

Making a Difference, One Child at a Time
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Part I - 4 minutes to read

I used to lie awake at night, worrying and wondering. What will his life be like? Will he ever live on his own? Will he learn to speak so that people can understand him? Will he be able to read? My worries about school were the most disturbing, knowing how cruel children can be, and knowing, as an educator, that "those kids" were not always welcomed by educators - on a campus or in a classroom.

My son, Toby, has Asperger's Syndrome, an autistic disorder. The incidence of autistic disorders, including Asperger's, has virtually exploded since my son was diagnosed in 1988, years before Asperger's was listed in the Diagnostic and Statistical Manual of Mental Disorders, the reference most often used to diagnose learning disorders and other cognitive disabilities.

Now 26, Toby holds a part-time job, drives, and is able to live on his own. He still needs guidance with predicaments and uncertainties like junk mail masquerading as a tax bill, a discrepancy between his check register and an ATM receipt, a plumbing problem, or a difficult coworker. Many problems that are somewhat routine for most of us can be troublesome for him. Yet, as time goes by, he continues to learn and grow in his independence and ability to deal with life's challenges.

He is a happy and cheerful individual, with circles of friends at work and at his condo complex. He still socializes, hikes, and works out with some of his high school friends who have now finished college. He is easygoing and delightful to be with. He works out regularly and volunteers at a public botanic garden several times a month. He's run the Los Angeles Marathon three times. I am as proud of him as any parent could be of a child.

Yet, the years between today and the day of a nurse practitioner's pronouncement that he appeared to have "developmental delays" have been anything but easy. To be the parent of a child with special needs is to break

into an elated celebration dance at his smallest accomplishment or minor bureaucratic victory. Any setback can feel like an abyss.

The greatest extremes of these arose from his public schooling, from age 4, when he was placed in a preschool "communicatively handicapped" class, until the day he graduated from high school, having transitioned from 10 years in special day classes to the Resource Specialist Program as he began his freshman year. After a rocky start in the ninth grade, his graduating GPA was 3.6.

I have spoken to countless parents over the years who have sought my advice about their special children's education. My experience as an educator has caused these parents to think I must have an insider's view, not to mention an insider's advantage in navigating the public education system.

What I actually experienced in many instances, especially in the early years, was that being Toby's mother caused me to be treated very differently than I was treated in my role as a teacher, staff developer, or anything else. With a degree of objectivity that only arrives with time, my feeling today is that the historic stigma attached to special education students simply extended to us as parents. Over those years, I had things said to me as a parent that made my blood run cold as an educator.

As a new teacher, I made a pact with another neophyte that if one of us ever related saying to her child's teacher, "Well, I'm a teacher, too, and . . ." we would take the other to task (as in, "Just smack me if I ever say that."). Neither of us actually had children at the time. A number of parents in the affluent community we served were teachers themselves, who often had strong, very specific suggestions and expectations for their children's teachers, concerning everything from classroom routines to curriculum. This agreed-upon taboo statement was made to us any number of times, especially in our early years when we both resembled teenagers more than 20-somethings.

I can state with a clear conscience that I never took issue with any teacher or SELPA team member using the rationale of being a teacher myself. We had many points of dispute, but our advocacy came from what we knew to be best for our son. As a young teacher, having both witnessed and experienced a few emotional outbursts on the part of upset parents, I had a heightened awareness of the need to curb my own emotions and breathe deeply before responding to some astonishingly inappropriate statements made to us over the years by educators.

These experiences shaped my leadership as I became an administrative designee, and eventually a principal. In disagreements, I would often find myself emotionally, internally, taking the parent's side instead of the teacher's. This forced me to develop a diplomacy and mediation skills beyond what I had ever imagined I would.

In an attempt to distill from these years of experience some key suggestions for leaders, I've decided to use the vehicle of contrasting things I've either actually said, or would say if I could, first to leaders, and then to parents. Although parents are unlikely to read this article - excepting those school leaders who may also be parents of children with special needs - I hope the view from the parents' side of the table might be informative.

Question: In your personal life, do you have any friends/neighbors/relatives with a child with special needs, who have had difficulty with the medical or educational community getting appropriate services for the child?

STOP: 5 minutes for group sharing of reflections. Use ordered sharing.

Part II - 5 minutes to read

Expectations

What I say to leaders: Never tell parents they are expecting too much. I cannot say how many times this was said to me. If I had listened, I believe that Toby would have spent 14 years in highly restrictive environments, and would never have attained a high school diploma.

What I say to parents: Never say never. You have no idea what is possible until you push the envelope. Toby didn't learn to read until he was in the fourth grade. Until I insisted on a placement change, his success in reading mirrored the effort and expectation of the teachers. In the words of more than one of them, "These kids really can't do much." Keep your hope alive, and make sure that your child is with teachers who will push his limits, lovingly and with support. Learn about the work of Reuven Feuerstein to help raise your own sights about what is possible with the human brain.

Mutual respect

To leaders: Make eye contact with parents when you talk to them, and speak to them as if you regard them as equals. Our first IEP meeting, determining Toby's placement in the preschool communicatively handicapped class, included at least 10 team members from various offices of the nine-district SELPA consortium for the area where we lived at the time.

Once the formal introductions had been made around the table, no one addressed his father or me again. The conversations about his assessments, his private preschool experience which we had documented, and his placement options took place as if we were not present. No one made eye contact with either of us until we were asked if we would agree to sign the IEP.

In my experience as an educator, there are any number of parents who do not come to IEPs dressed in business suits and speaking grammatically correct English, but neither these things nor anything else about us seemed enough to merit the courtesy of seeking our input, or acknowledging our presence again during the fairly long meeting. It was a strange experience, and a harbinger of what we would encounter over the next six years. It certainly brought home to me that as educators, if we convey a sense of our own superiority, parents will feel it as arrogance, and it will compromise our effectiveness in working with them.

To parents: Dress up for the IEP as if you were going to church, or a job interview requiring business attire. If you own a suit, wear it. We educators can be guilty of interacting differently with a parent who is very casually dressed vs. one who is dressed professionally. Be on time.

Prepare yourself by looking over the IEP and see what your child was supposed to have accomplished since the last meeting, and bring your copy with you. Re-read in the IEP what the teacher and school agreed to do to support your child's progress. Write down your questions in a notepad. Call people by name when you talk to them. If you can't remember all the names, write them down on your notepad as they introduce themselves, and refer to it as you speak to each of them.

To leaders: Don't interrupt parents when they're talking. This conveys a great lack of respect. It can also make parents angry, and you will not enlist the cooperation of an angry parent. In "The Seven Habits of Highly Effective People," Stephen Covey urges, "Seek first to understand, then to be understood."

To parents: Figure out a strategy to use with someone who constantly interrupts. One school psychologist had a terrible habit of doing this, and it frustrated and irritated me. I dreaded meetings where I knew she would be present. I decided to begin simply holding up my hand when she interrupted, and saying, "Let me finish." Toby's father and I practiced this before putting it into action. It obviously startled her, but it worked.

To leaders: Never disparage statements parents make. In your secret heart, you may think the parent is untruthful, misinformed, unreasonable, a bit crazy, blind to their child's problems, or perhaps not terribly intelligent. However, any hope of getting the parent to agree to your plans and suggestions is lost if you insult them. Also, don't disparage the parent *en absentia* in front of teachers. This is not good modeling. It may feel like this builds camaraderie, but make not mistake: your teachers are looking to you to be their leader - not their pal - in dealing with a challenging parent.

To parents: Don't lose your temper in the meeting. If your spouse does, kick him under the table (not too hard, of course). As a preschooler, my son exhibited an array of bizarre behaviors at home and at school, but for the most part, not the same ones in both places. Uncontrollable laughter - classic with Asperger's - was common to both. The stress of the classroom - and probably peer influences - made him begin to rock back and forth in class, and end each spurt of laughter with whooping, crowing noises. He also bit holes in the knees of his jeans.

It was distressing enough to learn of these new behaviors, but I really objected to his being put in a refrigerator box for time-out. The teacher explained that this was to reduce the stimulation from the classroom, which she believed made him start laughing and crowing - an obvious disruption to the class. When I said he didn't do all these things at home, the highest-ranking SELPA official at the table just laughed, saying, "All the parents tell us that," while the rest of the team nodded with knowing smiles. Already quite angry over the refrigerator box, it took every ounce of my restraint to keep myself from simply walking out of the meeting.

Question: What would parents in our school be likely to say if they were asked whether they feel respected by school personnel when they come to school? What would they say about expectations for their child/ren?

STOP: 5 minutes for group sharing of reflections. Use ordered sharing.

Part III - 3 minutes to read

Teachers

To leaders: Forget fighting a parent who wants a better teacher for her child. Just start working on it. Your special education subgroup - which is probably not making AYP - is only as successful as its teachers. In fact, it is not a subgroup at all, any more than any other such-named entity, but individual human beings, each with unique gifts and needs. The achievement gap for these students will never close until their teachers are the most gifted we can find for these challenging assignments.

Researcher Robert Marzano (2000) found that students achieving at the 50th percentile, assigned to ineffective teachers for two consecutive years, fell to the 37th percentile if they were in a highly effective school, and to the 3rd percentile in a highly ineffective school. More alarmingly, the studies were conducted with regular, not special education students. Conversely, however, 50th percentile students assigned to highly effective teachers advanced to the 63rd percentile in two years, even in highly ineffective schools, and to the 96th percentile if the school as well as the teacher was highly effective.

The 11 research-based factors that make schools highly effective are discussed in Marzano's "What Works in Schools" (2003). I believe that Marzano's research makes a compelling case for the potential of the AYP data reflecting the achievement of students in special education to improve dramatically, given both highly effective teachers and highly effective schools.

Certainly we are constrained by contracts and unions, teacher tenure, and a shortage of qualified teachers. Yet, there may be no area more pressing for the attention of educational leaders than ensuring that we have teachers for *all* students, including those in special education, who are truly "highly qualified," not merely NCLB-compliant.

To parents: Insist on the best teacher for your child. If you are told there is no option for changing teachers, find out who the administrator is at the next level, and ask again. Ask, "What is the *procedure* to have my child placed with a different teacher?" Do not say bad things about the

current teacher. Talk about your child, his needs and lack of progress, and what is happening or not happening in the classroom. Pay less attention to the label of the program or class than to what the teacher is like. Next year, the best teacher for your child may be in a program with a different designation.

Advocates

To leaders: Don't drive parents to the point of such frustration that they decide their only avenue is to engage the services of an advocate. Once they bring one, the game will change. Principals, if an advocate shows up without your advance knowledge, reschedule the meeting so that you can have a district representative present.

To parents: Avoid getting an advocate if you can. They push educators' buttons, and too many advocates these days are extremists with agendas of their own, not your child's. If you decide to get one, do everything you possibly can to check reputations very, very carefully. At one point, we felt we had no choice but to get an advocate. The team simply didn't listen to us. If I were faced with the choice today, I'm not sure I would get one, but in our case, it worked. She hardly said a word. She simply asked a few questions, but her very presence made a huge difference.

Question: How do we, as individual professionals, assess our own effectiveness?

STOP: 5 minutes for group sharing of reflections. Use ordered sharing.

Part IV - 6 minutes to read

Empathy

To leaders: It isn't easy being the parent of a special needs child. When a child is born with Down's Syndrome or another obvious physical birth defect, the joy and expectation of the pregnancy instantly turns to heartbreak. When a child who appears normal in infancy and toddlerhood

begins to display troubling signs of delayed development or behavioral dysfunction, and is finally diagnosed with his label, there is a sense of loss, and grieving begins for the hopes and dreams the parents have cherished for him. Layered over all this is the knowledge that the child may never be independent. This is a heavy burden to add to the normal stresses that we all have. Remember this when you are dealing with a "difficult" parent.

To parents: It isn't easy being the teacher of special education students. There are many, many good teachers, and good teachers work very hard for their relatively humble salaries, and the lack of public regard they get for their years of education and experience. Your child may be a behavior problem, and if he isn't, others in the class are. Teaching would be demanding enough if there were *no* behavior problems, and expectations for teachers are higher than ever before.

If the teacher is out of patience with your child, do everything you can to cooperate, and reinforce any reasonable plan that appears to have promise for helping him behave better, so that he - and others - can learn. Remember that the school is charged with serving other students as well as yours, which includes ensuring a safe and orderly environment for everyone. If your child presents a physical threat to others, be prepared for the school to move to have him placed in a more restrictive environment.

In general

What else I say to parents: Keep everything. Make a folder for each year's IEPs and other school documents. Do the same for any medical records that have a bearing on your child's learning and schooling. Keep a journal.

Expect to do your part to support your child at home. Work out a system with the teacher so that you know what the homework is. Don't do it for your child, but make sure it gets done. Limit TV watching on school nights, and get your child to bed early. If you are unable to help with the homework - such as high school math - and your child is confused, talk to the teacher about ways he can get extra help at school.

What else I say to everyone: Toby is a living example of Marzano's research on the impact of highly effective teachers. He had many very good, even extraordinary teachers, beginning with his fourth grade Special Day Class (SDC) teacher after the placement change. This young, energetic first-year teacher had no idea what her kids couldn't do. Within weeks,

Toby was not only reading, but writing. Never having composed anything but single-word answers for meaningless fill-in-the-blanks worksheets and workbook pages, he was writing two-page stories by the end of fourth grade.

The next two years, Toby had another teacher who collaboratively planned her curriculum with a team of sixth-grade regular education teachers. In addition to adaptive PE, for the first time Toby got to experience "real" PE - sports and games - with a class of about 100 mostly regular education students and four teachers.

When I approached the teachers and principal with a request for mainstreaming in science or social studies, the idea was met, at first, with considerable skepticism. But the team stepped up to the challenge, although it required even more planning and coordination of schedules. Toby and several classmates began participating in regular sixth-grade science, accompanied by the SDC aide. Cooperative learning was carefully engineered so that each SDC student was placed in a small group with regular-education peers, and assigned a role that s/he could successfully perform for the group. This laid the groundwork for significant social development in middle school.

Great academic and social gains came in grades 7-8, when Toby gained five years' progress in reading. His SDC teachers were extraordinarily skilled, and tireless in their carefully planned instruction of each student. Mainstreaming was a cultural norm, thanks to his teachers' relationships with the rest of the staff, and their relentless commitment to ensuring their students' success by addressing any obstacles that arose. To this day, Toby still returns from time to time to visit Ms. Bizzell and Mrs. Yoss, and his PE teacher, Mrs. Murphy.

High school was as emotionally challenging for Toby as any teen. For the most part, it is not a happy memory. Now in regular education classes with a period of RSP (Resource Specialist Program), students in class often made fun of the odd cadence of his speech, and many teachers just let it happen.

Sports - a great motivator

Perhaps the single most significant adult in Toby's high school experience was his cross-country and track coach. A long-retired former teacher, Mr. Loney was dedicated to his boys, and took a special interest in Toby. My long-held opinion that athletics were a drain of educational dollars and energy was positively shattered. I am convinced that without sports,

many high school students wouldn't get out of bed in the morning. My son was one of them.

Staying eligible was a motivator to attend class, study, and do homework. The benefits of social development that came from being on a team, and the social standing of being an athlete - wearing his letterman's jacket and being recognized at assemblies - were incalculable. After graduation, with his teammates, Toby mourned the passing of Mr. Loney.

With the advent of California's Public Schools Accountability Act, which brought us STAR testing and the Academic Performance Index, followed by No Child Left Behind and Adequate Yearly Progress for all children, I have had hopes that things are changing for special education students. I hope preschoolers are no longer put in refrigerator boxes for time-out, and that educators are more responsive and respectful toward parents.

Certainly there is serious attention now being placed on the progress of these students, and the idea that regardless of the severity of the disability, an acceptable IEP is one written to show a year's progress in a year - when the child is years behind already - is hopefully going out of vogue.

The Essential Program Components have been developed for schools in sanctions with a School Assistance and Intervention Team, and for schools in Program Improvement districts working with a District Assistance and Intervention Team. The EPCs are forcing the issue of providing State Board of Education-approved curriculum materials for most special education students, instead of watered-down programs using commercial boxed kits and below-grade-level workbooks, or teachers' homemade worksheets.

There are SBE-approved intensive intervention programs for reading that are proven to work with regular and special education students, and the EPCs require that districts purchase and implement them. There are those who object to this kind of pressure. I may irritate some educators by saying this, but if we had been serving these students effectively all along, we wouldn't be under so much pressure today to make them successful.

I can't say why, but I still have the box of Toby's old IEPs and other documents, and my journals that I kept over all those years. I hadn't looked at any of it in over a decade. To write this article, I pulled out that box and started looking through it, and quite frankly, I found myself choking back tears as I relived those difficult experiences. Perhaps this article will make an impression on a few educators, who will take these suggestions to heart in their own leadership practice.

Just like the parents and students we serve, we are human, and the frustrations of our work can challenge our humanity. In our office, we often refer to the story of the star-thrower, the little boy on the beach who was making a difference by throwing the starfish back into the ocean, one at a time. To make a difference, one at a time, is significant. Every time you can prevent even one of these special children from being left behind, your leadership will have made a difference.

I hope you do.

Question: What situations have you experienced that allowed you to put yourself "in someone else's shoes?"

STOP: 5 minutes for group sharing of reflections. Use ordered sharing.

FINAL DISCUSSION:

1. Ordered sharing, 1 minute each, to share whatever you wish. OK or pass.
2. Open discussion as time allows.

References and resources

American Psychiatric Association (2000).

Diagnostic and Statistical Manual of Mental Disorders DSM-IV-TR (Text Revision). Washington, D.C.: American Psychiatric Association.

California Department of Education:

- www.cde.ca.gov/ta/lp/vl/documents/hsaps.doc (High School EPCs)
- www.cde.ca.gov/ta/lp/vl/documents/mgaps.doc (Middle School EPCs)
- www.cde.ca.gov/ta/lp/vl/documents/egaps.doc (Elementary EPCs)

Covey, Stephen R. (1989) *The Seven Habits of Highly Effective People*.

New York, NY: Simon & Schuster, Inc.

Educators 2000. Terry Wilhelm founded this company in 1994 and put up a website in 1999 to keep parents and educators abreast of information about Asperger's Syndrome and related topics. Links to a variety of informational websites can be accessed from

www.educators2000.com

Feuerstein, Reuven; Yaacov Rand and John E. Rinders (1988). *Don't Accept Me As I Am: Helping "Retarded" People to Excel*. New York, NY: Plenum Press. This book is out of print, but still available from Vendors such as Alibris, Banned and Noble, and Amazon.com. The authors describe Mediated Learning Experience, a methodology that significantly raised the IQ and functional development of countless "retarded" and cognitively traumatized individuals following World War II.

Feuerstein, Reuven; Yaacov Rand and Raphael Feuerstein (2006). *You Love Me! Don't Accept Me As I Am!* Jerusalem, Israel: ICELP Press. This is an updated version of the 1988 book (above), and can be ordered directly from the International Renewal Institute (see next citation).

International Renewal Institute. This is the North American branch of the International Center for Enhancement of Learning Potential, founded by Reuven Feuerstein; see www.iriinc.us.

Marzano, Robert. (2000). *A New Era of School Reform: Going Where the Research Takes Us*. Aurora, CO: Mid-Continent Research for Education and Learning. (ERIC Document Reproduction Service, No. ED454255).

Marzano, Robert. (2003). *What Works in Schools: Translating Research Into Action*. Alexandria, VA: Association for Supervision and Curriculum Development.

Taylor, Jill Bolte. (2006). *My Stroke of Insight: A Brain Scientist's Personal Journey*. New York, NY: The Penguin Group. This account by a brain scientist of her recovery from a massive stroke is a testament to the regenerative potential of the brain.