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

Jennifer Cook O'Toole Foreword by Liane Holliday Willey ISBN 978 1 84905 902 2 eISBN 978 0 85700 647 9

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www.jkp.com

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Library of Congress Cataloging in Publication Data

O'Toole, Jennifer Cook.

The Asperkid's (secret) book of social rules : the handbook of not-so-obvious social guidelines for

tweens and teens with Asperger syndrome / Jennifer Cook O'Toole.

p. cm.

Includes bibliographical references.

ISBN 978-1-84905-915-2 (pbk. format : alk. paper) 1. Asperger's syndrome in adolescence. 2.

Asperger's syndrome--Social aspects. 3. Asperger's syndrome--Patients--Life skills guides. I. Title.

RJ506.A9O86 2012 618.92'858832--dc23

2012015213

British Library Cataloguing in Publication Data

A CIP catalogue record for this book is available from the British Library

ISBN 978 1 84905 915 2 eISBN 978 0 85700 685 1

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Acknowledgments

There are times where you may find that you are part of something much bigger than yourself. For me, "right now" is such a time. And it is so very well with my soul. I am humbled by the voice I get to have in this world-wide "Aspie" conversation, and am honored to be given the chance to tie my life's experiences up in a bow and offer them, like a gift, to the next generation of Asperkids. So, thank you...

To the parents who've called me crying and afraid, and to the kids whose renewed self-esteem has made me burst with joy: thank you for sharing your journey and your trust. May I always do well by you.

To those who've taught me—through kindness or hurt, through love or abandonment—exactly who I am, thank you for showing me my own originality.

To the "Super Jessica" Kingsley (yes, I do think you should wear The Cape to board meetings) and her brilliant publishing team, thank you for believing in me—again. Know how sincerely I appreciate your vision and dedication and how proud I am to bear the JKP mark.

To Brian Bojanowksi—thank you for hours of sketching my crazy ideas and sometimes funny words into life. Thanks to Wendi and the boys for loaning you out, and thank you all for sharing the belief that this was never about us to begin with.

To my dear friends, Aileen, Lori, Amanda and Elizabeth, for continuing to encourage and support me always in all ways—no matter what life is throwing at you. I am inspired by each of you every single day.

To my mom. I know foreign languages were never your thing. So thank you, from the bottom of my heart, for trying so hard (for me and the kiddos) to learn to speak "Aspie." I love you and am so proud of you. Pink roses, Daddy. I miss you.

To my Asperkids, Maura (great cover idea!), Sean and Gavin (my little men): you rock. You are each such unique, precious bits of tomorrow. I fully expect you to change the world. Thank you for being mine.

Last, to my husband and best friend, John. I love you, Asperguy. Here's to a lifetime more of comfy routines, label-maker vs. Diet Coke can battles, and utter geek chic contentment. When it comes to being BFF, John, we wrote the book.

- Introduction -

Rules, Posers and Speaking a Foreign Language

We Aspies have a weird relationship with rules. In some ways, we love them. They kind of act like those organizing tubs you see in container stores. Sort this here, this does NOT go here, and move this out of the way. Rules aren't about telling us what NOT to do, as much as they tell us what we SHOULD do. They prevent chaos and confusion and stress. They create calm when the world feels messy and unpredictable. Rules, you might say, can be an Aspie's best friend.

On the other hand, we can take them a little bit overboard. "Rules" about healthy eating can become "food rituals" that restrict social activities; "rules" about homework can become perfectionism that causes great anxiety. Which is why the number one rule about rules is that they are almost never absolute. Confusing, but true. There are variables, exceptions and escape clauses, and you know what? No one gets this stuff right all the time. It's just that we Aspies like either/or a lot better than "sometimes" or "maybe." No big surprise that so many of us love games, hobbies and stories with predictable patterns and logical construction. Even our imaginations prefer facts and good versus evil basics: sci-fi, fantasy or historical fiction. What can I say? "Maybe" is just not our thing.

You've probably noticed by now that I'm saying "we," not "you." That's because I, too, am an Aspie. Although, if you're reading this, and you're an Asperkid, you have a major thing going for you already. You are SO lucky to *already* know what kind of mind you have. I didn't find out that I was an Aspie until I was an adult and learned that my own three kids (and husband) were Aspies, too. That means that I spent thirty-four years pretending to be just like everyone else. Which I wasn't. Growing up, I was "the brain." There was no word "Aspie" or "Asperkid," or anything else other than "dictionary head" and "know it all," and that kind of thing.

As I got older, I created myself on stage. Having started dancing at two, being on a stage in front of hundreds of people was, in many ways, a whole lot easier than being in a room with one person. If you have a script or choreographed dance steps, you just follow the plan. You can't really mess up—in fact, a very strange thing happens, or at least, it did for me. More and more, my real self popped through on stage, and the roles I played leaked into my daily life...until often I couldn't even tell when I was being real and when I was acting. I had enough scripts memorized and body language programmed into me that not only did I "act" well enough to blend in, I even became somewhat of a social butterfly.

Let me tell you, after all of that, I am one heck of an actress. I wore costumes in real life: cheerleader uniform, sorority letters, big hair (that was a good thing in the 1990s), and got so good at playing the "social game" that I earned the nickname "the flirt." At the time, that felt pretty cool-looking back, though, it was pretty sad. I didn't know I was an Asperkid. I just knew I'd spent enough years getting pranked, left out, made fun of and taunted. Enough nights crying at having to go back to school in the morning. Enough lunches hiding in the woods outside my high school rather than try to find a seat. So once I had the chance to play the role of "vamp" and "glamour girl," I took it for all it was worth-to extremes. Going from "nerd" to "hottie" felt like a promotion. It wasn't though, because either way, I was defining my self worth by someone else's label. I had no idea how to be authentic (a little nerdy, a little flirty) AND happy. So I'd play my "role" pretty well...but never convincingly enough to fluently "speak" neurotypical (NT). With no idea that I'd done something wrong, I'd bother, embarrass, annoy, hurt or disappoint someone. Through college, and in job after job afterwards, no matter what I

achieved or where I managed to fit in, I always felt like a "poser," just waiting to be outed for the "fake" normal girl I was.

Less than two years ago, when I was identified as an Aspie, everything changed. Turned out, I wasn't defective, I was different. Being down on myself for making social blunders was as dumb as if I got mad at myself for having red hair or being a girl. We Aspies are hard-wired differently. Without trying, we can focus for hours on the tiniest details that other people seem to miss, and we understand wrong versus right down deep in our hearts. Being Aspie isn't bad or good, it just is. I will never be a brunette. I won't ever be male. And I am totally OK with both of those things. I'm also never going to be NT. It's not my normal. And if you are an Asperkid, it's not your normal either.

Part of understanding Aspie meant that I could forgive myself for messing up along the way. That was great. As my daughter said, "It means I'm not a dumb-bunny when it comes to people." No, she's not, I'm not, and you're not. But it also means that in order to get along in this world where most people's minds operate differently, we have to learn their rules. The problem is that nobody bothers to explain those rules to us-they just expect that we will "know" them, too. We learn manners, of course...or at least we should. Simply put, good manners make people more comfortable around us. They make other people feel good when they are around us-which means they WANT to be around us more. So? Sooo...if people want to be around us, it's easier to get help from teachers, find small group partners or gym teammates, get a date for the prom, even get hired for a job. Only as Asperkids, we don't think or learn or play like other kids. So we don't understand "manners"-or "secret rules"-the way that others do.

What Comes Naturally, and What Doesn't Mind-Blindness

"Manners," generally speaking, are the traditions or customary ways a particular group has to guide the way people treat one another. Their purpose is to make social interaction smoother, less chaotic. Less about "me" and more about "we." And they change

from society to society. So, in the Middle East, for example, to even show the bottom of your shoe to another human being is considered deeply offensive and rude. In Japan, not to take off your shoes upon entering a home would be the insult. In Bulgaria, nodding your head means "no" and shaking it from side to side says "yes," but the opposite is true most everywhere else. Argentinians expect you to arrive about thirty minutes after a set arrival time; many other cultures would find that disregard for time to be costly and arrogant. And in the United States, driving five miles over the speed limit is technically against the law—yet it's also expected, and sometimes even necessary if you don't want to tie up traffic.

Rules are relative, from one place to another. Expectations change over time (like women going to work), and from one situation to another (talking on a cell phone is fine, but not in the middle of a restaurant).

All this "fuzziness" confuses the heck out of us, right? Is someone being rude or just sarcastic? Or are they being sarcastic AND rude? Argh! Why can't this stuff just be simple? Why are these ridiculous "rules" secret to us, and not to the NTs?

Mostly, our trouble stems from two main challenges. The first is called "mind-blindness." That means that we have an awfully tough time figuring out someone else's point of view. Oh, we THINK we know what they are thinking...but usually, we don't, without actually asking.

Please get this. Mind-blindness doesn't mean Aspies are uncaring. Once we find out someone has been hurt, or is afraid or alone, we can be the most sympathetic people around. That's compassion: feeling sorrow or pity for someone else's misfortune. Heck, I couldn't even read *Charlotte's Web* (White 1952) as a kid, and I still have to actually get up and run to turn off the television if a commercial for hunger relief or animal safety comes on. My heart can't take the ache I feel. Strangely, my own son, an Asperkid, does the same thing when he knows the plot of a cartoon will involve a character's feelings being hurt. He runs. My dad, definitely an Asperguy, used to walk out of a room if anyone cried. He wasn't cold. I think it was the opposite. The feelings were just too big.

How Not to Make a Light Bulb

Why Everything is Hard Before It is Easy



Need-to-Knows

- Persistence means dedication even when you royally and publicly mess up.
- · Skill develops over time, not overnight.

- Everything is hard before it becomes easy.
- Failure hurts. But it's the best way to learn.
- When you feel trapped in your mistakes is exactly when you have to start getting creative.
- Success is about what you do when—not if—you fail.
- The biggest mistake you can make is being too afraid to make one.

Asperkid Logic

Have you ever watched a toddler who is learning how to walk? It's a very clumsy thing. No matter how strong or how sturdy he is, no matter how smart or how coordinated she seems, every single little kid falls. A lot. There are a lot of skinned knees and split lips. And suddenly, everything in the house is geared toward preventing a trip to the emergency room. Diapers serve double duty as tush padding. Baby gates suddenly appear everywhere. Table corners are covered with foam bumpers. Catalogs offer baby crash helmets, and even mini elbow or knee pads. There are even "professionally certified babyproofers" (I am being completely serious, people) who, for several thousands of dollars at a time, promise to help safeguard toddlers as they, well, toddle around their homes.

OK. Got it. Learning to walk is a super-huge life moment, an enormous business, and very ungraceful. So?

Well here's my question to you: do you remember learning to walk? Of course not. Yet you obviously did it at some point. And it was a big deal to your little baby self (this was serious exercise and not a little bit frustrating). You wanted to check out some shiny thing or reach that cracker. You didn't want to wait for somebody to get your favorite stuffed animal or hand you a sippy cup. You wanted it, and you wanted it NOW. You wanted to be part of the fun. Maybe follow your dog or your brother. There may have been times when you screamed your head off in frustration. Or maybe you sat and thought about it, trying to plan your next daring escape from the crib. Whatever you did, the fact

is that for a good long time, no matter how badly you wanted to walk, you just couldn't.

This whole walking thing was also a big deal to everyone watching close by—those people who cared about you, helped you up if you stumbled, and cheered when you tried again. They may have even made home movies as you pulled yourself up, cruised along the furniture, carefully tried to balance...and then fell flat on your face. Repeatedly. Eventually, though, you got strong enough and had enough experience in what NOT to do to manage to keep your balance for a step, or even two. And within a matter of days if not weeks, your wobbly toddle became a "Frankenstein-ish" waddle and then a ridiculously fast (though not at all coordinated) run that probably terrified your parents all over again.

If someone were to watch that last bit, it might have even seemed that Baby You went from floor-bound crawler to nutty little marathon kid practically overnight. But you didn't. Don't forget the face-plants and split lips, the safety gates and bruised tush. No, this wasn't an overnight success. It was hard-won and worked at—by a small child, yes, but an achievement made no less worthy or admirable because of your age.

That's why you need look no further than your first triumph to remember this rule: everything is hard before it becomes easy. That's true for walking, talking, riding a bike, driving a car, doing multiplication, figuring out irregular verbs, quantum mechanics, going on a date, job interviews, and everything else that comes along. Life, in general, takes persistence. Which doesn't just mean long periods of dedication. Persistence means dedication even when you royally and publicly mess up. It means falling on your face and getting hurt. Feeling completely mortified when someone (or everyone) sees you topple over. Walking into a party with your skirt tucked into your underwear (OK, that might have happened to me), then getting over it, NOT running away, and sticking around to try again.

As one of my favorite TV characters of all times (and a total Aspie), Dr. Gregory House, said, "If you are not willing to look stupid, nothing great is ever going to happen to you."

Television talent shows make a huge industry out of taking folks and turning them into superstars. Of course, they don't show the backstory—hours of music lessons or practicing scales or getting laughed off stage. They don't show that because it's long and not too exciting to watch. But those bumpy days happened. Because everything is hard before it becomes easy. Skill develops over time, not overnight.

Being patient can be really hard—I know—especially when it comes to what we, Aspies, expect of ourselves. Ever try a new kind of math equation and end up completely furious with yourself, or lose it when you didn't "get" a new lesson immediately? What about trying to learn to jump rope and being the only one in the class who couldn't get the hang of it? (My hand's up, here.) Usually, this is when Asperkids want to quit...or scream...or just freak out at anyone who gets in their way.

Exactly why, though, should we know how to do something expertly right away? How come we think that—unlike everyone else—we don't need to put in time and effort before we are able to do (or maybe even fabulously achieve) something? The answer, of course, is that we can't do everything well the first time we try. And we shouldn't expect ourselves to. EVERYTHING is hard before it is easy...for a reason. If you can stick around through feeling embarrassed or disappointed or frustrated, there is something to be gained in the time it takes to learn. Something you can't gain any other way. Character and creativity. Resilience. Winston Churchill, that great, stubborn force, famously said, "Success is not final, failure is not fatal; it is the courage to continue that counts" (Vilord 2002, p.36).

As a baby, your legs got stronger by having to get back up over and over again. Your arms got more flexible from having to pull back up. Your reflexes got faster at detecting off-kilter balance only from learning what it felt like to fall. So, yes, this rule is partially about being nicer to yourself, and being more forgiving of mistakes. And it is partially about tossing the idea that anyone else thinks you ought to do everything right the first time. They don't (really) and you shouldn't (really). Somewhere, we get this crazy idea in our heads that smart people or cool people or people who are just generally worth having around don't fail. Wrong. They do. Happy people, content people...they just won't allow a blunder to be their final statement. The biggest mistake you can make is being too afraid to make one.

"No" or "you're wrong" or complete and total public humiliation—as awful as they feel at the time (and I am so agreeing that they DO feel awful)—can give you the chance to do and imagine and be things you never imagined. Give yourself a little time to see what can happen. When you feel trapped in your mistakes is exactly when you have to start getting creative. It's when you really get to see the genius you have inside.

The fact is that everyone—EVERYONE—messes up. Fails, even. That's not what determines who succeeds in life and who doesn't. In fact, many people will let early successes give them a false sense of confidence, that everything will come easily to them. Like I did at dance.

I started dance at age two, and right from the beginning, I was really good at it. It felt wonderful and without much effort, I could do whatever my teachers asked, and more. So pretty quickly, I just took for granted that dance would always be a nobrainer for me. Then, somewhere around age thirteen, I had the chance to audition for my first off-Broadway company. Everyone in the room was older than me, they filled out their leotards a lot differently, and they just seemed to walk around like they owned the place. I was totally psyched out.

So it's probably no big surprise that when the choreographer broke us into trios, demonstrated the combination we were to instantly absorb and then turned us loose to show her what we could do, I choked. I can't even remember if I managed a leap or a turn. All I know is that I ran out of the room crying. I wasn't upset about not making the company or even about looking ridiculous in front of everyone else (OK, maybe a little bit about that—although they'd all probably done the same thing at some point).