

ASPERKIDS

An Insider's Guide to Loving, Understanding
and Teaching Children with Asperger Syndrome

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Foreword by Liane Holliday Willey



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FOREWORD

Just a few pages into *Asperkids*, I knew I was reading something special. Jennifer Cook O'Toole's writing eased me into feeling as though I were having a charming conversation with a trusted old friend. It is so easy to settle into O'Toole's words, which are rich and well crafted, attentive and honoring, even when they are speaking of the sad bits we Aspies will inevitably struggle with. It is also easy to quickly recognize O'Toole knows what she is talking about. She is clearly a gifted thinker and uplifting member of the Asperger community who has worked hard to figure out the world she struggled with as a child. She is a remarkable tutor who can teach Aspertalk to neurotypicals so they will fully understand the importance of seeing the world through Aspie eyes. And she is a devoted mother and social worker who helps parents and society predict when their Asperkid may fall so they will know how to save them from hurt and help them to love the gifts that make them Aspie.

Asperkids is a book about advocacy as much as it is a book about understanding and assisting children with Asperger syndrome. For example, the book discusses how difficult it can be for Asperkids and their families to stand up to bullies in the playground, as well as authority figures who would have us believe our gut instincts and parental decisions are off-base and clouded. We read first-hand accounts of the misunderstandings society has concerning our kids in general, and the typical ramifications of those misunderstandings. A much-needed ray of light is shed on the differences between Aspergirls and Asperboys. O'Toole also elucidates on the

complexities of Aspie friendships and then provides insight into how to find and maintain relationships that can become mutually enriching. Each chapter, in fact, holds a follow-up section filled with insightful learning and social designs that will support our kids. All in all, a comprehensive read on Asperkids.

Before you know it, you will be finished with this book and though you will have oodles of fresh perspectives on Asperger syndrome and piles of new ideas and strategies to offer anyone interested in helping our kids, you will wish you had more pages to turn, because with each page comes a new anecdote that turns into a creative learning experience that morphs into a helpful curriculum guide and faithful manual for Asperkids! O'Toole is the real deal bundle of experience and knowledge our Asperger community can turn to for compassionate understanding and wise advice. I can't wait for her next book.

Liane Holliday Willey, EdD

*Author of Pretending to be Normal: Living with
Asperger's Syndrome and Asperger Safety Skills for
Women: How to Save a Perfectly Good Female Life*

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Mom, I admire your courage in allowing me to share such an intimate story. Thank you for seeing the potential in me, the work-in-progress. Daddy, I miss you beyond words, yet hear you so often. This book is truly your legacy for me and for your grandchildren. So for everything, I love you, Mom and Daddy.

I would never have felt the import of writing a single word were it not for my children. Now, Mama's words are forever here for you to remember how powerfully I love you, and how precious you are in God's eyes. You make me laugh at every day, and joyfully share the dance parties by my side. Thank you, Maura, Sean, and Gavin, for being mine. Mommy loves you...more.

Last, to my funny, hunky, steady husband: John, I still look at you and feel the flutter of new love. I am so grateful for your bravery in the adventure and in your candor on behalf of our children. Thank you for being my best friend every day – good and bad – and for showing me that this was the moment to change everything. With your arms around me, it is and always will be “a wonderful world.”

INTRODUCTION

How Asperger's Saved My Life

The single most important lesson my mother ever taught me was spoken from the doorway of my bedroom just after I had had a major meltdown. It was two weeks before my senior year of college was to begin, and I had to get back – there was an honors thesis to write, sorority work to accomplish, packing to do.

But I was not exactly ready to pick out a duvet cover. Only two weeks before, I had ended a dating relationship that was abusive in every way you could imagine. I drove the three hours to my parents' house, and completely fell apart. My brain is one that demands logic, and for the life of me, I could not figure out what I had done so wrong that had made my world implode. So, I did what I always do when life throws me a curveball. I research. A lot. Facts are comforting. They make sense out of chaos.

Late one sleepless night, I caught a television announcement about dating violence, inviting viewers in trouble to call their information hotline; and I did call – right away – asking for any literature they could send. When the thick manila envelopes arrived, I buried myself in the information inside. There were charts and blueprints, clearly reoccurring patterns of interpersonal behavior – that most confusing of subjects. Suddenly, things which had been nebulous and fuzzy were organized and logical. Light bulbs flashed above my head, and the relief flooded over me – in collecting and analyzing data, I had been able to make sense of the endless cycle that had bound my life for almost two years. Feelings were fuzzy, motivations unclear. I never would have been able to make sense of the interpersonal craziness that had broken me. And now, after

1 THE THEORY OF MY MIND

How Asperkids Think

The unexpected redhead

“She’s got red hair!”

This was, apparently, the first thing my mother ever said upon seeing me. She was merely surprised, she has always explained. She hadn’t expected a little redhead (even though she says she had been “Titian-haired” as a girl). But then again, what we expect and what really is are often not quite the same, are they?

The ginger hair did continue to be my calling card, though. I learned throughout my childhood that this unique feature was the source of quite a lot of attention. It was a pretty, coppery color which adults constantly admired, and as I got older, turned quite a few glances my way. Per cliché, perhaps, I was perpetually cast as the femme fatale in school plays, wrote my high school thesis on the history of redheads, and – apparently – was the turnaround answer to my husband’s prayers. Just days before we met, he asked God to please send him a special someone, and “if she could be a redhead, that’d be even better.”

Being different can make you special. A stand-out. Desired. It can be part of your identity in wonderful ways.

But I know of many other redheads who had quite different experiences. They were the butt of jokes and called names, or they simply hated the attention their ginger locks brought them.

For them, the “different” that nature endowed upon them (quite without their request, mind you) was altogether unwelcome and maybe even resented.

Different can do that, too. It can cast you in a role and include you, if you’ll play along. It can discard you instantly when you don’t.

And such is the label “Aspie.” Without my knowing it, my need for a script to follow, my hyperfocus on details and Mensa-level IQ, my profound loneliness and social naivety were all the product of being different. Yes – they were part of being “Aspie,” a word not exactly commonplace in the 1980s or 1990s.

So time goes on. Years pass. Another mother, another daughter.

“She has Asperger syndrome.”

This time, it was my voice speaking, now as the mother, seeing an unexpected but familiar reality in the child who is my own little girl. This “different” was unrequested, too, a simple genetic expression as much as my red hair had been. And yet, honestly, in my daughter I had long since recognized the most personal, vulnerable parts of me that had set me apart, for better and for worse. It is an identity that has made us both stand out, both brilliantly and flinchingly.

A little fiery, a lot intense, passionate, and driven. Those descriptors have followed me my whole life long. They resonated as I graduated with honors from a top-tier, Ivy League university, studied graduate level social work and education, and became Mommy to a Make-A-Wish kid. They have done great good for the world, made me a loyal wife and champion for my children. They have also left me completely alone along the way, lost as to what I have done wrong, or how I have messed up. If only people were as simple as formulas, sentence structure, or historical fiction, I would have had it all figured out long ago.

I can’t tell you what it’s like to be a redhead any more than I can tell you what it is to be Aspie. It is who I am, and I know it innately, intrinsically, inherently. I know nothing else of reality but through careful observation and study. But it is that same tendency to analyze details others ignore, and to remain (hyper)vigilant on behalf of those I love that has forced me to fill a void in the educational and life skills needs of Aspie kids – first, specifically, my own.

In 2010, at an autism conference, I heard Tony Attwood say, "Don't let the brilliance blind you to the challenges." My kids *are* brilliant, endearing, and lovely. They are also abrasive, learning challenged, and obstinate. I have looked and read and listened and questioned, but nowhere could I find answers to their disparate academic, social, and practical living abilities. How could a child read with the fluency of someone ten years her senior, yet not be able to negotiate the morning routine of getting successfully from the car to locker to classroom without tears? She could build Lego® versions of the Empire State Building, but couldn't write legibly enough for anyone to read. How could a little boy of four years do multiplication but not be able to figure out how to get through the steps of successfully using the bathroom when the time came? My kids were like Swiss cheese – powerful, but full of holes.

Though she read multi-chapter books by age three and sounded (to quote her preschool teacher) "like a little professor," my daughter was bounced between five classrooms in two years between the ages of five and seven – and this in the most expensive schools in the city. Too "smart" for one grade level but too socially immature or unfocused for another, she was tossed around with little regard for the psychological impact upon her. No "expert" knew how to manage a child with skill sets spread so far across the charts. Nights filled with tears and mornings with tantrums.

Her little brother was following suit exactly. He was already an encyclopedic expert in superheroes, then planes, then dinosaurs, but couldn't play alongside buddies without turning into the playground rule enforcer, and had meltdowns if he had to sit on a different letter on the classroom's alphabet rug. By the time the little guy was three, we pulled him from preschool to try other special education options, but nothing jelled for them. No one curriculum, school, theory, or approach seemed successful, and between running from therapist to therapist and school to supplemental activities to try to make it all better, the family was emotionally, physically, and financially exhausted.

Eventually, a confluence of unrelated medical and psycho-educational demands had us pull the plug. We would have to homeschool. My background in teaching kids with learning

differences as well as in social work kicked in, as did my own life experiences. It was mine to make up. Improvise. Invent. Show time. Game on.

We, like most families with special needs kids, have a lot of professionals involved intimately in our lives – sometimes uncomfortably so. Between endless appointments, assessments, interventions, reassessments, advice, and opinions on every aspect of life from toileting to the state of the marriage, there isn't a lot of room for privacy, or for just *being* versus always *doing* – a simple thing that neurotypical families probably never much consider.

Still, we respect learned opinions and professional dedication. Over the years, our family has accumulated an amazing team of experts whose willingness to think outside of the box is both exciting and challenging. Needless to say, this unexpected educational byway had me extremely self-conscious. I had confidence that I knew my kids best, that I was dedicated to them as no one else could be – but I was still uneasy, I promise you. What would all “the professionals” think of what I could or couldn't do? Really, though, what was there to do but try? So, typically me, I took that challenge and ran.

Improvising

Isn't it the way of the world that when we finally are brave enough to follow our instincts, things have a strange way of working out exactly as they should? Since the dawn of the “Great Homeschool Improvisation,” the very same mental health and educational professionals I was so worried about began approaching me and asking me more and more vociferously to share the recipe I was creating at home. Apparently, not only did they *like* it, they *loved* it!

I was flattered, but befuddled. Like many Aspies, I was diagnosed in adulthood secondary to my children's evaluations, and I was still teasing out which parts of my personality and thinking patterns had to do with Asperger's and which didn't. I wasn't really sure what it was about my approach with Asperkids that was so original.

My problem was mindblindness, a classically Aspie tendency to have trouble delineating between one's own thoughts and understanding and other people's.

That's part of what makes it so hard for us to tell you what we are good at, or what we need help understanding – we can't always tell where our knowledge ends and yours begins. My Aspie son asks me what "that" is on the DVD screen, even though it is playing behind my head in the car. I can't see it. But he can, so if he doesn't think about the question first, he still intuits that I can, too. My daughter answered a test question by explaining that no, one couldn't ice skate across the Atlantic Ocean, but perhaps one could cross part of the Arctic Ocean on foot. She was right, but she didn't get credit, because she never explained why the illogical scenario was impossible – that the Atlantic is never solid while part of the Arctic might freeze. She just assumed the knowledge in her head was obvious to everyone.

As we grow up, we Aspies learn to "connect the dots" between our thoughts and our words a little bit better, but it has to be a consciously acquired skill. And even then, it's not easy to delineate what we know versus what everyone else knows. Therein lay my problem. If I was going to make things better for the millions of Asperkids out there (not to mention their families and caregivers), I had to figure out exactly what it was that I, as an Aspie, had to share that the rest of the neurotypical world needed to hear. Perhaps it sounds strange to your ears, but this was a painfully difficult task for me. Even specialists, who worked with spectrum kids constantly, didn't seem to grasp the source of my confusion. I wanted desperately to be the voice for our beloved children, and was being told by professionals I trusted that I could "help to change the way we do so much for these kids." That's a monumental responsibility that I did not want to blow. But to get inside your minds and then be able to ascertain what you need to know from us was almost impossible for me.

I am a teacher and a mom, but I am no curriculum expert, well-paid psychologist or lifelong special educator. So, in a very "typically Aspie" get-to-the-point-without-sugar-coating-it way, I put this question to a close friend, a college professor and herself the mom of a spectrum child; she had been to the same lectures, read most of the same books, learned the same lingo and put a ribbon on the back of her minivan, too. "So why," I asked flatly, "don't you know