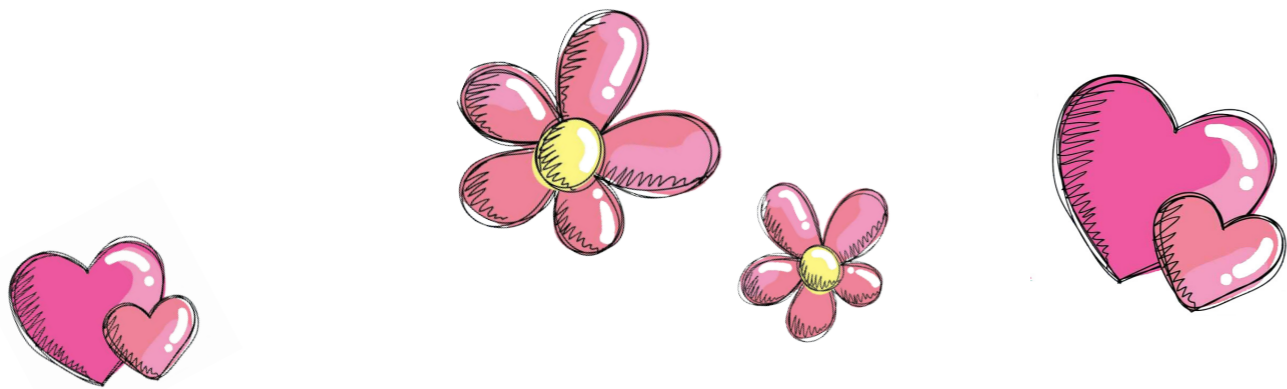


sPink on the sPectrum

By JENNIFER COOK O'TOOLE



Did you know that a rue-anemone is an imperfect flower? Now, until yesterday, I'll admit I would've guessed it was actually some oceanic creature. But it's not. It's a pretty little wildflower - albeit, an "imperfect" one.

OK, let's stop right here. Let me promise you something. This is not a lesson in botany. So even if plants aren't your thing, just go along for a moment or two.

Alright. Back to the rue-anemone. Let's be very clinical and professional now - looking carefully and taking notes. And what do we see? Well, beyond saying, "Ooh! It's pretty!", if we truly dedicated a year to watching one blossom on this pretty plant, we might record that the flower:

- blooms in early spring
- has petals
- has sepals (small leaves under the stem)
- has a peduncle (a stem)
- has pollen-producing anthers
- has slender filaments

Let's say, in fact, that we notice many rue-anemone flowers, and while they may vary slightly in size or shape, they all have the same characteristics. And so, we report our findings: a flower is the part of a plant that has...and then we fill in our list. Hereafter,

these characteristics will be the diagnostic criteria for whether or not something is a flower.

Would that be accurate?

Well, partly. Some flowers do have all of these parts. However, if we had picked another bunch of rue-anemones, we might just have easily seen all of the same characteristics - except the last two. Instead, in this second bunch of flowers, we would've seen observed a carpel - containing the ovary, stigma and style. So - what does that mean now? Are these other blossoms not flowers?

Of course not. You see, it turns out that a rue-anemone is one of the very few plants whose flowers have either male or female parts, but not both.

That's what earns the designation "imperfect."

Most flowers we know - roses, tulips, daffodils - are "perfect." They include both male and female parts; we'd never have to make a qualification that "Male" roses and "female" roses are similar, but a little bit different in the way they express their 'rosiness.' We can just say "roses are...." and finish the sentence.

But in the case of rue-anemones, one blossom - or even many of them - cannot represent all.

Who cares? We should. I certainly do - at least in "people" terms. Here's why: the vast majority of foundational observation of, and work with folks "on the spectrum" was conducted by male clinicians with male patients.



They saw, noted, and reported a pattern of characteristics, just as we did with our flowers. But instead of recording petals and filaments and then creating a "diagnostic criteria for flowers," these scientists (like Dr. Hans Asperger himself) watched people. Children. And primarily, they watched boys.

Not surprisingly, then, the constellation of behaviours, strengths, challenges, and tendencies that became the medical and public "profile of autism" (and Asperger's) is distinctively, decidedly "male." More boys are, logically, going to fit a profile that was created by observing and describing boys!

The male experience of floweriness or autism - or hunger or laughter - is neither neutral nor universal. It's valid. But it's only part of the story.

Until quite recently, women around the world were dying in terrific numbers from heart disease because they were looking for "traditional, expected" symptoms of heart attack, like shooting pains or sudden weakness. And these are, most definitely, symptoms of heart attack - in men. Women (and their doctors), by and large, were dismissing sudden onset lethargy,

indigestion, even nonspecific, general malaise because they didn't experience numbness down their arms or shortness of breath. In other words, they fatally ignored normal female histology simply because everyone expected female bodies with the same medical condition to present exactly as male patients did.

Let me be clear. I don't believe that doctors were intentionally being irresponsible or unprofessional. They did the best with what they knew - but what they knew was decidedly (and disturbingly) incomplete. And as Maya Angelou said, "When you know better, you must do better."



As the red dress campaign has gone international, gaining much more public awareness, popular culture - and medical professionals in general - have begun to integrate the female expression of heart disease into their understanding of overall symptomology. In other words, symptoms that "look like a female heart attack" are finally catching eyes and minds and attention as many additional manifestations of "a heart attack," regardless of the patient's gender.

Autism is pretty much the same.

Official diagnostic tests - even the general way society at large conceives of autism and Aspergers - deploy criteria developed by men based upon patterns they observed in boys. Of course more boys than girls will fit those criteria - even now. If you define a "child" as a young person with a head, gut, and testes - girls don't fit the bill then, now, or ever.

Like the "imperfect" flowers, there are commonalities between the sexes - both blossoms have petals and both genders of Aspies have sensory challenges. But one rue-anemone or one gender of Aspie cannot represent the entire population.

Neither can a clinical and “vernacular” idea of “what autism/Asperger’s looks like” be complete if it is “skewed” to more readily include one gender and frequently overlook or mislabel the other.

An inclusive representation of the spectrum includes all phenotypic expressions of our neurological hardwiring. But that’s not what’s being taught. Yet.

Present high-level mental health and educator training (I studied both), testing procedures, and the public’s general conception of what is or isn’t Aspie/autism, like our flower, is “imperfect.” And that’s a VERY big deal. Clinically, the result is a 4:1 (or higher) male/female ratio of diagnoses; when more “gender neutral” instruction is provided and assessment tools are employed, that number is much closer to 1:1. (Dr. Judith Gould, The Lorna Wing Centre)

Like their struggling male counterparts, young women are just being entirely themselves -- loyal, curious, intense, and often, lonely. They don’t meant to, but no matter how intelligent they - we - are, they miss a lot of social cues... not because of egotism or laziness... because of Aspergers. Yet within the gift of a spectrum diagnosis is the balm we all need: self forgiveness, explanation, and great, great hope.

Girls are no “less Aspie.” We’re just less obvious. Diagnosticians looking for “typical” Aspie traits are, unwittingly, looking for typically “Male Aspie” traits. So without malice, they miss and mislabel the girls.

For example? Special interests like Thomas the Train, dinosaurs, space, architecture or transportation are very common among boys. Not so much among girls. Instead, girls may adore Smurfs or become professorial about historical figures (like Laura Ingalls or Helen Keller), or maybe fairies or Barbies, especially if those

Barbies are quietly acting out a historical event or favorite Greek myth. Maybe a child is fascinated with medieval times. While a boy dons his sword, his sister may be dressing up in a princess gown. Looks “typical.” That’s because with girls, it’s less the topic that’s unusual and more the intensity of knowledge.

Go ahead. Ask that “princess” if she’s “Cinderella,” and she’ll promptly tell you which of Henry VIII’s wives she is impersonating...and then will proceed to list all six - in order.

My work with families around the world has shown me time and again, correct diagnosis is the key to accurate self-concept, independence, productivity, and overall happiness. On the contrary, the damage of missed or misdiagnosis is unfathomable.

Among women diagnosed as adults, rape, abuse, and victimization is, in my personal observation, the rule rather than the exception. “When you’ve come to believe you’re difficult to love,” said one woman, “you’re willing to accept crumbs of affection, no matter what degradation comes along with it.”

It has been reported that girls and women on the spectrum are uninterested in traditional gender roles or in “looking girly.” That can be true. By and large, these girls “stick out” more, and thus are somewhat more apt to win clinical attention.

However, other girls are deceptively adept at and very eager to get “being a girl” right - as much as their perfectionism drives them to get everything else “right,” too. So, we - as this category certainly includes myself - overachieve and intellectualize. We study fashion magazines and popular culture as instructional texts. We expertly copy alluring mannerisms, witty turns-of-phrase, coy gestures, and a “traditionally” attractive (often provocative) appearance. We try to embody a caricature.

For example? At two Ivy League universities, I achieved a 4.0 during my undergraduate and graduate studies. Yet (as a WOMEN’S STUDIES minor!) I saw my real “successes” as having been accepted into a sorority and chosen as a college cheerleader - two stereotypes that, to me, indicated (FINAL) social acceptance. Albeit subconsciously, I even used my academic acumen to ensure those feelings of having “made it” would last. The chosen topic for my honors thesis? “Barbie” as a didactic tool of postwar modern femininity in America. In other words, I literally made a thesis out of researching my own role in my own society.

But there’s a very big “catch” to all of this. As I wrote to the teenagers reading The Asperkid’s (Secret) Book of Social Rules:

When I was in high school, I was cast as the lead in the musical “Damn Yankees.” My part, Lola, was a vamp -- “Whatever Lola Wants, Lola Gets,” by means of “A Little Brains, A Little Talent” with the emphasis on the “talent.” And Lola’s talent was winning men. She was -- and therefore I had to be -- “hot.” Dancing and singing about in front of 1,000 people a night, I stripped down to fishnets and lace. “Dictionary Brain” had shaken up the scene, indeed. And it made quite an impression on the student body.

It also made quite an impression on me. In the span of one weekend, I literally went from having almost no social life to feeling like the honeypot surrounded by awfully-hungry bees. Boys were everywhere. Calling, flirting. Walking me here or driving me there. There were party invitations every weekend. It felt like I was Alice through the looking glass, and I did NOT want to leave.

But I learned, fellow Aspergirls, that when you are put up on a pedestal, you can get knocked down fast. No one looks you in

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Girls who don’t fit in are casually dismissed as “too smart,” “oversensitive” and “dramatic.” Adults will shrug, “Girls can be so mean.” Or they pejoratively attach labels like, “bossy” or “stuck up” when they ought to use the one that can help: “Aspie.”

the eye as an equal when you’re up there. They look at you like an object. And every object is disposable. Which is why it annoys me to no end that the world now uses the word “hot” to mean “beautiful.” They are NOT the same thing, and the difference between them is where I got very lost. And very hurt.

In the simplest of terms, the “hot” girl is the one all the boys are staring at. The “beautiful” girl is the one all the girls are staring at. The “hot” girl needs attention, and gets it. She will be “hit

on” or approached by lots of guys. The “beautiful” one may not -- she’s intimidating. She’s intelligent, she is kind, she’s confident in who she is, and she seeks the beauty in other people. Learn to be her by learning to be the best you.

The truth is that girls who “perform” convincingly do not really understand the underlying nuances of their behaviour, and often give the impression of being much more savvy than they actually are. Sadly, perfectly-mimicked, naively-wielded flirtation often lands these girls



Image courtesy of the Asperkid’s, Not Your Average Coloring Book

in precarious situations which they are not truly prepared to handle, becoming easy targets for sexual predators and self-medication (through tobacco, drugs and/or alcohol).

Social naïveté makes them prime targets for elaborate practical jokes, and damaged self-esteem leaves them apt to seek approval or affection through sexual encounters -- a risky, heartbreaking exchange that only brings further ridicule and mockery. Further, the prevalence of anorexia and bulimia - a common "female" manifestation of anxiety and cognitive rigidity - is tremendous among this group. Yet traditional eating disorder treatment - expensive and often humiliating - misses the root cause almost every time.

As years pass, brilliant, capable, undiagnosed girls grow to be undiagnosed women who have had to endure bullying, violence, and systematic professional failures. Even more heartbreaking, these women and girls often find themselves blamed for their victimization. Almost without exception, female Aspies find themselves with a litany of mislabels (often "bipolar disorder") even as clinicians agree their patients never truly "fit that criteria."

As the mother of a daughter and two sons -- all on the spectrum -- I never ceased to be amazed at the difference in the level of advocacy I have always had to take on my daughter's behalf versus my sons'. In fact, the meticulous work I had to construct to "prove" her Asperger's was what, in one year's time, led to the subsequent "easy" diagnoses of my husband, my two sons, and finally, of myself...and the writing of my first book.

Though we sought out "experts" with excellent credentials and good intentions, the onus fell upon me - time and again - to prove the "case" for her Aspergers.

In "Asperkids: An Insider's Guide to Loving, Understanding and Teaching Children with Asperger Syndrome," I describe the exhaustion that comes with the never-ending "proving" of our "invisible disability in pink."

"In an arrogant tone, [the career teacher] doubted the accuracy of [our daughter's] Asperger's diagnosis (as if it's an easily-achieved rubberstamp); however, when I asked her... how many GIRLS with Asperger's she had actually taught, she conceded the answer was "none." [Somehow, ma'am, I replied, 'I doubt that.]"

...the teacher continued to lecture [my husband and me], observing that yes, our daughter did hold back from groups, but 'I think she's just a lot like you, Mr. O'Toole!...' six months later, John's own psychologist diagnosed him with Aspergers."

Our child psychiatrist (who eventually encouraged me to write Asperkids) agrees that the didactic roles, for a time, were reversed. "I didn't see her Asperger's at first, as I did with your sons. You made the case, point by point, and asked me to stick around without judgement for a month or so.

You were tired and had been through a wringer of psychologists and specialists and I'll be honest, I thought you'd be wrong about her. You weren't. Every observation was spot on, and four years later, not only do I have no doubt about her Asperger's, you taught me what some of the world's best medical schools couldn't."

As the daughter of a litigator, I met the "prove the case" challenge head-on. But I shouldn't have had to. I should not have had to be the educator to the psychiatrists, psychologists, and teachers. It was their job to help her - to help us. And I do believe they tried. The simple fact is that they didn't know better.

I love it when you talk nerdy to me.
I punctuate my texts.

Jennifer O'Toole
www.asperkids.com



Language semantics (really understanding underlying/implied messages) and pragmatics (using language appropriate to the social setting) is part of ASD/Aspergers. Ironically, for many girls, the disconnect shows as a great hunger for WORDS - especially fixed, written words - alongside difficulty sustaining, reciprocal conversation. They prefer to text or email and fear making phone calls. In fact, they may even visualize words, rather than images, when hearing speech, asking how a word is spelled to be certain it is grasped. Grammatical errors are utterly irksome. Instead, a rich vocabulary, hyperlexia (early, self-taught, profoundly-advanced reading skills), and a fascination with punctuation, grammar, letters, and word history wrap the girls in a world of language... without spontaneous demands. Thus, in an equally-powerful yet somewhat "quieter" way, the issue of part-over-whole remains distracting for girls. Misused semi-colons and dangling participles trump a grasp of the "bigger picture" every time.



Perhaps it's not coincidental that my daughter's favourite colour since infancy has been purple - and that we celebrate her birthday every year with "Purple Day." Because as a woman with Asperger's and the mother of an Aspergirl, I ask that when we "light it up blue," we add some pink. "The spectrum," after all, contains pink, blue, and a mix of both.

Girls who don't fit in are casually dismissed as "too smart," "oversensitive" and "dramatic." Adults will shrug, "Girls can be so mean." Or they pejoratively attach labels like, "bossy" or "stuck up" when they ought to use the one that can help: "Aspie."

My daughter and I have one another; we are unique in that advantage. Too many women and girls are without equal access to the support and understanding they deserve via proper diagnosis. Of this I am reminded constantly.

Only two days ago, a mother named "Sara" wrote to me:

"A few months back I commented on one of your posts, saying that our doctor told me our daughter was just 'tired'. And I was like, pretty sure tired kids don't pace the house in a set pattern and swing all the time. I will never forget leaving that doctor's office in tears.

You encouraged me and told me why it IS important to diagnose. Well, we went back and the doctor finally said 'Yes. She's on the spectrum, I just don't like to diagnose it because it's a hard label to remove.' Even now, she said she is only doing it for us because she thinks it will get us more services at school. I pushed thanks to your encouragement, and she is finally willing to "say it!" Now my girl can understand why the world is so frustrating AND we can work on the positive in this. She is crazy-smart and will do AWESOME!"

A hard label to remove? As an Aspie and the mother of three Asperkids, I could not be more profoundly offended. Insert another minority "label" - racial, religious, ethnic - and I doubt such a thought would be tolerated.

Built into that casual phrase is extreme bias toward the "shameful" spectrum label which, I for one, would not wish to "remove." Sadly, though, this one clinician's ignorant attitude is not only professionally irresponsible, it's extremely common.

So let's clear something up. Diagnosis is identification, not commandment. A name does not make anyone an "Aspie" any more than declaring "It's a girl!" causes a newborn to become female. We are who we are whether or not the pediatrician, psychiatrist, or teacher knows what to look for or why to bother.

But naming the "difference" sure does help. The consequences of "lighting it up purple" are profound and lasting, and they

go far beyond "getting more services at school." Around the world, marriages, careers, families, and futures depend on gender-blind recognition of all unique minds.

Asperkids, you see, are like "perfect flowers." They are boys. They are girls. They already ARE the entire "perfect" spectrum. Nature is inclusive even when under-informed adults aren't.

And so I implore you who, like me, tend the kinder-"garden." May we take the time to spot all of the seedlings. To support them during the storms and nourish them as they each need. Let's recognize the "perfect" flowers - the roses "by any name." And then, we can watch them grow, full of the promise and possibility, beautiful people just beginning to bloom. ■



RECOGNIZING Pink on the spectrum

Look closer. Ask more questions. The girls need you.

✂ Girls' "special interests" are often similar to their peers' (fashion, popular fiction, historic eras, animals, faeries/mermaids) -- the level of intensity/ factual knowledge, rather than the topic itself, is what sets them apart.

✂ The special interest still serves as an escape - note its function: transport to a distant time, place, species or social scenario where interpersonal rules and customs are clearer (fantasy worlds, folklore, historic periods where customs, clothing, relationships and languages can be "studied & mastered").

✂ Girls often collect information on people and cultures rather than on things.

✂ "Lining up" of girls' figurine collections (Smurfs, American girl dolls, books in a series) looks less conspicuous than rows of toy cars. Those displays still reflect an interest in setting precise "tableaux," not spontaneous, interactive play.

✂ Girls often hyperfocus on having one, all-encompassing "best" friend; later, this may evolve to an all-or-nothing self concept of being in or being able to "keep" a dating partner/spouse, at any cost.

✂ Relationships may be much more about perception than substance.

✂ Asperkids in general have a limited understanding of the "levels" of friendship - so that they cannot clearly distinguish an acquaintance from a close friend, nor can they define what constitutes an actual friendship.

✂ Rather than asking if a girl "has friends," a qualitative investigation is more productive: descriptions of her "friends" may reveal little evidence of reciprocity or depth (question how we know these people are friends, do they play together outside of school, how often? - Asperkids may perceive a classmate who never invites outside socialization as a "best friend.")

✂ Girls will often take on the role of "boss" of younger children, needier/"new kids"/exchange students or of a precocious "little sister" - peer-to-peer collaboration is MUCH harder.

✂ They may come across (unintentionally!) as braggadocios know-it-alls, and frequently see compliments to others as insults to themselves. Both behaviours reflect theory-of-mind challenges and low self-esteem, not arrogance.



✂ Parents or teachers may see girls playing "typically" with dolls or dress up clothing. But a closer look will usually reveal play scenarios that are restrictive to strict, special-interest-driven scripts (i.e. "Barbie" dolls who are actually re-enacting Greek myths or news events).

✂ Asperkids - especially girls - are likely to research and intellectualize the social roles others glean organically. They will gather and memorize as much information as they can on social roles and sexual expectations, sometimes endangering themselves in the process.

✂ Looking or sounding "fashionable" is as common among girls on the spectrum as is disinterest in appearance. Girls on the spectrum are frequently fantastic mimics (often augmented by involvement in theatre) who meticulously assemble a "desirable" persona or "facade."

✂ Eating disorders like anorexia nervosa and bulimia should be considered "red flags" - indicators of perfectionist tendencies, internalized self-punishment, a need for artificial control, extreme rigidity and adherence to routine (Dr. Tony Attwood, 2009). More often than not, they are rule among women on the spectrum, rather than the exception.

✂ Being overly "bubbly" and magnanimous is a common (yet exhausting) way many girls on the spectrum camouflage their social anxiety. Diagnosticians and teachers must look beyond the surface to determine organic from affect.

✂ Look for "phases" of intense friendships with "break-ups" or sudden ends. Being able to establish friendships is very different from being able to maintain them.

✂ As boys may study train charts, map coordinates or military tank schematics, girls can also focus on graphic organizers and charts, most often pedigrees or family trees, devouring limitless dates and names ■