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Understanding Asperger's Syndrome

by Johanna Sorrentino

For parents of children on the Autism spectrum, consider this: maybe it's not only about your child's understanding of the world, maybe it's the world's understanding of your child.

Michael John Carley has come full circle with this concept. He was diagnosed with Asperger's Syndrome at the age of 36, just one week after his 4-year-old son received the same diagnosis. "Not only was my son being presented with an explanation, but I was finally presented with an explanation of what I'd endured my entire life. I don't have the words to describe the biblical weight being lifted off me," Carley says.



Asperger's is a neurological condition, and is one of five diagnoses that comprise what's called "the autism spectrum." The "autism" label has carried some serious baggage. So much so that in the 1960s there was born a movement of "antilabelism" where children were no longer stamped with a diagnosis, and instead their condition was referred to only as "special." Carley says this trend swung too far in the other direction--"that's the comic tragic thing." Now, he says, it's time to embrace terms like "Asperger's" and "Autism," so that those with the condition can begin dealing with exactly what it is that makes them different—both the negatives *and* the positives.

And that's why the ideas he presents in his book, *Asperger's from the Inside Out*, are so new. In the book he provides a table of common Asperger's characteristics and the positive and negative interpretations that go along with it. For example, one of the characteristics that Carley discusses is an intense absorption in a topic or field of interest. While the negative interpretation is that the individual is obsessed, the positive interpretation is that this individual is passionate about something. Another common element of Asperger's is the inability to read nonverbal communications such as facial expressions, body gestures, and shifting vocal tones. The downside is that many miscommunications with what Carley calls the "neurotypical" world are guaranteed, leading to failed socialization and lost opportunities. The upside is that communicating using text--either in reading or writing--is heightened. Often, those with Asperger's say whatever comes into their head, unaware of the potential damage the statement might cause. To many, this is construed as rude, but could it not also be seen as honest? And on this list goes.

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Carley says the point of all this isn't to invalidate the challenges, but to consider how those with Asperger's *can* function in society, rather than thinking about all the ways they can't. "Yes, life is harder rather than easier, but we don't consider this a blanket negative," Carley says.

And society is beginning to catch on to the idea that people should be seen for who they are, Asperger's and all. When Carley was a child, before the word Asperger's made it onto anyone's list, his behavior was explained away as emotional difficulties due to his father's death in Vietnam.

Carley says his son will benefit from living in a world that knows more about this neurological condition. "The upshot to knowing more and more is really just that you're weirdness has an explanation. You know you're just wired differently, you're not rude. You process thought differently, instead of being an insensitive creep," he says. "It's a much better way of thinking about yourself."

This self-awareness is critical, according to Carley, because being able to educate others about your condition is an imperative life skill for people on the spectrum. "You want to be creating in kids the best self-advocates they possibly can be because we hope that they're going to leave home, and they need to be the ones to explain why they come across as different to that potential landlord, significant other, or employer," Carley says.

What else can parents of children on the spectrum do to handle stress, embrace their child fully and help to raise an independent adult? Carley, who has worked with thousands of families as Executive Director of GRASP (The Global and Regional Asperger Syndrome Partnership), offers this advice:

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1. Read up on the history of Autism Spectrum Disorders to find out how the iconography has developed over the years. Carley says depending on the challenges of their particular child, parents will feel some sense of pressure to change that child—maybe due to an outburst in the supermarket or an awkward conversation with the neighbors. “We can all forgive ourselves when want to secede to societal pressure. What's important is loving your child for who she is. That can't begin until we look at how iconography has affected us,” Carley says.
2. Make sure you're taken care of. Carley says there's a good reason that airlines instruct passengers to put the oxygen mask on themselves first, before assisting their children. “If you can't be there in a healthy, operating way, you're not much good to your child,” he says.
3. One of the biggest challenges for individuals with Asperger's, Carley says, is an ability to shrug off life's failures. But, parents can help their children process failure better. “Praise, and praise, and praise for trying,” Carley says. “Very often parents say 'This is a special child, and I want to shield him from failure.' It's a good thought, but it's not the final resting ground. The final resting ground is independence and bravery.”
4. Finally, Carley says joining a support group can be a great way for families to relieve stress. “When someone tells you 'I understand. I've been there.' Nothing feels better at that moment,” he says. GRASP, the world's largest support organization for Asperger's, has a list of families and clinicians on their website. Check it out at www.grasp.org (<http://www.grasp.org/>) .



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