievement in Italian. He is delighted to be in the driver's seat, in his car and in his life. Johnny graciously gave permission to share his story, and hopes it will smooth the road for others.

Pat Amos is a member of the TASH Board of Directors. Comments about this article may be sent to Ms. Amos at pat.amos@comcast.net
