Asperger's Syndrome:

A Therapist's Perspective

Living with the Possible

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As an experienced teacher but a novice educational therapist, I had to learn that I could do only so much for my clients. I learned this especially from a young boy with Asperger's Syndrome whose brightness, peculiar charm, and learning difficulties taught me to work in the realm of the possible. This boy cannot be fixed but he can learn. As a novice educational therapist, I wanted to do more than help someone learn; I wanted to fix what was wrong. In fact, I know that's not possible, but it didn't stop me from wanting it. I was doomed to frustration. Then I met Dan. He was the client who helped cure me of the need to fix, the one who taught me to live in the world of the possible—head out of the clouds, feet on the ground.

Dan had been diagnosed by a psychiatrist as being "somewhere in the autism spectrum," which site I am willing to call Asperger's Syndrome (AS). He presents these characteristics denoted in Tony Attwood's (1998) book Asperger's Syndrome: A Guide for Parents and Professionals: one-sided interaction, little ability to form friendships, pedantic speech, poor nonverbal communication, intense absorption in certain subjects, and odd postures.

Of course, there are other complications as well, including Tourette's Syndrome, Attention Deficit Disorder, Obsessive-Compulsive Disorder, and Depression. Attwood's book talks about the possibility that AS characteristics may be confused with these disorders. In any case, Dan, as any other person with Asperger's, is a walking symbol that no one and nothing is simple.

I had previously worked with one other 18-year-old man, Richard, who showed every characteristic of Asperger's Syndrome. However, his mother denied (and, therefore, so did he) that he had Asperger's because he had a few friends. He made those friends in a school for children with autism. I should have learned from him that I couldn't "fix" the problems that interfered with his learning, but I didn't. I thought I couldn't make too much progress with him because he was older. Richard also had ADHD and OCD, but not Tourette's. He also seemed fairly depressed, although that wasn't in his diagnosis. He could read anything (great phonetic reader), but didn't really understand much. He wrote very slowly, often getting so involved in forming his letters that he forgot what he was writing about. But he

typed well and could—if focused—write fairly well using a computer. Most significantly for me, he appeared to have no imagination. He couldn't make up a story, even using characters from stories he knew from reading or videos.

In contrast, Dan, was a bright, imaginative, nine-year-old, quite dyslexic reader. He also had difficulty writing by hand, forming letters painstakingly, backwards, and slowly. Like Richard, he was a great talker, knowledgeable about some little aspects of life (Japanese animation and Britney Spears for Richard; garbage trucks, and later marine biology, especially sharks and whales, for Dan). I think of Dan as "the little professor" because he is always lecturing/teaching about what he knows. He shows little, if any, sense of whether the person he is talking to shares his enthusiasm for his subject.

Dan is an adorable, freckle-faced boy who lives with both parents and a younger sister who is a brilliant reader and free from any of the disorders that plague Dan. He loves her anyway. He attends a public school in an inclusion program and has a one-on-one aide who had been with him for a year and a half when I started working with Dan.

Dan has an amazing memory for shapes, and a remarkable auditory memory. His knowledge of subjects he's interested in is almost encyclopedic, yet little of the information stored in his brain did he acquire through reading.

My contact with his parents has been entirely through his mother who says the father cannot deal with Dan, so caring for Dan and his sundry syndromes falls entirely upon her. Despite my repeated requests to meet with the father, the mother has not complied. Apparently, he does not admit his son has a problem, and does not know that the mother takes Dan to a psychiatrist (for medication), a psychologist, and an educational therapist.

Not surprisingly, the mother is a needy client who wants to talk to me much of the time. At first I thought her questions and suggestions were annoying, as did most of the school personnel she dealt with. It took me a while to acknowledge that as a former school teacher who is quite knowledgeable about appropriate education for Dan, she is also the expert on what's going on with him at any given time. Unfortunately, she experiments with Dan's medications to try to get the right dosage, but doesn't give any experiment enough time to work. Also, she doesn't have much confidence, and asks my advice more than she needs to. Much of my work with her is to build her confidence in her knowledge of Dan and to try to slow down her impulsive dealings with the school. Is it a

surprise that kids with ADHD have parents who are impulsive?

When she hired me to work with him, Dan's mother's agenda included improving his reading and handwriting. My agenda added some social skill work. He wouldn't let me teach him phonics in any systematic way because he said, "I learned that already. I'm not a baby." I found this frustrating because phonics and blending were exactly what he needed. What I had to do was sneak it in when we were reviewing his spelling words for the week. "Oh, look, there are two different ways to say C in circus." During fourth grade, we made some kind of pass (usually cursory) over the 20 spelling words each week. I would look for the patterns and find something to emphasize: these syllables all end in double letters; these G's sound like J when they're followed by E or I; these suffixes always mean the word is a noun. He wasn't nearly as interested as I was, but I got to make the point. It became the land of the possible.

I was never truly successful at building an organic curriculum, a whole way of teaching around something that interested him, as Dorothy Ungerleider writes she did in *Reading, Writing, and Rage* (1995) and in *The Organic Curriculum* (1995). I have been able to seduce him into reading snippets on subjects he's interested in. There aren't a lot of kids' books out there about garbage, so I found materials on line which I printed out. There was lots of information about recycling, but he already knew all of that, so there was no incentive for him to read.

The seduction became more important than the subject matter. I had something he wanted, and in order to get it, he had to read first. I would read to him at the end of every session from *Harry Potter and the Sorcerer's Stone*. He would do almost anything to earn his 15 or 20 minutes of *Harry Potter*. By the end of the school year, he was so frustrated about not having finished *Harry* with me that I loaned him the book, and he finished it, with some help from his mother, by midsummer.

These days he has become the foremost authority on marine biology. So I got a sticker book on sharks, whales, dolphins, and other sea creatures, which has informative snippets under the sticker pages and under the places where the stickers are to be placed. I suggested that I would read one part, and he'd read the other. All we are doing is practicing reading, but he is motivated to participate because he wants to know what the book says. He wants that sticker book. We had done another one on insects, which he also got to keep after he had finished it. After we have finished a sticker book and placed all the stickers where they belonged, and read all the information, I give the book

to him. If I discover he is interested in something, I seize on it, and use it to get him to read.

Handwriting was another story. Dan was willing to do pre-cursive handwriting exercises—making some of the forms of cursive writing such as waves and loops—but when it came to applying those forms to actual handwriting, he was unwilling to change the flow or pattern of his writing. It would take him so long to write that, as with Richard, he would lose the sense of what he was trying to say. I recommended an assistive technology assessment because I believed that, like Richard, he would be able to type faster and keep up with his thoughts. To that end, his mother bought him an Alphasmart—a dandy little light computer that does nothing but process words and is quite inexpensive. (See Aplhasmart.com). The assessment recommended that he have some hours of keyboarding instruction each week. Unfortunately, no one at the school or at home works with him in any consistent way on keyboarding skills. I've been teaching him the Hanbury King (1986) alphabetical method, and he's doing quite well at it, but it tires him and he doesn't practice on his own. I bring my laptop to the school, and we practice at least part of each hour that I'm with him. Living with the possible is not my first choice, but there are other things to learn, too.

Some days he is responsive to working with me, and other days he is not. Sometimes he puts his head down on the desk and pretends to be asleep when he is being what I call, "unresponsive." His mother says he's tired when he does this, but it feels more like passive resistance to me. After the second time he did this during our weekly hour together, I said, "Dan, when you don't want to work anymore, I would like you to say, 'Susan, I don't want to work anymore right now.'" Remarkably, he complied. The next time he put his head down, I said, "Do you have something you want to tell me?" And he replied: "Susan, I don't want to work anymore right now." I said, "Okay," and offered to read *Harry Potter* to him.

It is true, as Tony Attwood tells us, that everything has to be made verbal for a child with nonverbal learning difficulties, such as Asperger's kids have. I have to tell him how I am feeling, and he has to learn to tell me how he is feeling. I can't just give him a disapproving look, but have to say something like "Dan, please stop kicking my chair." I talk about how I feel and encourage him to talk about his feelings. I haven't given him extensive social skills training because that is not what I was hired to do. And we have only one hour a week together.

Several issues about his progress trouble me.

Although now in the fifth grade with a wonderful teacher, Dan is still not able to show that he knows the material the way the other children do. He knows the material, but is slow to perform on tests, of which there are many—sometimes three in one day. Too many tests create tension, so Dan becomes less able to finish them. Should he be given separate, shorter tests, or should he try to be like the other kids? His mother thinks the former; the teacher thinks the latter. I wonder whether he should be allowed to see what the consequences of not doing his work would be, or whether they would be too devastating for him. There are no manuals on how to teach children with AS because they are all different. However, there is an online AS information and support site with some excellent suggestions for modifications and support of AS students: http://www.udel.edu/bkirby/asperger/ IEP Modif Checklist.html.

Sometimes this boy, Dan, seems so able, and sometimes he seems so very fragile and ultra-sensitive that it seems like an act of bravery for him to show up at school each day.

I wish I didn't go through bouts of self doubt of not doing enough for him, of regret for not fixing him, somehow, but the lesson for me has been to give him my best and to live with what is possible. Right now he is learning to type. He is reading with me without my even asking him to read. He will say, "You read this, and I'll read that." I say, "Okay."

References

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