



By Caryn Sullivan

A TEENAGE SISTER'S STRUGGLE

Autism Speaks Newsletter
8/19/08

It was a difficult summer. After nine months at boarding school, our 17-year-old son with Autism Spectrum Disorder (ASD) returned for a 12- week break. While he was thrilled to be home, our 14- year-old-daughter was distressed when the brother who absorbed so much of our attention settled back into his old routine. She'd enjoyed the tranquility that settled in the household in his absence, as well as her parents' undivided attention.

When she was younger our daughter loved to be different. Her motto was "never be normal." Who cared if her socks didn't match? What was wrong with getting down on the floor and barking like a dog? The dynamic changed dramatically in middle school when being accepted became more important than being unique. Suddenly, her family became a potential threat to this goal. We all became an intolerable source of embarrassment to her, but none as great as the brother who is socially challenged.

The reason is clear to me. As kids mature, the circle that encompasses acceptable behaviors shrinks. Kids turn on their peers who don't fit a certain mold. The mavericks that hovered at the perimeter of the social circle either shift toward the middle (like my daughter) or become ostracized (like her brother).

Last spring, the Pioneer Press published an article by John Campanelli in which he talked about how kids embarrass their parents. Campanelli related how a 4-year-old girl loudly commented about a gentleman's "big butt" in a quiet setting. I suspect I'm not the only parent of an ASD child who has suffered through many such outside-the-circle remarks in public – and expects that phenomenon to endure throughout my lifetime.

I also imagine there are families dealing with other behavior-involved conditions like Tourette syndrome or ADHD who are well acquainted with the mortification zone, where my daughter and I often dwell. Since I, too, have a relatively low threshold for embarrassment, I've been mortified by my guy's behavior on countless occasions. But is he to blame? He doesn't have a Jiminy Cricket on his shoulder, counseling him not to blurt out comments or do things his peers might consider, but reject.

I feel guilty because I know the nuances of what is cool and what is taboo are confusing, and the line between entertainment and embarrassment is fuzzy for him. If I don't always know how to deal with his unusual remarks or behavior, can I expect his sister – or her friends – to "get" him? Absent a white cane or wheelchair to broadcast his challenges, I fill the void by letting strangers know that this normal-appearing guy has ASD, so they won't judge him (or us) unfairly. My daughter is less interested in running interference. She just wants him to look *and* be "normal."

Lately, I'm wondering whether I'm observing the unintended consequences of years of coaching him into the circle, manifested at times by high anxiety, low self-esteem and

defiant behaviors. Is it time to accept that he is who he is? Is it time, as Campanelli suggests, to "let it go"? Is it reasonable to expect my daughter to do so?

I hope that with time, my daughter will develop the maturity and perspective that will help her to accept her brother and others like him. Those who know her assure me that one day she will not only accept him, but will be proud of how he has addressed the myriad challenges in his life. Until then, I'll continue to encourage both of them to be considerate and compassionate and to co-exist, regardless of where in the circle they reside.