FEATURE STORY

Asperger's Syndrome In Adulthood:

One Woman's Journey towards acceptance and peace

By Collen Fisher

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> *"Just as I (along with my therapist at the time) thought that I was about to free myself big time from the webs of my past and all its incumbent emotional baggage, in 1997 I found out that I had Asperger's Syndrome."*

A.J. Mahari, 47, has Asperger's Syndrome, is a writer and the creator and webmaster of www.aspergeradults.ca

It was summertime in the early '60s. Young A.J. Mahari stepped out of her house to play like any other little girl. She walked down the street in stocking feet, not noticing she had forgotten shoes. A simple mistake most 4-year-olds make in pursuit of fun and play. Some neighbouring kids spotted her outside. They knew A.J. as the weird one; the odd girl they could target for cruel amusement. They certainly noticed her feet that day. To them, it was just another thing A.J. did "wrong" -- a perfect occasion to target her, once again.

The group of kids collected caterpillars and approached her. They dumped the squirming, ugly insects onto her head and body. They watched, entertained by her misery and helplessness; punishing her for being different.

"I was in excruciating discomfort just at the feel of them on me. I was freaking out. All the kids laughed and finally as a few crawled down my face and I stood there, essentially paralyzed with YUCK and fear, one kid finally knocked them off me," ***Mahari said.***

One Woman's Journey Towards Acceptance and Peace

She did not know it then, nor did she know for another 35 years that she has Asperger's Syndrome, a developmental disorder affecting social interaction and communication. Named after Austrian pediatrician Hans Asperger who published a paper in 1944 about autistic-like qualities in a group of boys, AS was not officially recognized until 1994. AS is currently grouped with four other conditions – including autism – called autistic spectrum disorders or pervasive developmental disorders. AS is generally thought to be at the mildest end of this spectrum.

AS is also classified as a non-verbal learning disability (NLD). Although many people with AS have above average intelligence, the academic environment is equally a social learning environment. The inability to follow unspoken social codes results in low self-esteem, rejection by peers, discord with teachers and ultimately lower grades.

Mahari has struggled all her life to find herself. She grew up in a troubled and abusive family. She is a sexual abuse survivor and has climbed her way through the mental health system.

"I spent years in therapy getting help for these known issues and not having a clue about the fact that I had Asperger's Syndrome. It was like pure hell for me to be in group therapy but I forced myself," she said.

When first diagnosed with Asperger's Syndrome, Mahari did not take the news well.

"I felt such grief. It was unexpected. I had not sought out a diagnosis," she said. *"It was too all-consuming and I was SO LOST in it all and what the heck it meant for my life. It wasn't for long, though. I quickly shut that down and went into denial for the next four years."*

By 2001 Mahari went back into group therapy to deal with a surge of unexplained anxiety. She could not place its origin and turned to therapy as she had done for years.

"Ironically enough, on 9/11, after we'd been informed of the terrorist attacks on the United States in group, I had one unbelievably powerful full-blown panic attack. Other people were phoning spouses, children, parents and I had no one to phone and frankly didn't really understand why everyone had to phone someone else. At any rate, I felt this tragedy very deeply. The paradox that it illustrated for me was my profound isolation, aloneness and disconnection from others and the so-called 'norms of life'.

"Around 1 p.m. when group was ending I asked to speak to my therapist. We talked in front of others in the room, which I remember feeling very stressed by. She looked at me (I was still freaking out trying to listen to her) and said, 'You know, usually when I get anxiety,' (and I was shocked she ever got anxiety as I had no idea what others felt or experienced and didn't quite know this, or why yet) 'it usually comes to tell me something.'"

"What a profound message that was for me. Somewhere between riding my bike home from therapy on a day that felt like I was dying . . . the sun was still out and life was still going on. I realized my anxiety had returned to get me to deal with the Asperger's," Mahari said.

This epiphany did not come easily. Mahari sunk into a hopeless despair that left her feeling suicidal for the next six months.

"It was one of the most difficult and challenging winters of my life," she said.

When Mahari climbed out of this despair and tried to seek help for Asperger's Syndrome, there was nothing available. No support, no counseling, no developed communities. She was alone, again, blindly supporting herself.

After conducting her own education and research about AS, Mahari discovered she had a lot to say and share. She began writing articles about AS on the web. It was not long before she

created her own website: www.aspergeradults.ca.

Mahari continues to write articles for both websites and will soon be publishing her own series of ebooks. She believes strongly in sharing her experiences and insights to benefit other adults with AS and their loved ones. LDAYR is very lucky to have her share with us some of her wisdom and experience. The following is an interview with Mahari and myself regarding her life with AS.

Knowing you have AS and looking back, tell me how frustrating it was to work through the mental health disorders you were diagnosed with.

“Very frustrating because lying underneath it all, the central reality and effects of AS are unknown – not understood by me or anyone else. Some things about certain mental health diagnosis and Asperger’s can look like each other too. This can make it very difficult to sort out what is what. In my experience, the more I ferret out what is what the more self-acceptance and peace I am able to achieve. I have found the same to be true in terms of needing to understand what is what in order to change, if it is possible to change, or to develop compensatory strategies (mostly regarding AS) if that is what is needed.”

What could you share with other adults who have been diagnosed with a mental health disorder [such as social anxiety] but they may feel they have AS instead?

“I would say that it is crucial to get to the right testing diagnostic professionals so that people can hopefully save themselves from a lot of pain and frustration. The truth is, though, that whether there are other mental health/abuse issues or not in one’s life, way too often adults with AS must first go through years of misdiagnosis before they find their way to finding out they in fact have AS.”

“I would also say that even though AS isn’t a mental health issue as in a mental illness, it does create issues that the mental health system needs to make room (i.e. to learn and be available) for treatment and support of adults with AS. This, as far as I know (and with one rare exception I’ve found in one therapist in my life) is non-existent and a tremendous lack of service for an entire group – adults with AS.”

“[When I was diagnosed] I phoned the centre (it was called a Developmental Access Centre) for help they said there were no services for adults with AS and that I had a “mental health history” so I should call the Mental Health Association for a referral. Of course, when I followed that up to get counseling for all the despair, grief, even suicidal feeling I had regarding Asperger’s they promptly said they didn’t know anything about Asperger’s, that it is a “developmental disability” and that I needed to call – you guessed it – the Developmental Access Centre. One could play ping-pong with these systems endlessly which is painful and results in no HELP.”

What are your views on gender differences and diagnosing AS?

“I believe girls are socialized (overall) differently still from boys because, even with AS, we learn to be more aware of our feelings (even when we can’t express them the same as I never really did) that many diagnosticians don’t make allowances for the different expression or presentation of AS in females.

One assessment I had was so obviously incorrect and was totally gender biased. The professionals made statements that because I didn’t do thing ‘a’ or ‘b’ or ‘c’ like this guy they had worked with or that guy they had tried to have a conversation with that I couldn’t possibly have AS . . . I felt penalized for being female and also for all the work I had done to learn to do things like eye-contact, taking turns talking, being conversational (hard work for me with my tangents), having some empathy. Oh, that was a NO NO! They maintained they had not had one client (read all male) who expressed those things.

. . . So much about which traits are most predominant in most females with AS has all to do with

how women have been taught to be in the world. I believe slowly this is beginning to be looked at but not near enough."

You've described your relationship with a "Neuro-Typical" individual as a "rocky road for sure that has just begun to show some promise of a healthier survival." What has changed to create this promise of survival?

"As much as I hate to admit it, my ability to relate, I think. I am starting to 'get' some more of things, which requires enormous, almost endless processing of information, reading, etc. Also on my part, compensatory things like learning to transcend my egocentrism and work to extend what she needs towards her. I still struggle with this often." She sometimes has to point out to me, *'this isn't about you A.J., what I'm trying to say is that I . . .' and this helps me clue in that I am to listen to her and what she is saying she thinks or feels. I have to set aside what I think and feel. I've also learned that most things I understand and/or believe about the world (in terms of relating, socializing) are limited.*

I have a tremendous amount of difficulty communicating my needs at times as well. Being reminded that she isn't a mind-reader and her taking the time to sit me down and say that she cares, loves me, wants to know what's wrong or what's going on or what I need but that she won't guess – puts the responsibility back on me to do all I can to communicate in ways that we are learning now to meet each other in the middle of.

I think for me it's also largely been about really making the choice that I will step out of my world more to join her to the best of my ability in hers and she allows me my world without challenge as long as my world isn't imposing on hers in some way that could leave her feeling like she's my parent instead of my partner. It's about knowing each other more deeply and letting the love win out over the differences and hard times."

You mentioned recalling "ah-ha" moments from childhood as you work through issues with your partner. Could you expand on this?

"I guess what pops out in my mind is the issue of communicating and both parties needing to be heard and respected, what this entails and how it is done or achieved. There is so much about our communications that lead me back to realizing that, even though my parents were abusive and lacking in all kinds of ways, there were times that due to my AS they tried to reach me and I wasn't really reachable.

The more I learn to communicate and interact with my partner the more I realize how little I've known about this all my life. Unbeknownst to myself, my family and friends in the past there was so much I didn't "get", didn't understand because of the way that I think and process information and not because I was unfeeling or even uncaring or unsympathetic. Also, I didn't express most of what was going on inside of me, needs wise, feelings wise and so forth. Even now, many people who meet me might wonder if I'm all there in the sense that I don't smile much, don't' have many facial gestures or hand gestures in communication, can often be stilted in language and expression. I might feel a lot but look blank and unfeeling. The "ah-ha" moment for me is now I get this about myself and I get why so many people in my past reacted so negatively towards me. I didn't read their cues and I essentially didn't give them cues that they understood or recognized as having commonly understood meaning."

Can you clarify between what is Social Anxiety or just Introverted Behaviour and what it means to have AS?

"I wondered about this for some time. I thought maybe I just had social anxiety disorder at first – part of trying to deny the AS – but really from what I know about social anxiety it centers around the actual anxiety and how one feels about themselves around others. Some this may on the surface look similar to AS (as introverted behaviour might also). The key thing is the inability to "get it" socially. Even though I realize I am largely introverted too, if I were just introverted or if I just have social anxiety disorder I

imagine I would have a better working knowledge and understanding of social mores/rules/norms and such – things I absolutely lack.

For example, a friend of mine keeps inviting me out to dinner. I never want to go, don't get it and find it stressful, but once in a while I'll go. The thing is, I "don't get" why anyone would want to go out to dinner as a "social thing". It has been reported to me by people that it is enjoyable. I don't "get that"; don't experience that. I think dinner is about eating dinner. For me there is no enjoyment there.

I prefer to engage (when I choose to engage, which is rare really) through activities. For example, I like to play table tennis or pool and I'd do that with anyone because for me, it is about the table tennis and the pool. It isn't about the "social whatever" that it seems to be about for most others. I continue to learn what is expected in these "social" situations so that I can try my best to "act", "be", "seem normal".

Can you describe the social disconnect you felt in your youth?

"Most of my childhood and even adolescents there was total social disconnect for the most part. What I loved to do and did very well was play sports (here's a place where I believe many girls with AS may differ from boys in the coordination department?) I was highly coordinated. Most of my childhood was spent playing sports or swimming. It was all about the sport, or the swimming. It wasn't about relating for me . . . knowing what to do or even having a clue about friendship and the like.

When the games were over, even as I got older, I didn't see any purpose in hanging around to do "the social thing". I played on many sports teams and entire games would go by and I wouldn't have said a word to anyone. I was there for the love of the game and the personal challenge, nothing more nothing less.

As I got older, teen years and so forth, I didn't go to one social function at all. I didn't date. I played a couple of sports and actually didn't endure going to class that often yet got the marks required to graduate."

The following is a quote from "Exceptional Children Magazine" (2001):

"Fortunately, learning about the social environment continues through adulthood, giving many individuals with AS the opportunity to lead productive and fulfilling lives."

Given your experience, what is your response to this statement?

"Yes, very true if you can stay open to how painful it is to continue to learn things as an adult that, "developmentally", most get in childhood and teen years.

Sadly [learning about the social environment] *doesn't happen for many because they are not properly diagnosed. Even when they are, as adults, there are no services and supports to assist them. Without the necessary supports and "therapy" needed to help those with AS, people with AS establish AS ways of coping and being in the world (or rather in one's own world) which might be dysfunctional. These coping mechanisms may not commensurate with learning to cope with all the attendant stresses of change needed by those with AS. Rather an "old habits die hard" scenario. This is further complicated as many adults with AS tend towards wanting to (feel safe only with) stick to dysfunctional and often isolating routines or lack thereof.*

I guess I'm saying [the quote] *has truth, but I wonder how much truth for those without family or strong significant-other relationships. These relationships support the connectedness needed to grow and learn to compensate for formidable limitations.*

[The quote] *may be truer for kids diagnosed given services and family support and intervention from much younger ages.*

On your website, you mention "efforts made to 'socialize' only end with me experiencing abject boredom and lostness. Everyone takes this personally." How do people react to you in social situations?

"I think most people find me somewhat odd. I have had lots of that feedback. In conversation I know that you either can't get me talking beyond the stilted or if I get going due to interesting subjects (that are in line with my narrow focus of interests) it then can be difficult to shut me up. I am very intense in this regard. I am not good at the mechanics of socialization, or even conversation in terms of sharing back and forth, knowing how to begin and/or end.

People do tend to take much about me personally. I'm not sure why that is. I rarely dislike anyone.

I would like NT's [Neuro-Typical] to be ready for and more accepting of difference. For them to know that not everyone is as social or comfortable in all that is "social". I do not enjoy that at all. My lack of enjoying a lot of what they enjoy doesn't mean I don't like them or that I judge them. I want to be accepted for who I am (or how I am) just as much as they do."

Today there is still an inadequate number of services for adults with AS. The focus remains on children. What do you feel adults need in terms of services?

"Adults need information and support when diagnosed. Many who, for example, don't have family support, need assistance to varying degrees to even be able to make contact with others. I also believe there is a need for therapy and counseling because therapy can help address much of the "social and relational" and even communication aspects of AS that are so limiting and challenging. Group therapy (though I never should have been included by rights just based on having AS) actually taught me a lot about what interactions with others are for and why they pursue them and want/need them. It taught me a lot about my own self-absorption – egocentrism, mind blindness and so forth. Even when I was being misunderstood by most group members their painful feedback was very valuable to my learning process."

Even though AS is a developmental disorder and not a psychiatric disorder, the ramifications of AS cause enough problems/issues that many with AS (as adults) could really benefit form the support and information professional therapy can offer.

"I continue to wonder how the Ontario government can put so much money (as they did recently) into autism/AS/ASD for kids knowing full well all of these kids will one day reach adulthood, still being AS or autistic – and then what? No one cares about that. Burdens are left with families. The truth is, though, many with AS don't have much if any family support."

What ultimately led you to create www.aspergeradults.ca?

"A strong belief that I couldn't be alone even though I felt alone. That I can't be the only one grappling with all that I feel; that I don't have tremendous emotional or social understanding regarding the NT world. How much I just needed to write about things and how much I also believed that perhaps by sharing my thoughts, insights and experiences I might lend some support to others reading. I would even like to give insight and a look ahead for parents of AS kids right now who will grow up and fall into the "great abyss" of lacking services.

I also proposed a topic area to www.suite101.com, Asperger's Syndrome and Adults. I have been writing articles there now for over a year: http://www.suite101.com/articles.cfm/18681

What do you provide on your aspergeradults.ca website?

Currently information -- more to the point my own experience, insights and thoughts. I sometimes answer the questions of others. I have four e-mail lists now for those with AS, partners of those with AS and women with AS, as well as one for adults with AS. I will be doing much more writing including selling ebooks in the near future designed to provide others with insight and ways to continue to keep living the best lives they can.

I would love to make some connections to work with women with AS, parents of girls and girls with AS. I would welcome questions and input from anyone who knows, cares about, or loves someone with AS. I seek to help those NT's with spies in their lives understand more as well."

How has sharing this on line service helped you with your own personal challenges?

"It has led me to understand myself a great deal more. The more I write and think about my experience of AS the more I process and gain insight. I have been growing as a person who seeks to also help others. This, along with my current relationship, has helped me to continue to gain much needed insight that enables me to challenge my limits and create more compensatory strategies to keep opening up my world.

It has given me greater perspective . . . we are not all meant to be the same. The world is big enough for all of us."

What will your upcoming ebooks entail?

"The Asperger's series of ebooks I will be writing and selling on my web site will be up in the near future. The first ebook which I believe will shed a lot of insightful light on what it is like to have AS as an adult and be diagnosed as an adult, what that process and pain is like an how one can move through it to self-acceptance. It should be ready for sale by the fall. Check http://www.aspergeradults.ca/asebooks.html for availability.

I also have a couple of other ebooks coming in months to come aimed at helping parents understand more from the outside-in. I will talk a lot about what is painful about having AS in an NT world and what others like myself can do to continue to develop compensatory strategies for living the best life you can create. Too many with AS sit back and accept their limitations like prison sentences when the truth is there are ways to learn more and to be better understood. There are ways to bridge the gap between the world of Aspeger's and the world of those who are NT.

If you could broadcast a message to the world of NT's, what would it be?

"The AS mind is often an intellectual wonder – an almost "computer-like" processing machine with its roots in untold pragmatism that has tremendous value. The creative spirit and genius of so many with Asperger's needs to be encouraged and assisted to flourish. There is much for humanity to gain from those of us who find our purpose outside the NT box in life. We may not be the life of the party and we may not be the same, but we have a lot to offer to this world in our own says and we are here as we are with purpose, not by accident."

Watch for A.J. Mahari's ebooks by checking her websites at:

http://www.aspergeradults.ca/asebooks.html

http://www.phoenixrisingpublications.ca/prpebooks.html

A.J. will be writing ebooks about her experience as an adult with Asperger's Syndrome. She also writes on many other subjects, including mental health issues that she has recovered from. A.J. will be examining the co-morbidity of other underlying mental health issues with Asperger's Syndrome. She will also be doing extensive writing about the mental health challenges that having Asperger's Syndrome in and of itself often presents.