

Asperger's Syndrome and Promoting a Healthy Self-Esteem

Dr Wendy Lawson 1999

Asperger's Syndrome (AS) and High Functioning Autism probably have very similar characteristics. Many researchers today consider AS to be part of the Autism Continuum with all the same fundamental difficulties associated with Autism Spectrum Disorder's (ASD). According to the DSM1V (1994) Asperger's Syndrome is diagnosed when all the typical signs of Autism are present, but the individual has normal language development.

Being diagnosed with an ASD (specifically Asperger's Syndrome) in August 1994, I would suggest that I experience the same kinds of difficulties as others diagnosed with ASD. For example, I dislike change (prefer routine), I tend to be obsessive, I become anxious very easily and I tend to take what is said to me literally (For example: "Hop up on the couch for a minute while I talk to mum" say's the doctor. After hopping up and down on the couch for exactly one minute...I tell the doctor that his minute is up!

Before I received a diagnosis of ASD I thought that my difficulties in every day life were because I was not as intelligent as other people. The only way that I could cope with my daily confusion and frustration was by living according to my rules, rituals and routines. If someone projected into my thinking or conversation I felt almost violated! "How dare they interrupt my space and distract me from my course. Didn't they understand that now I would have to start over again, recapture my thoughts or plans and schedule it all again!" Well, actually Wendy...No, they did not. You see...people talk to each other quite often. They don't need to put their thoughts on hold to do this, or even take time to go back to the beginning of their sequence of events after the conversation finishes. They can move from one thing to the other....most of the time.

What is my name?

You call my name. "come play a game"

"We want you here with us"

I hear you not, in Time's forgot,

"Leave Wendy out. She's lost the plot"

You laugh at me, you run away,

I'm so glad you didn't stay.

But angry or discomfort now,

Could mean for me the biggest row!

To have a sense of 'good self-esteem' means to have a positive image of one's self, of one's identity. The word esteem, itself, means, 'to hold in high value of...'. If a child grows and develops, over time, with the knowledge that they seem to upset people frequently, misunderstand the world around them often and constantly be in trouble for one thing or another... what is this going to do to their sense of being a valuable and positive contribution? I know that for me I felt a constant pull between being angry with others for failing to see my view point, and despair at my inability to get things right.

"I want to be like Superman"

the answer to all things is "He can",

His name gives hope,

He don't smoke dope.

He doesn't sit around and mope!

"Why can't I be like him?"

"Why do I not fit in?"

"I'm not the same, can't play your game,

What, I wonder, is in my name"?

Each of us has a script that is both contributed to by our own evaluation of self and the judgements made of us by others. What is written in your script? What is written in mine? Does it say positive things about you or about me? I believe that the internalised script that I live my life from can either promote a healthy sense of self, or, a very unhealthy one. If I feel valued and welcome, then the image I have of my worth and of myself should also be one of value.

You called my name, your tone was soft.

I looked at you with questioning eyes...

"It's OK", you said "I will not scoff".

You noticed my fear and my surprise.

"Am I really welcome here?"

"You'll soon get fed up with me".

"Well, if I do I'll just tell you so,
We'll work it out, so have no fear".
"But I so often get it wrong".
"We all do that my friend".
But what if I hurt you?"
You will, I'll mend".
So, how can I know if I should go,
When to be fast, or to be slow?
When to speak or silence show,
It's your turn now, you have a go?
We'll learn together, explore this land.
But you must allow me to hold your hand.
It won't be easy, but we'll stand our ground,
And come out triumphant, our friendship sound.

Since receiving a diagnosis of ASD I have been able to come to terms with both who I am and what I can do. For example, I avoid social gatherings because they are very confusing and scary. I find it difficult to know how to maintain a conversation... unless it's about a favored topic of mine. I also get over loaded with all the sensory information that comes from people in a social situation, such as conversational noise, movement of people, clothing, doors and so on. The only time I enjoy social occasions are when they occur on my terms with friends that I know and trust. I can plan these times, enter and exit when I want to and I can be myself. I know that I will never be neuro-typical. I will all ways have Asperger's Syndrome. If I am to have a sense of pride and dignity, of high self-esteem, then I need to accept me as being who I am, value my sense of difference and work with my talents, attributes and disposition. I also need others to do the same!

Difference is always uncomfortable. We all like to be amongst that which is familiar, predictable and comfy. Imagine how uncomfortable it would be if you took words and people literally? You would so often feel let down, disappointed, lied to and so on. How could you ever depend on someone? However, when folk take the time to reassure me (I need this many times a day) and clarify both my needs and their's, then I cope much better.

I am very unevenly skilled. I have huge problems with being disorganised, getting lost, using public transport, understanding others, and just the practical interactions of social situations. If my sense of value came from being good at every thing, being an achiever at school, work and home, being able to get into other's minds and be in tune with them all of the time. Well, my self-esteem would be zilch. However, when my self-esteem is high, rated on the fact that because I am, I am of value and any extras that I might possess are a bonus, then I can begin to build a positive picture of me!

Some Practical Tips

1. Focus in on the successes, not the failures, mistakes or 'could be improved's'.
2. Discuss with your child/spouse how they view their own achievements and/or progress.
3. If they think they are 'the best' ask them to explore their reasoning with you.
4. If they think they are 'the worst' ask them to explore their reasoning with you. Be careful not to use 'why' questions and always frame or structure your question so that they have a framework to respond in. Avoid open-ended questions, we don't know how to answer them!
5. Ask permission to work with them on any improvements they think might be necessary.
6. Ask permission to comment on their progress from your perspective.
7. Never assume that your comments for their improvement will be welcome, either ask to be invited to comment or share your own experience with them, if allowed to, being careful NOT to compare yours to theirs. Just state the facts.
8. Always comment on any procedure that is done well, but aim not to comment when it is misdone!
9. Avoid using words that denote something is 'bad', 'rubbish', 'a mess', 'awful', 'could be better', 'poor', or 'incompetent'. Individuals with AS can be quick to pick up on all that they are not, rather than on what they are or could be!
10. Offer lots and lots of positive reinforcement. I don't mean bribes, but well-timed approval is terrific. Not only does it let us know that we are OK, but it's useful in teaching us what the most appropriate response might be. An example taken from a book I read states: "...He always monopolises the dinner table conversation, so one day I waited for a pause as he was eating, and I said 'you know Barry, you talk much less at the table than you used to.' ...and sometimes you listen to what others say and follow the dinner conversation' (Dewey, 1992, cited in Frith, 1992).

HELP AT SCHOOL

Building self-esteem at home is terrific, but it needs to happen at school too. Knowing what a student's study skills are is a good place to begin to know what skills they will need most help with. Designing a student inventory for both study skills and social interaction is a must at the start of every new term. For example, have the student complete a questionnaire, like the one following:

Study Skills

- My hand writing is messy
- I write too slowly
- I do't like making decisions about what is (or is not) important when reading a book or journal article.
- I get distracted easily.
- I find it much easier when people use concrete examples; I don't know what to focus on in exams (and I always run out of time).
- I don't like sitting exams in strange places.
- I am a perfectionist.
- I'm not very good at problem solving (I don't like making decisions about particular responses).
- I find it hard to be motivated about some topics (and some topics upset me).
- I'm not always able to sit still for long periods.
- I'm not good at setting long term goals.
- I am not good at getting to class on time or remembering all the equipment I need.

Social interaction

- I like to be left alone at times.
- I'm never sure when it's OK to interrupt in a conversation.
- I have difficulty knowing when people are joking.
- I find it quite hard to look people in the eye.
- I'm not very good at interpreting non-verbal cues.
- I'm not competitive (winning or losing is not important to me).
- I'm not good at conversing with others.
- I don't understand what is funny in many jokes.
- Others have said my speech is odd or eccentric.
- I find it difficult to make friends.
- I'm not very good with sarcasm or metaphor; I like people to say what they mean.
- I can get impatient when people don't understand me.

(taken from 'Towards success' in Tertiary study 1997)

When relating to people who have an autism spectrum disorder (I prefer to call it **delay** rather than disorder) it is important to remember the keys to understanding ASD, these are:

- a. we are singly channeled (we either look or we listen, rather than doing both at once).
- b. we take words literally: ("Can you make your bed James?"). Neuro-typicals mean "tidy your bed James", but a person with ASD might understand "Do you know how a bed is made?" to which the answer might be "yes" or "no", but it might not mean that James complies with the request, because he hasn't understood the instruction as it was intended.
- c. we are not good at predicting consequences. For example: child picks up stone to throw it and is very upset when it lands upon another's head!
- d. We do not like change, because of difficulties with predicting outcomes.

Therefore it is good to:

- Check out the autistic person's perception of what is being asked, demonstrated or said.
- Teach that behaviours, emotions and desires can have particular facial and bodily expressions. Explain what these are.
- Rote learn rules for specific situations (i.e. we hug family members, not strangers).
- Give time, whenever possible, to acclimatise to change and don't suddenly 'spring things' onto the person.
- When the individual is anxious: use music, space, reassurance, relaxation and breathing exercises, a calm voice and any other acceptable know anti-stressor.
- Place expectations into context via 'social stories'. This gives the individual a fuller picture of the 'what's', 'wherefores' 'whys' 'hows' and so on.

THE FUTURE

Life on earth is but a moment caught within the crease of time,

The seasons come and go again,

You have your life, and I have mine.

The seed that's planted within the ground

Cannot choose what to become.

A potato, an apple or a rose for some.

However, for it to be the very best,

It needs rich soil, not poor.

The sun and the rains must come,

To open that seeds door.

I may be born to nourish others,

I may delight the senses.

I may grow tall,

I may grow small,

I may stay stunted beneath wire fences.
My future may not depend on my stock,
So much as it does upon sources.
Sources of warmth, sources of care
I depend on the nurture to be for me there.
Then I can blossom and sing with the birds,
Then I can grow my potential.
So plant me in goodness and all that is fine,
Please keep the intruders away.
Give me a chance to develop, in time,
To become who I am, in life's future, one day!

SOME USEFUL REFERENCES

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