

During July of 2008 I was honoured to travel to Orlando Florida to attend the national conference of the Autism Society of America

The conference was a good one. I was very pleased at the quality of the various presentations given. Much valuable information was shared freely among presenters and attendees. Further, I enjoyed the fact, so obvious, that many autistic persons of various stripes were there in attendance, and giving presentations. While I did miss some of the talk on my first day there - which was not an official conference day, I did attend presentations at every time in which presentations were offered. I will try to condense herein my experiences at the conference and the information that I gained there.

The trip was a wonderful adventure. I had not flown on an airliner for more than a decade. I have very few places to go and less money to get there. I was aware of changes in airline and airport operations since the tragedy of 9/11, and had some worries about the flight. I am so glad that I did not have to make all the arrangements myself! I can handle changes, including the adding of personal capabilities, but that was a lot of change and a lot to do all at once.

I knew that certain anxieties would be triggered. As is apparently common among auties of various stripes, I have continual intestinal trouble. I live in fear of the coming of the evil intestine god. While I tried to plan the hours of the journey around this, I simply could not be sure. And airports and airplanes are great places for the violation of my rather outsized personal space bubble. And then there are probably security personnel around, and authority figures generally frighten me. And then my car will be so far away and I will be entirely at the mercy of other persons and their abilities.

All that I could see well in advance. Other things happened and taught me things that I had not thought about. As an instance, let me write for a few moments about finding the correct gate. At the ticket counter I received my boarding pass. That pass had my seat assignment enscribed upon it and other numbers telling at which gate I should wait, and when I ought be there. So I took this precious slip of paper in hand and went in search of the gate. Now, the actual navigation about the airport was easily done. My sense of direction is quite good. My learning experience was other than that.

I followed the signs to locate the gate. There I compared my boarding pass to the information displayed. Flight number on pass to flight number on gate. Gate on pass to gate on sign. Departure time to departure time. Yes, this is it. For the moment. . .

I do not do many big things alone. I did this big thing alone. Approximately fifteen minutes after I sat down with my checked bag and travel purse and a book I wondered to myself: "Am I in the right place?" And so I took the pass in hand and walked to a point from which I could view all the gate information and again compared flight to flight, gate to gate, and time to time. And I would continue to do this every fifteen or twenty minutes until the departure!

I then thought to myself that if I did have a travel companion along, none of this would have happened. I would have allowed my companion to find the gate. Not that my trust would have been absolute. I would certainly have prompted that person by saying a thing like: "I guess this is the right place is it not?" To which my companion would probably reply something akin to: "Yes, it is." And I would have trusted that, and my friend and I would have sat then easily in certainty that I was indeed at the correct gate. Not anywhere near the conference; I already learn of autism!

But I had brought apsie toys. I had binoculars to look at landing airplanes with, and a cheap graphing calculator, and two books. One on calculus - and not very good but I read it anyway. The other on engineering - altogether a better book. And I passed the time.

The flight itself was without any trauma. Just a brief span of life in a five hundred knot aerosol can six miles or so above the ground. I like and trust airplanes, as I know how they work. I do not always trust schedules. And airliners are loud as boiler factories and crowded. I sat in a chair that was at least ten inches in width and could not avoid some contact with the passenger at my right. But it was night and everyone slept a lot and the time passed quickly enough. Then we landed in Atlanta. And I had the airport issues all over again.

As I sat there in the airport I saw Transportation Security Authority officials all over the place. I do not always comport myself quite exactly as does everyone else. "Am I looking pensive?" Hell, I don't know! I am not at all certain that I could sense pensiveness in someone else' facial expression or body language. "OOOOOM! Did I just look at that dude over there?!" Quick move my eyes, look over. . . "Oh Noooooooooo! Now I just looked at her!" And I wondered if I appeared a terrorist or perhaps simply mental.

But the flight came and dragged me again into the sky, and all was again well packed into the thin aluminum tube blazing across the sky. Yip! Orlando, here I come. And then landing in Florida. There would be a bag to find. Oh, the bag. . . As I sat in Phoenix, it dawned on me that I did not know whether my checked bag was en route Orlando direct, or if I would have to locate it in Atlanta and transfer it to the next flight myself. So I found a Delta representative and asked. She perused my boarding pass and stated it was all the way to Orlando. Then she elaborated a bit. And she finished with that it was going all the way to Atlanta!

Okay, I knew she had miss spoken that final time. But upon landing in Atlanta I bored a hole through the crowd and located a Delta rep. And asked anew. Then I quickly located another one and asked again! Then I sat and wondered if I looked suspicious. Then I went up and down again and had to find the bag at Orlando. So I asked where the baggage claim was and found my bag and went looking for the transportation company entrusted with getting me from the airport to the hotel. But I was overthinking the situation. While I was looking for the company desk, the woman with my ticket was looking for me. No real trouble, and off to the hotel.

As we pulled up to the Gaylord Palms I had two thoughts. One was that my IBS was about to be an issue. The second was that I had no bloody idea how to behave in a place like this!

I am a low class, socially impaired Aspie hag from Williams. This place looked like an advanced prototype for Heaven. How will I deal with this? OOOOOOM! Again.

However, the staff was wonderful. They made even me feel quite comfortable there. However, my room would not be ready for a while. So I wandered about in the place for some time and then later that day - I had arrived pretty early in the ayem - got checked into my room. I got in to the room and decompressed with a call to my sister and then a long shower. I had been in transport for roughly twenty hours. I was zapped. I took a nice nap following the shower. This was the unofficial day prior to the actual opening of the conference. I went to the day's unofficial presentation for a while. It was good.

Then I wandered around within the Gaylord. This place was big and wonderful. A glass and steel roof topped a central courtyard within which were fish ponds and restaurants. The conference center was outside this courtyard, across a bridge. The conference center was large enough that the Gaylord can host several conventions and conferences at once. While we were there so were martial artists and Florida funeral directors. I thought that after the martial artists kill all us autie spazzes, the funeral directors could clean things up! Ahhhh, everyone was nice and we were in no danger from the karate guys.

As I sat on a bench in a quiet part of the central yard that first night, I saw a young man with cowboy boots and hat walk past. We scanned each other. I thought to myself that he is one of us, bear in mind that name tags were issued the next day. I said to him: "Cool hat!" He returned a curiously modulated: "Merci boucoup!" (Sorry, I cannot spell that! I am lysdexic and have trooble wit English.) With that I knew. And indeed, the young man was Bradley Debbault, son of the officer who would host the driving seminar that I would take part in. I would meet Bradley correctly the next day.

Between sessions we - that is to say: spectrumites - could and did notice each other from across rooms. We would talk. It was good. These off the cuff conversations with others of mine own ilk were instructive. We seemed to communicate between ourselves with the sort of smoothness that normally only entees are supposed to be capable of. I wonder if we truly lack this magick ability to communicate in non verbals, or if perhaps we have our own code book. Or perhaps we do lack those entee skills, and do not require them. I would love to see some studies done on inter - autistic communication.

NOTE: my day number indications begin on the unofficial day that preceeded the official start of the conference. That pre day is my day one.

DAY ONE

Wednesday, 9 July 1400

"Who am I?"

This was a session paneled by several persons on the informal day prior to official opening of the

conference. One of these panelists was Dr. Stephen Shore, an educator and an Aspie. We now communicate via email.

There were some very basic issues being discussed within this session. Stephen personalized this talk with information from his life. He noted that as a child he liked to “hang out” with older people. Then as he grew older he found more comfort with persons from other cultures. He theorized that these people from other cultures, and now in the United States are also outside much of society and its mores, and therefore in a similar condition to autistic people. He noted that he married a Chinese woman, and that they have been happily together for a long time. He also noted that Dr. Tony Atwood says that auties tend to fit better with “different” sorts of people whether of different cultural backgrounds or handicapped, or of different races. I thought this made sense.

Other points were made by the panelists in this forum. One such point was that biomedics ought not be aimed at “curing” autism, but to make people healthy. I took this to be the idea of making autistic people the best auties they can be, not trying to make us entirely normalized. I tend to agree with this. Stephen made what I saw as a good statement that no one is truly “independent”, but that we are all “interdependent” in that no one makes their own car and shoes and peanut butter. That this “independent” word is inappropriate and that it is interdependence that should be aimed for. Only a hermit is independent.

It was stated that we auties must learn to deal with our main issues, which were seen as behavioural, developmental, educational, and sensory. Stephen said, and I will quote: “There may be an autistic person out there without sensory issues, but I haven’t met him.” And then I thought that neither have I. And I wondered if then sensory issues ought be classed as ASD symptoms rather than comorbidities.

Discussed were issues such as how we can become employed at a greater rate than is current (stated: 9% AS and HFA employed, 11% suicide). And then he asked a question about what would YOU do if your workplace caused you to be near a machine - such as a fan - that made a noise that you can not stand. I answered, when no other hands rose: “I would quit.” that was the answer he was looking for. And apparently many of us would take my path: based upon a belief that the situation would not be repaired, and that I avoid confrontations anyway. He said that we should learn to speak up and get the conditions altered.

That led to the question of disclosure. Should an autistic person - when faced with a need for a conversation such as needed to resolve an issue like that above - tell his employer that he is autistic. This is a tough issue. On one hand to tell of one’s autism is a good idea because it makes the request to be moved to a location away from the noisy machine real, not arbitrary. Also, only if we speak out will the world learn that we exist and are not always Rainman. But the individual must balance those positives against possible discrimination. There are no easy answers at this point. I would note that I have disclosed, and to no harm in my life.

Interestingly another possibility of employment for auties was mentioned. Become self

employed! And I thought how it was school that made my suicidal thoughts common, but work made such thinking a habit. I am self employed. It is not fun, but it is less not fun than any employment I have ever had.

And also a topic was the becoming of self disclosure to self advocacy. That is wherein an autie speaks up not so much to get a specific issue resolved, but to further the social cause of autism and autistic people. I like self advocacy!

The question of housing came up, and the issue of appropriate housing - that being housing appropriate for a specific autistic person. Mentioned was that this is difficult and that most group homes allow very little dignity. Quite often in these talks, it became obvious that no truly good solutions currently exist, that there is a lot of work to do in accomplishing good solutions for autistic individuals in society.

Work should be more than a paycheck! Work should be intellectually satisfying. I agree. And I think this is less often true than should be, for everyone. The basic underlying thought here is to use your strengths. Do not do things that make use of weaknesses, work around those and go to your strength! This is good advice. And for being a session on an unofficial day, I thought it was quite informative. Note that as I spent some time in meltdown recovery this day that I came into this session a bit late.

Encouraged were part time employment for auties who cannot for whatever reason make an entire day, day planners to set and keep schedules.

DAY TWO

Thursday, 10 July 1030

“Continuing Medical Education”

This was an actual credited course. It lasted all day and I did not stay for all of it. I caught the first speaker: Martha Herbert MD PhD., and thought she had done some interesting work. Her presentation was entitled:

“Whole Body system of Autism”

This first subsession (The whole Continuing Medical Education session ran all day and with several speakers.) was probably of less immediately practical and more academic importance. Okay, I will admit that little here will be of pragmatic use to parents of autiekids or the auties themselves. But ever since I located myself on the autistic spectrum, one of my aspie obsessions is autism. I think this one of my more useful obsessions. So I will state quickly the heart of this talk.

Dr. Herbert has been part of a group doing actual physical work on autism. That is to say she has been involved in an attempt to find physical differences - primarily in the brains - between auties and entees. To do this work this team of persons dissected the brains of autistic people. I thought it very polite that they waited until the auties had died and therefore had no

further use for these brains before disassembling them. Yeaaa, Dr. Herbert! Thank you!

There is some real difference in our brains. Well, at least within the twelve autistic brains that the team inspected.

She began stating that autism is defined by behaviours, not physical issues. She went on to state that there are currently no physical methods of diagnosis of autism. Then she continued by stating that it would seem that there ought to be underlying physical features to autism. She listed secondary autism issues and related issues such as seizure disorders, GI distress, sensorimotor difficulties and food allergies; that these would seem to point toward real physical differences between autistic persons and neurotypicals.

She quickly explained the current model of autism, which would call autism an overlap of three specific areas of performance of an individual. These aspects of a person's performance were given as: Communication, Socialization, and Behaviours; autism being the area in which all three of these overlap. Then she pointed out that there are anomalies that violate the above rule, and that as such, this model of autism is probably simplistic. She also explained that if autism is entirely - to its set of effects - genetic, then autism would have to be considered a hopeless condition.

However, she says, autism does seem to be far more than simply genes. She pointed to possible prenatal conditions, localized brain differences not of purely genetic origin, and brain differences occurring after birth. If there are aspects of autism which are not genetic in their entirety, then there is reason to hope for autistic people.

She displayed a far more complex model of autism which included such specific and labeled areas as: Genes, Environment, Epigenetics, Molecular and Sensory Signaling, anatomy, Communication, Behaviours, Social Interaction. . . All of these would be interacting with each other in a dynamic development of the autistic individual.

Some issues she raised that I thought sufficiently interesting to have included in my notes were: 1. Is autism a brain disorder, or a disorder that affects the brain? 2. That there are possibly hundreds of genes involved. 3. That genetic alterations may not be inherited, but de novo - occurring spontaneously, 4. That sometimes the genetic difference might not be the gene itself, but expression of that gene, 5. Is this related to the use of new chemicals by our society?

She noted that infectious diseases may be involved in formation of autism and so might be substances such as pesticides; that recently a study found 287 dangerous chemicals of various sorts (many complex hydrocarbons, some mercury compounds) in newborns. Some of these chemicals are known teratogens. Out of 2863 chemicals known to be in use only 20 - 30 have known data on potential neurotoxicity. She notes that the apparent rise in autism (possibly related to changing diagnostic standards) correlates well with the rise in the use of artificial chemicals. She specifically pointed out a possible role of organochlorines (Yup, they are nasty things). She notes that some genes might be environmentally sensitive, that is to say that a gene

may lead to different outcomes depending on the organism's environment. Autism might be both genetic and environmental.

Then she noted a few known and typical physical features of autism: brain enlargement that can continue well into life, greater head circumference (I have a head like a Pez dispenser), and then she went into the thing I found most interesting about her talk, the thing found by way of dissection of autistic brains.

Apparently the autistic brain has a disproportionate amount of white matter. Now, I am not primarily interested in biological things. Blood and organs make me far more than squeamish. I had never heard of white matter. As she described it, white matter is less a thinking and more a communication related sort of neural tissue. This white matter is not a neuron at all, but something called glial cells. We auties have less white matter within the brain and therefore connecting various portions of the brain. But we have more white matter outside the lobes of the brain. These glial cells are radial: They radiate outward from the brain rather than serve the usual role of communication between areas of the brain.

She therefore suggests that there may be a lower level of functional communication within the brains of autistic persons. This could lead to a lesser level of coordinated thinking (coordination between different areas of the brain). She noted that for whatever it means, the brains (while alive and active) of autistic persons tend to display a higher level of EEG coherence in the range of three to six Hertz, but lower coherence at eight Hertz. She wondered if some form of intervention may be eventually possible to alter this ratio. She wondered if we may be more easily "maxed out" in performance areas such as stress.

She noted brain inflammation activation of micorglia in all twenty brains. She thinks that ASDs probably will not resolve to a simple and single cause. She would include in the likelihood of ASD formation: body reaction to infection, and oxidative stress, and that the timing of such events may be critical. She notes that between forty nine and ninety six percent of autistic children have some form of GI disease, and that between thirty and seventy percent of autistic children have some autoimmune issues; some with anti self antibodies. Clearly autism is not merely a brain issue.

She noted that in 1943 Kanner found that eating difficulties, large tonsils, ragged tonsils, diarrhea, fever, recurrent infections, and troubles with thyroid and pituitary glands were common in the children he studied. She notes too that the blood/brain barrier is hardly absolute; and not present until a person's second year. She related the brain to our largest non brain set of nerves: the gut.

She focused on issues seen as anomalies, and ASDs are full of anomalies. Some children experience a lessening of autistic symptoms while experiencing a fever. And she wondered as to self perpetuating cycles. She concludes that all of the autistic spectrum may be but the tip of a much larger iceberg.

ALSO

There was the Exhibit Hall

In the hall were booths in which various organizations, both for and not for profit, displayed their products and services as relative to autism. There were purveyors of books and other publications related to autism. Companies peddled electronic devices, including one very cool electronic PECS device. There were companies with electronic child locators, companies with foods and information for GFCD diets. There were enzyme makers, There were makers of educational toys. There were schools and teaching aids and organizations devoted to assisting autistic and other special needs persons in getting higher education.

The exhibit hall pointed out something that was true about the ASA conference in general: The conference was a happy event! I try to be involved in all matters autistic. About two years ago as I write this I was scouring the web for any and all data in relation to Asperger's and to autism in general. I had to know who I am, and I was not an easy sell. So I visited a great many sites. I went to the DSM IV, I went to other scholarly and clinical sites, I went to sites of various autism organizations. I took the RDOS Aspie Quiz and Simon Baron - Cohen's AQ test. And I heard so much that was so negative, not only about autism; but about people who are autistic. One organization whose initials are AS seems to hate autism so bloody much that they dislike autistic people.

Indeed, even in the public forum on that site I find all too many parents and grandparents entirely freaked out by the word autism, and the underlying concept. I know from my personal experience that autism is a difficult road. I do not mind the "D" in ASD being for Disorder. But when I see that a very nice grandmother would sell her house to get stem cell therapy (not proven effective not safe), for her grandson - a boy who is "as near NeuroTypical as one may be and still be autistic", I wondered: "Then, if he is that normal, what aside from the word "autism" is making you so fearful and sad?"

I have read stories of parents talking to others about just how hard it is to raise their children, how little hope their children have, how terrible autism is - *right in front of their children!* I have read so many posts by young auties and Aspies on "hang out sites" (such as Wrong Planet) wherein the kids are entirely depressed and write of things such as having no hope to ever have a job or live on their own or go to college or have a spouse or even a relationship. And yes, again, this is a more difficult than normal life. But: To be this depressed all the time is probably not healthy for anyone. There is a air of sadness surrounding autism, and this aura does no one any good in their dealing with autism.

At the national ASA conference I saw everywhere happy faces of optimistic people! This was not some seeing the world through rose coloured spectacles. This was not a denial of the reality of autism. It was simply indicative of people being able to look autism right in the face and get down to work.

There were companies begun by parents who saw a need, and found that no existing

company was filling that need, and so who went out and created new things. There were all about people whether autistic themselves or people related to auties, or people who professionally or for whatever reason care about us. And there was no mass depression, there was optimism and happy fellowship. I was so impressed by this. Certainly this reflects deep philosophical positions of our society. Indeed, the feelings (and remember, I am an Aspie and have no empathy) that I encountered there at Orlando were overwhelming; overwhelmingly good. I ended up feeling better and more positive about me! There were (Oh G-D! A bloody cliché coming.) Good vibes everywhere I went.

Well almost everywhere. I went up to one organization's booth. I wanted a few minutes to speak to one of the persons manning that booth to ask a question or two and make a comment or two. I stood there. There were no other persons standing at this booth. Two older women (Older than me, even.) In the booth talked to each other about stuff that was in no way related to autism. They talked and talked. They saw me. I flashed eye contact at them (That was a toughie for me.). And I waited and waited and never got an acknowledgment from them. There I stood with my name tag in my shirt, waiting to get someone's attention, and never getting that. That was the Autism Speaks booth. They had no time for an autie! Given all that I have heard, mainly from other spectrumites, about that organization; I thought this was a moment perfect in its flaws. I am so glad to be part of ASA!

DAY TWO

Thursday, 10 July, 1230

“The Road Paved with Good Intentions”

By: Lars Penner, PhD. School of Business, USC (Note: he is an Aspie!)

This talk was largely about how the world might better deal with autistic people. The title hints that some of the ways in which the world handles auties right now may be well meaning, but misguided. One thing he very quickly mentioned was that he does have a sense of humor. (I would add that while we spectrumites got together that one topic was out lack of humor. We got a good laugh from that)

Mainly what I took from this lecture was a series of important but not so thematic points about people who are autistic.

1. Within autism there is much variation: One must take note of the individual. I like this point, and think that it ought be extended to appreciation of all persons, not only auties. I also note that in my vision I see autism similar across all of us: In the general, but quite varied in the specific.
2. He has a sense of humor. He used it well during the talk. He made a joke about having a sense of humor. Not all of us are humorless, despite the popular mythology. I think much of that which is said about us is too broad to be true.

3. A person on the spectrum may have such different perceptions from neurotypicals that even our very desires may differ from the norm.
4. He has poor spatial ability. I find such specifics as this so interesting. Some of us have better than normal spatial ability. I must admit though that whilst my ability assists me in architecture, it does naught for me in attempt to catch a ball!
5. The outsider must understand that autism can be so specific in effect that one cannot assume that because an autistic person is fascinated in (he used the example of baseball), that autie would like to play the game. The person may like the statistics or even to watch games, and not have any desire at all to engage in play. He gave an example of this exact case.
6. The non autie must not use the autistic person's interests without respect. . . this point is a bit difficult to state. Lets assume that a teacher attempts to reach an autistic person (Dr. Penner used the example of a childhood interest as dinosaurs) by way of that person's interest. This is fine, to be aware of that person's interest in dinosaurs may provide a door through which that person may be reached even for other studies. But never compromise that interest! If the use of that interest is as a door to entice other interests too, this should not be done cynically or in any way that demeans the interest of the person. (I thought of a short bit of my distant past. I heard an aircraft and pronounced it a turboprop - at that time a very new propulsion). Another child said: "It's a turtleprop!" I was angry and left.)
7. Ask the autistic person what special interests are of importance to him.
8. We may have a different sense of humor. Yeah, I will second that one.
9. Three points related to practicing any specific skill:
 - A. Fatigue equals frustration. That one hit me hard. I can go into what I call a "catatonic meltdown" by means of fatigue. If I do not allow myself to come to a halt at this point, I may begin to do things very poorly. That leads to frustration and then a violent meltdown follows.
 - B. More is not always better. In some cases, if the autistic person has grasped the concept with two workbook problems solved, it may not be such a good idea to force the repetition of ten more similar problems. (I like this guy! He could have saved me as a child - and my parents a lot of trouble!)
 - C. Pressuring for progress may not help. (I wanted to kiss him!)
10. While we may want to "mainstream" a child, it could be that a whole day of "mainstreaming" may be too much. And of course! Move the child forward in small steps.
11. See the individual! Do not simply see "an autistic person", but rather a specific person.
12. Do not necessarily combat special interests. This probably will not work in any case, and mostly the lost interest will simply be replaced by another one. (Bravo Lars!)

Let me just add at about this point that I love learning about autism. What a fascinating phenomenon this is. I mean: While I can easily see that a problem with eye contact might be related to a difficulty in noticing and decoding non verbal communication; that I find the relation of both these things to gut problems and silly walks to be wonderfully anomalistic. G-d must have hired a really good science fiction writer (Douglas Adams and Terry Pratchett both come to mind here.) To devise autism. What curious people we are.

As I sat and listened to various presenters, and especially autistic presenters, I so often thought of myself and my autism. And very rarely did I ever think to myself anything like: "Yeah, sort of." More usually in response to specific autismisms I would be left aghast with either a: "Not me at bloody all." or a: "Holy Ned! That IS me!" Many of Lars Perrer's points nailed me good. He stated things perhaps small, but tasty.

13. Some special interests may be embarrassing. Yes, but they are still there ind interests. Deal with as you must. Carefully.

14. He noted the associative nature of autistic learning. He then constructed a humble example in which the autistic person hears the word: "peanut", then thinks connectively of elephants, the GOP, President Bush; then leaps aside to the zoo and tigers. Yes. Ya' kno' one thing that angered me when I read it was a statement made flat out (And repeated, I have seen this statement in several places on the web - on autism and Aspie sites.) That autistic persons may be able to memorize huge volumes of data, but do so by rote and without deep understanding. Ha! I noted about me long ago that I cannot learn by rote, that is a major problem I have had in school and work. I memorize and understand at once and by the same method. I attach data points to each other by logical relation. If I cannot do this then I neither memorize nor understand. I have brought this up on Wrong Planet. It seems quite common among us. Go, Lars!

15. No fake assurances such as: "Everything is going to be just fine." We are not stupid enough to believe that sort of thing. Things will be as they will be, and that may or not be good. Rah, Rah, Lars! Even when dealing with a child, truth is good.

16. Indeed, to an autie and as given in regards a problem that autie faces - false assurances may seem not only misplaced, but callous! Yeah! Team! Done there, been that.

17. Instead of false and hollow assurances, provide the autistic person with clear time lines and tell of what will be done to address any problems. I swear this guy can read my mind! Wait! He just may own one kinda like it!

18. Bear in mind that an autistic person may not find surprises pleasurable. He gave the example of a surprise birthday party. This might delight a NeuroTypical, and may delight even an autistic person - but then again perhaps not. Be careful with: "SURPRISE!!!!!" I should have gotten his autograph.

19. The autie may take appreciable time in regrouping from a surprise.

20. A surprise removes from the autie the time needed to prepare. Oooooom! Yesssss!
21. And a surprise may remove from the autie the feeling of control. These issues clobber me in business all the bleeding time.
22. Beware of a surprise involving that person's special interest as the intended joy may be more than cancelled by the negative elements of the surprise.
23. We can dislike change. It is at least a violation of expectations, and then leads to the above problems. Yup, I do not like change. One of the hard parts of business for me.
24. Sensory vulnerability. Senses can overwhelm us and lead to exhaustion. This is so obviously true.
25. An autistic person may have other issues such as being bipolar as well as ASD.
26. Not all of us are visual learners. He held out himself as example and related to his poor spatial ability.
27. Our good and bad days may be extremely so.
28. We have strengths and weaknesses. These specifically differ for each of us.
29. A person who would teach one of us must make systematic observations of that individual! Hooray! Just because autism is in the book does not mean that Johnny is.
30. Some tried and true teaching strategies will not work well for the ASD child.
31. Immediate practice after learning might not be suitable. Yeah!
32. Imitating others may not be suitable. Do I lack mirror neurons? Probably.

All in all I found this talk to be enlightening and thus I have devoted a fair amount of space to it here. Doctor Herbert sees autism well, but from outside. Dr. Penner sees it from inside. I like his view. Okay, that is hubris. Yeah.

DAY TWO

Thursday, 10 July 1210

“Continuing Medical Education”

Continues with a different speaker: I will try to reconstruct who this speaker was! She began into good material so quickly that I did not catch her name.

She has worked with many children, both autistic and neurotypical. In her study video is used to document the progression of autism. She has developed some clear and wonderful thoughts about autism and those of us who are. I am having to think hard about the organization of this portion as her organization is quite at odds with mine, and so my ability to interpret is challenged. Also, she often had video of children on the screen. I am typing and lack those vids.

She has a far more complex model of the development of autism and the autistic child than the one so often referred to when autism is considered. I thought her model was a potentially great leap toward understanding. The videos were used much and so I must describe. She had vids of autistic and normal children at varying ages. The videos were made of children with their mothers in a very simple environment which with all could interact. There was a table. On the table were a few objects: a bowl, a ball, and I think a stuffed animal - funny that: As I sit here two months post seeing these dramatic vids and hearing the conclusions wrought from them, I must realize that I am uncertain about the stuffed animals. I saw the children and recall the mothers and recall the bowl very well. But he stuffed animal. . . I like real ones, but stuffed ones never made much difference to me. Selective attention in evidence.

I digress. The fixed camera simply recorded the children's environmental interactions within this simple setting. She began with vids showing children at approximately two years age. The differences between the neurotypical and autistic children were apparent. The neurotypical children played with the objects, but always looking for signs of love and approval, and attempting interaction with their mothers. The autistic children, however, were almost wholly object oriented. The autistic children spun the bowl and reached for objects and attempted barely any personal interactions at all. Now, this was at about two years age, approximately when many parents see "autistic regression" in their children.

Then she showed vids from earlier in the children's lives. And if one knew what to look for, being conditioned to do so by the very obvious differences apparent at approximately two years age, the differences were apparent! At fourteen months the difference between the neurotypical child and the autistic one were not so in-your-face obvious as they would become at two years; the differences nonetheless were there and consistent with the later differences. In that span of time: and these months are an appreciable percentage of such a young person's entire life to that point, both the normal and autistic children had changed. And the autistic children's behaviours had diverged much farther from normal.

She finds that even children under two years of age can show repetitive behaviours, and different environmental interaction. These children tended already to show restricted and intense interests. (Let me state at this point that I immediately thought of the vaccine hypothesis. If it is truly vaccinations at eighteen months or twenty four or so that trigger the autistic regression, then what exactly are these kids doing displaying autistic traits at fourteen months and perhaps even earlier?)

Here is what I consider to be one of the most important ideas that I heard during the entire conference: (I paraphrase, I cannot be said here to quote)

“It is possible that autistic behaviours may influence brain development.”

Let me elucidate this huge and important concept. What if there is a genuine and intrinsic difference, probably biological, between normal and autistic person? What if this difference drives the autistic persons, as still children, to behave in ways that select their environments? Then what if these children respond to those selected environments to such a degree that their developing brains develop around their autism selected environments? Would such a child then accelerate into autism?!

From that idea she proceeded to propose that early identification of a child as autistic followed by attempts to normalize not the child, *but that child's environment*, may be effective in assisting that child to develop into a successful person. She has at this moment no direct evidence that this would work, but I do think that based upon the initial idea and the vids that support it, and given that such an environmental normalization can be done for free and is not in any way a mediaeval behaviour modification programme, that it should be explored.

She listed several signs of autism - many hardly unfamiliar to us - that can appear very early in a child's life:

- Lack of vocalization
- Flapping (I plea guilty on this one!)
- Visual disregard of people (Mea culpa)
- “drawn in” to non human stuff (Has she been watching meeeeeee?!)
- “positioning” that is: the exact locating of objects to places where they are “right” to that autistic child (She has been watching me)
- “Clutching” or the intense holding on to comforting objects (This is getting serious)
- Anxiety and related symptoms (I had near constant insomnia as a child for fear that the next day was coming soon. Does that qualify?)
- Trouble with comprehension of speech (Nah, never happens here. . . What did you say?)
- That up to about two years social communication may seem about normal, but then its advance may be seen to decelerate
- One child had more repetitive behaviours at 19 mos than 13. This seems typical.
- Brain growth may cause larger than normal head circumference up to about 4 years of age. (Does this explain why I look like a Pez dispenser?)

- Questions: 1. If a child “clears up” was it a false diagnosis, or perhaps the intervention?
2. If found late was the ASD missed, or did it develop late?

She speculates with early intervention there is less autism to deal with. She speculated that some of the autistic person's behaviours may be as reactive to the frustration of inability to communicate even one's basic needs. The basic premise is that what we see as autism may be a cascade of effects descending from earlier and lesser core issues. The autistic child seems to self isolate. Therefore be certain to include the child into family matters - intensely and regularly (Dang it, I love spell checkers, I cannot spell anything right. No, I mean it. Watch: eenithang. Proof)

Her research continues. ESI and in relation to Autism Speaks. They did this right!

DAY TWO

Thursday, 10 July

“Continuing Medical Education Continues”

Speaker: Emanuelle Tagnol PhD.

This began so well for me. She stated that autism is a complex system of interactions between genes and the environment. She rejects the usual “deficiency model” of autism (What is *wrong* with the person.). She looks at functional anatomy such as the brain white matter difference noted in an earlier lecture. She has done whole brain EEG studies.

However. I soon had major issues in this lecture. Firstly, she has a thick European accent. While the sound of her voice was pleasant enough, I found that I simply could not make sense of about one word in three that issued from her mouth. 2. Then she went into a set of curves on a graph: presented on screen. Then she spoke of phase relationships between these curves. Between her accent, my CAPD, a very poor graphic representation of the relevant phase relationships that she was attempting to use in argument - a graphic representation that may have been intended to be either 3 or 2 dimensional; I could not tell; in any case completely obfuscating the underlying data, a seeming failure to differentiate between two distinctly different sets of curves of entirely different phenomena (one EEG trace, the other I quite and entirely forget) and my resultant and overwhelming intellectual vertigo “Phase relationships, of what, where?!” I left. But not before she stated that autistic people cannot handle complex tasks. Well, okay then. I give up. Put me into that file cabinet right over there.

Oh, but seriously, I think her work was good and interesting. The brain wave differences between normals and the rest of us may be of profound importance. I simply could not make head nor tails from her presentation. I do not watch foreign films either.

DAY TWO

Thursday, 10 July 1600

“Increasing Motivation in ASD Persons”

Presented by Richard B. Graff MS. BCBA

New England Center for Children

This talk was interesting, and most of his techniques and development of person specific techniques would probably apply just fine to the teaching of normals as well. The talk had less to do with actual teaching than it did with the methodology of causing motivation to learn in the individual.

The first thing he did was to muse about the nature of motivation. He stated that motivation is one of those words that we all use, but which actually has a vague definition. He then defined motivation, for the purposes of his talk, as the reasons that a person does anything that he does. He used a model which he refers to as: “A - B - C”, for Antecedent, Behaviour, Consequence. That is in contrast to the simpler Stimulus - Response model. Which is to say that the third step, being the consequences of a person’s behaviours, is integral to motivating the person to do things.

He then defined that third term: “consequence” as a stimulus reinforcer. He pointed to the paycheck as being a very typical stimulus reinforcer in normal society. In dealing with children, and he was speaking mainly about autistic children, simpler reinforcers may be easily used. He used as an example of a stimulus reinforcer: chocolate. Then he spoke about the conditions of stimulus reinforcers:

- The reinforcer should be as near immediate as possible to the action being reinforced
- Negative reinforcers need not be punishment. I like that idea. I do note that he did not elaborate much upon this point, and so I am at a loss of how to provide a non - punishing negative reinforcer.
- Use the least reinforcement possible: that is, use the smallest reinforcement that does operate to reinforce the wanted behaviour
- Be objective and technical. That is to say that rather than flying by the seat of your pants, keep records and analyze them.
- Question: how does one identify reinforcers? 1. Ask the child! “What would you like?” 2. Observe the child, see what that child is attracted to or demanding of.
- He notes that most care givers actually have poor ideas of reinforcers, most caregivers have not observed objectively.
- He notes that even if you do ask the child, the answer may not always be reliable: he noted that when comparing care giver’s judgements of a child’s reinforcers to actual ones based upon objective observation that false positives were approximately 29%, and that false negatives were about 13%
- He gave an example of this as a video game that a child may play, but only after a few hours of a different game, as not being necessarily a great reinforcer

_ He stated that most “preferred stimuli” make good reinforcers but not always. I do wish I could elaborate further on this point

Then he described a way to judge potential reinforcers. The essence of all the methods is to place on a table an object or more than one object and watch the child’s response to that set of object(s). In general, doing this with more than one object at a time work better than tests with one object presented at a time because there is with multiple object presentation a choice made by the child under test. He made a point that in multiple object testing one must be very careful about placement of the objects! I take this as meaning that not only should distance from the child be the same, but that one should be careful about a child’s positional preferences, such as left / right.

Further issues must be addressed during this assessment of the child's preferences. Only one category of object must be presented at once. His example is to test food items only against other food items. Test non food items separately. He states that one should observe the duration of the child's interaction with the chosen object. He also states that even very brief observations can yield good data. Then he said that a verbal reward: "That was very good, Jimmy." may not work at all if that child does not like social interaction.

He added that some severely autistic persons may not be able to acknowledge multiple objects at once. One must assess whether the individual is competent to the assignment.

The stated specific methodology of stimulus reinforcer assessment was given as follows:

1. Pick eight items of one category (food, activity, sensory)
2. Give each item a number
3. In each trial, place two items before the child, allow fifteen to twenty seconds, record the data (Which did the child choose?)
4. Make a table, like this:

TRIAL	LEFT	RIGHT
1	1	2

Where the number in the "trial" column is sequential, as in: trial one places object "1" on the child's left, and object "2" on the child's right

5. Circle the item chosen per each trial
6. Count each item selected
7. Selections per any item multiplied by 14 will equal the percent of the time that item was chosen
8. Graph the results

By doing this, one now has an objective assessment of that child's preferences for reinforcement. He notes one should not test any food items within two hours of a meal, and that one must be careful about the subject's access to any item under test prior to the assessment.

In rating an object for its effectiveness he uses the following: a high preference item is anything above 80%, moderate effectiveness is any object between 50% and 80%, and low effectiveness is anything less than 50%. He notes that such preferences change, so test often.

Always give the child choices of what he would want as a reinforcer. And he says that a simple reinforcer in case of inappropriate verbal from the child is simply to interrupt that verbal output.

I doubt that there is any single magick bullet in dealing with autism - I consider who I was as a child - but I did think that the objectively based A - B - C model as described above would have done me much better than what did happen to me!

DAY THREE

Friday, 11 July 1045

“Do You Want Fries with that Asperger?”

Presented by: Herm Fishbien, EdD - who also is one of us!

NOTE: I really loved that we were not resigned to dark rooms. The ASA likes us, they really like us!

As this presenter’s lecture was essentially a fleshed out set of observations in regards the Aspie’s troubles in society, from school to employment, I will record his lecture as a list.

1. Aspies may be able to obtain, and yet unable to hold employment. The skills and abilities to deal with social interactions are very different for getting from those required for keeping that job.
2. He called us “quirky” and noted that these behavioural differences may make relating to us difficult. (I like “quirky” much better than some of the things I have called myself!)
3. He cautions to look at your strengths, and not to be engrossed with your weaknesses. This may sound simple, I can well attest to its actual difficulty in practice. Personally, I note just how well society has for so long pointed out to me all my weaknesses.
4. He advises to get away from labels. Now, I see this as being more complicated. For me, the label has been liberating. However, there is a strong pejorative to all of autism, so watch out.
5. He stated that we must follow our own dreams, that we will be unsuccessful if we follow the dreams of others. I have personal experience with this. When I have deferred my goals to others around me, I find that I usually lack motivation to follow through, Further - even if I should obtain that goal, that goal is small regard to me because it was not my goal in the first case. I thought of the A - B - C model above.
6. He points out that self esteem in not twenty four hour social skills
7. Doctors may not necessarily sensitive. They might get the diagnosis right, and lack emotional empathy with the autie

8. Doctors tend to use the deficit model, seeing what is wrong with the autistic person
9. In his opinion, most doctors seem worried about the autistic person creating a culture. I would believe this, and I also think that if there is one critical thing that we auties must absolutely accomplish - that is creating of an autistic culture. To me, this means passing on of the wisdom that we gain during our lives
10. He states that frequently parents choose jobs for their children that are below those children's abilities. Such a job will not satisfy
11. He states that NeuroDiversity is a philosophy! WOO! HOO! I like him.
12. He states that ASDs are not simply a list of defects, but a different type of people
13. To him the essence of NeuroDiversity is happiness: specifically it is the acceptance of and happiness with who you really are. I wanted to hug this guy!
14. Disability = know your limits, but we do not necessarily need or want smothering support
15. He says that we tend to recall every bad thing that has happened to us, and disregard the good. I do not know if this is true for everyone, but he read MY mind for sure
16. REPEAT: We tend to not remember positive events
17. Support for the Aspie (It dawns on me that my capitalization of Aspie changes a lot. It ought be capped of course, I may have correct my cap problem, Herr Doktor Hans was a good man. He gave me my dignity. No exaggeration. Some Aspies do not like the name because it, in English, sounds like an ass-burger. I think I can put up with that unfortunate coincidence to honour the man who cared.) Should be based upon the actual outcome for the aspie, not on the system's requirements (Ohhhh, anarchist! Cool!)
18. He used as example that some life coach he heard of had broken tooth brushing into forty seven individual steps!
19. Everyone has some sensory issues, not only autistics!
20. No one says: "Hi! I'm a diabetic!"
21. When to disclose your autism: A. Do you have a history of being fired for reasons linked to autism? Could disclosure short circuit some of the potential for repeats? B. Do you think that any of your behaviours might lead people around you to think that you are mentally ill?
22. He says that every Aspie has a gift - even if that person has not discovered it yet. Even if that gift is not related to a job, that gift can be used as an anchor for self esteem

23. He said that we can be easily frustrated when our better idea is not implemented. People around us may not comprehend our ideas any better than they comprehend us.

24. His major definition of Asperger's Syndrome is that we lack social skills (Hoo Boy! I see much more of autism than that within me, but state that my lack of such skills has defined my life.)

25. More than 90% of Aspies are unemployed, this is a far greater - and worse - rate than for other disabilities

26. He says that Asperger's Syndrome is a civil rights issue. (Told you I like him.)

27. He also stated that adaptation is not a cure. Let me add this. . . As I have been studying autism I have found specifically listed characteristics. Some of these I obviously have - like the eye contact issue. Others I equally obviously do not have - such as synesthesias. I can check off boxes on a list of potential autismisms. I have often been surprised to find that some Lauraism that I have known for a long time turns out to be an autismism.

I was reading of these and I ran into "spinning and flapping" when a truly awesome thing occurred within me. You see, across decades of life attempting to be NeuroTypical (Even if I did not know of my autism, not of any definition of NeuroTypicality, but simply in a driving and mostly subconscious emulation mode.) I have lost some autismisms. Inasmuch as I was nearly placed into an institution in fourth grade, and that no one follows me around with a butterfly net now, I assume I have lost to extinguishing many of them, and have had others lessened.

This spinning and flapping must have been very important and near the surface because when I read that phrase my ears shot up and my eyes must have looked like saucers. I knew that this was a part of me. I did not then decide to consciously flap and spin - I simply determined to allow myself to flap and spin. And soon enough it happened. I have read of flapping and spinning being a thing done in times of anxiety. I have read of it being in several situations. I have found that I flap and or spin for one reason only: joy. I will pace or tap fingers or click pens for anxiety, but flaps and spins are for joy. Period.

An online friend asked me if this flap and spin thing was voluntary or automatic. I had to think. And I told him that it was neither, and both. It is akin to laughter. I can do it even sans motivating joy - but it feels silly and hollow. I can quite obviously squelch it, and have for years done so. But when I am joyful and just let it happen, it is wonderful.

Then a few days later I had a real revelation. I wondered what if. . . What if you had seen several bits of a movie that seems the funniest in history, but never seen it through? What if a friend gets a new home theatre and wants to christen it with a double feature: a real heavily effects loaded action movie, but the lead in is to be that exact comedy you have yearned to see? So you venture over to that friend's house on the appointed night. At the door that friend greets you with a warning. . .

. . . His uncle has come over. This uncle has a real issue with laughter. If anyone laughs, this uncle is likely to bolt from the house and become lost in the unfamiliar neighborhood. You cannot laugh. So you sit there as the very funny film rolls, unable to express your mirth and self-conscious about each little and quickly suppressed spasm. Question: Do you enjoy the film?

Not only “no”, but “Hell NO!” For an emotion suppressed is frustration. Mirth went to the dark side. Then I thought that I have been without my main expression of joy, and probably for decades. And I thought just how many times people have asked me if I am ever happy. And I think there is a correlation here.

Some adaptations may have to be made, but adaptation is not victory a priori.

28. He states that England is well ahead of the USA in dealing with Aspies (But I know several online, most of the ones I know are on the dole.)

29. He lists: “How are you?” as the sort of small talk that we are not good at.

30. He states that for an Aspie, overtime is likely to be an issue. Was for me. Lack of control. Lack of time to recover.

31. He stresses that a person is the product of his actions, not of his words

32. He lists stress and anxiety as major issues for Aspies. Yup!

33. He says that we must learn to both listen, and APPEAR to listen! That is a good adaptation indeed.

DAY THREE

Friday, 11 July 1345

“Driving”

A panel that I was on (Thank you, Jerry the most wonderful of whales!) Along with Stephen Shore (We passed many notes - primarily related to bicycles), and Bradley Debbault (Merci boucoup!) (I cannot spull enGlush, let alone frensh)

As I was on the panel, I took few notes. I was busy listening to the interaction, taking part in the panel discussion, and passing notes to Stephen Shore.

Funny, when the possibility of being on a panel discussing autism problems with driving, I thought to myself: “But I don’t have any.” Then I thought. I actually gave up on attempting to learn how to drive for a period of about two years after trying for several months. It could not have been as easy as I recall. I still have a bad time with clutches, and with stick shift car truly dread hills. Complex visual environments can fluster me, and in Flagstaff I must watch very

closely and with intent or I will miss the “One Way” sign. Learning involved multitasking as I had to drive whilst listening to my mother’s instructions. I can be subject to sensory overload. And then I thought of all the issues that would be triggered by an accident!

We spoke of all of these things. The audience asked questions, and in that group of audience question askers were several autistic people looking forward to getting licenses. I think the panel was a success. I was glad to be part of it. Now, let me add to this. . .

As I type this I am sitting in my house and without use of my car. My precious little Jacques - a 2002 Chevrouke Tracker - is in hospital. I put him there. I took my first “vacation” a week off, in twenty six years just a short time ago. I visited my sister in California. It was a nice trip. Sort of. I lost a crown from a tooth while there and therefore face more fiscal and dental problems: the former being the result of the latter. Then there are the kids. My sister is so often a mother to her grandchildren. As I returned home I realized that I needed a second vacation to recover for the first.

The day after my late night return to Williams, I took my little kayak: Pelikan - the cheapest and lightest kayak I could find to Kaibab lake. To float around was wonderful. But then it was time to leave. So I put Pelikan atop Jacques and then backed into a tree! Oooooom!

Now, I know, I KNOW that in meltdown many specific things can happen to me. I lose some portion of my logic, and since logic is who and what I am I can suffer as deeply as having temporary identity crisis from this effect alone. I can lose physical coordination to the extent that I cannot correctly open a can of soup for dinner - that is a statement aspieliteral. I can become more than usually flustered in complex sensory environments such as acoustic and visual.

It was that one that got me. I was fatigued and more than just a bit melty as I backed my car. I simply lost track of the tree. Yeah, logically there ought not be a tree in the middle of the lot! But it is there and I lost it and then found it by the Braille method of driving. I should have stayed home, shouldn’t I? Yes, but too late to avoid injury to Jacques and to my pocketbook, and to my ego - an ego never in great shape. I should not drive while in meltdown, right? Right! I think this applies nicely here.

LET ME PAUSE A MINUTE OR TWO

And write a bit more about the place where the conference was held. The Gaylord Palms was a marvelous place, I hope that G-d is taking notes. If there is a G-d, and if there is a Heaven, then that Heaven should be as much like the Gaylord as possible. However, it is not conveniently located to anywhere. Well, it is convenient if one has a car. It is about one and a half miles from the dreaded Disney World. But it is about one and a half miles from the nearest anything. I could not have walked there and would have needed a cab each way each day except for staying there.

I could not have walked for two reasons. One being that the temperature and humidity

were each near one hundred by about oh six hundred each day. I truly would not have wanted to be a sweaty goat in conferences. The other was that no sidewalks existed between the Gaylord any anywhere. Walking would have had to be along the grassy shoulders of a highway. I do not know what Florida's laws are in regards pedestrians; being who I am, I would not have risked such a walk.

Each day I did get in some walking. The Gaylord has a large center courtyard. I could and indeed had to walk some distance within the structure under the steel and glass roof the structure of which reminded me of Germany's great rigid airships. Then each day and following a full day of lectures and socializing I would head outside and circle the complex.

That place had the main building with the central courtyard, and that was quite large. Then there was a planned in addition along one side of the main structure housing the "Florida Keys" themed area, with seafood restaurant that featured a simulated sixty foot gaff rigged ketch with restaurant seating on its flush deck. Then off another wall and past two outside swimming pools was the conference center. Add to this a miniature golf course - not a children's feature but rather a small real golf course with greens and sand hazards, and a croquet green, and the service area of the complex, and three specific function entrances, and the entire building was very large indeed.

It was large enough that a circle of it was approximately one mile! Each day I would do three circuits (well, one day I got in but two before a storm hit) about the place. It was hot and it was humid. The air smelled of nearly nothing, but sometimes a hint of damp earth and floral. My schnozzle worked well. My lungs filled with heavy air. I sweated like a goat (Do goats sweat?) And saw small lizards and large seabirds and exotic plants. Then back to my room to take a longish shower.

My room was on the external side of the hall so I had no balcony onto the enclosed courtyard. But I had things better than that. I had a view of the marvelously flat and green Florida countryside, replete with cattle grazing across the street, from more than eighty feet above ground (I have heard that the highest point in Florida is Disney's Matterhorn!). My view was limited by the water suspended in the air. I also had RF energy entering my room! Yip! I took my Grundig G-5 radio (An Eton / Grundig re-engineered version of the somewhat odd but legendary Degen / Kaito 1103: a small radio capable of: LW, MW, SW, FM, FMS reception.) Along with a bought for this trip Kaito KA - 33 active loop MW, SW antenna. I spent the evenings listening to stations with "W" rather than "K" in their call signs and scanning the SW band. I like dxing (listening to distant radio stations), and enjoyed this. And although I can routinely pick up Radio Habana at 9550 kHz it was fun to hear it from so nearby to the commie's lair.

Oh, and I talked with my sister and emailed and talked with my boyfriend. But since I dumped him since that time - who cares about that?!

DAY THREE
Friday, 11 July 1530

“Sensory Processing 101”
Presented by: Chris Filler, a “transition coordinator”
“Implications of Sensory Challenges in ASD”

I will attempt to organize into written language a talk that worked very well in spoken, but which is a bit confusing to me as I scan my notes. As the title suggests, this talk was concerned primarily with sensory issues prevalent in autistic spectrum conditions. Of course, these sensory issues are related to other factors of autism and being autistic.

She noted that just as with an autistic person, our responses to any sensory input can be conditioned not only by our self, but also previous experience. She quickly defined the “power senses” as tactile (primarily touch), vestibular (the sense of balance we get from our inner ear’s vestibula), and proprioception (The body’s ability to know where parts of it are in relation to each other. Example: close your eyes and touch your nose.)

With that in mind she noted early on that the autistic person can have issues with the very taking in of sensory data. She told that some auties can drop out a lot of data and gave the example of feeling temperature as applied to our skin less severely than normal folks. She then says that an autistic person is likely to interpret the sensory information differently from a normal person. From there we are likely to develop a different from the normal response to that sensory input. (A lot of these lectures seem to take an autistic person as a robotic device reacting to environment. I have no difficulty with this as a basal assumption. I think everyone is a lot like this.)

Then she asked just how is that autistic person expressing the situation? To this question she added that in that person’s expression (I took as a reaction to some specific sensory input.) The observer can consider the underlying way in which that autistic person reacted to that sensory input. (Sounds good thus far: let me state however that inasmuch as auties can react differently in general, that the observer must be knowledgeable about that person in specific.) And then she stated in a sentence regarding potentially explosive emotions that the autistic person’s reactions may be incongruent and even lacking entirely.

She noted in brief the idea of “Perseveration” and that the autistic person may go back to something that that person knows. Let me add here that from my experience, what else ought we expect of an autistic person lost and alone in a world that is not his? That is to say that as I recall the gestalt of my childhood I recall innate feelings and thoughts based upon personal and anecdotal observations that I did not fit anywhere at all being reinforced by adult’s scolding and other children’s teasing and brutality. Better believe that whenever I could, I would “run home” to my books and drawings and the great TV series: *Mr. Wizard*.

She then categorized people as follows: 1. Seeker. This is a person who has high

awareness but low sensitivity, and so is drawn to seek sensory inputs. 2. Active avoider. This is one with high awareness and high sensitivity. These people tend to avoid sensory inputs. This one is likely to cover his ears and flee any sensory input. 3. The Overwhelmed. This one too has high awareness and sensitivity. This person will not usually flee sensory input, but will complain of sensory inputs. Her example was: "It's too loud." 4. Underresponder: this person has low awareness and sensitivity. This person misses cues routinely.

Then she notes that seekers and avoiders can appear somewhat similar to the outsider, while underresponders and overwhelmed are typically quieter. And she noted that a person can occupy different modes at different times. I noted that I certainly do this. She asked then "What can we do (to deal with a person's sensory issues)?"

Her basal term for what to do is to offer that person (Assumed to be an autistic child.) (Let me add that there is a lot of consideration of the autistic child, considerably less for adults - within the research community. Most adult related lectures - insofar as I could tell by the lectures I attended - were given by autistic adults.) Is "Sensory Diet." That sensory diet is a combination of sensory experiences needed by a person to adaptively interact with the environment (That is: to make it through the day.). Okay, now she has me by the ears.

I still have all this stuff going on. Some issues rarely bother me anymore as I am now in control over some of my life. I do not buy clothes of fabric that feels to me like sandpaper. I will own nothing that is a pastel colour. But as a child my sensory diet was externally determined. And it sucked!

She suggested that the adults in charge alter the child's environment so to make that environment offers reduced stresses on that child. (About this point, I wanted to take her out for pizza later and continue the listening.) She said that ASD people may not be able to filter out all the offending sensory inputs that cause trouble, and that we may not be able to focus. She added that in sensory trouble the ASD person may appear maladaptive, I took as implication that such a person is adapting to improper sensory stimuli. She stated that the adult must give that spectrumite skills to cope. This was not entirely explained - yes, but she had only an hour to speak and some things must be left out. Then a mnemonic:

D do informal assessment (seeker, avoider, overwhelmed, underresponder)
I individualistic: tailor your behaviour to the child
E environmental support (I took this to be the modifications of environment)
T (The) power senses

(I really hate cute acronyms. If you ever catch me doing anything such, please throw something at me - like a cup of cold liquid.)

She said that for a seeker, that sensory experiences should be built into that day's activities. The active avoider may need environmental modifications to allow that person to escape, and that one should introduce that person gently to new experiences. For the

overwhelmed, control the environment to lessen surprises and changes. Provide schedules and Limit stimulation. For the underresponder she suggests use of visual support routines.

As to those power senses. . . She reiterated the nature of the three sensory types as I listed above and then went on to say that the work of Bonnie Hanshu (Available at www.sensoryprocessing.com) is a usable model. She explained by way of a term: “sensory bucket” wherein the bucket is the maximum sensory input that a person can properly deal with. She says that a person’s sensory bucket will fill to capacity quickly with inputs from the three power senses. The adults in charge of the child must take care to not overfill that child’s bucket. This care must be taken all day long and must be non contingent (Which is to say that one ought not drop the sensory control even if the child behaves poorly - as in a form of punishment.)

Then she went more deeply into the tactile system of senses. She stated that the tactile system is protective and discriminatory. This system triggers the fight or flight response. It is primal, being a limbic system, and is not cognitive in nature. This system is discriminating in that deep pressure or vibration activates the parasympathetic system and can be calming. This can be cognitive and can reinforce responses and assist the person to learn and think. She states that often ASD people have a greater parasympathetic response than do normals (I do apologise for terms like “normals”, but what else to use?)

She warned that tactile defensiveness can trigger aggression and that accordingly one should not deal with the child in a confined space.

The proprioceptive system is essentially motor planning. This is the feedback that does such things as allowing us to walk smoothly. This sense is body awareness. She notes that some people with truly poor proprioceptive sense may have to confirm body position visually. With proprioceptive dysfunction a person may be clumsy, have poor handwriting, eat sloppily and have difficulty with small objects. (I plead nolo contendere here.) This sense is neurologically based. She equated this sense with joint compression and good heavy work. She suggested calming autistic children with such techniques as involving joint compression, but stated that the specifics of such would be beyond the scope of her presentation.

DAY FOUR
Saturday, 12 July

“With Open Arms”

Let me add another bit of trivia from the trip. During the first official day of the conference a woman came up to in recognition. She had been to our local (Northern Arizona chapter: ASA) conference and had seen me on a panel..I did not recognize her (What else would I suspect!). She was Brenda Myles-Smith (Sure hope I got that right!), and she invited me to a party outside the Gaylord that night. There would be shuttles leaving the conference center and hotel from the shuttle portal that evening.

Well, the shuttles became privately owned vans. These vans were late to show. Now, this is important not so much because I survived a party, largely by heading outside into the swimming pool enclosure in the back yard with a few other spectrumites. The salient point here is that whilst waiting at that shuttle portal I met another conference attendee (identifiable due to the wearing of her name tag). She was quite interesting, and the woman who presented this very talk. I made certain that I attended her lecture. I was not disappointed.

Mary Schleider is a school teacher. She had been handed - cold - the special education programme for her school. She was intimidated at first, but determined to learn whatever she needed to manage the schooling of special needs children. She recounted her successes in this endeavour, with many types of special needs children, including autistic children. She states that her implementations have not cost any additional money to her school system. She also notes that her system can work with children of all ages.

She begins with a simple but wonderful premise that every one wants to know that they are smart, and that there is hope.

The center point of her method is so simple: inclusion. Try to include the special child in as much normalcy as is possible. As she continued on with specific methods to accomplish this, I recalled one of the earlier lectures that I attended, and the name of the presenter I had not recorded, wherein the lecturer made a profound statement. The concept that so interested me was the notion that an autistic child may by way of some relatively small initial autism, choose an environment which accelerates him into greater autisms. And I thought here is the flip side: Inclusion. And I wondered what could have happened to me with greater inclusion; what may have happened to me if the plan to institutionalize me (fourth grade) had come to fruition.

One point, and this woman was not autistic - her mind organized very differently from mine, so I will reorganize here so that I understand what I am typing - that made my day was just this: That autistic children need friends too! This tugged my cold emotionless heart strongly. As I have pondered who and what I am in Light of knowing of my life long residence on the spectrum, many specific thoughts have raced through my head. One is that while little me faced every fear and stresser that any other child my age did, I went on to face many more, specific to my wonderful syndrome. I needed other children, I needed a support group. And yet I had none. The thing that increased the troubles of my life was the very thing that kept me from having friends.

She creates for each special child a “circle of friends”. (I do not like the American punctuation within the quotation marks; I am not closing the quotation. I am closing the entire sentence. Please excuse my affectation of proper British punctuation.) She asks children to become part of one specific special child’s circle. She wants volunteers - and surprisingly - has no trouble in finding them.

These children do not have to be at all ideal students. The children who will become friends do have to be good social role models. It is better, but not necessary to find children who

share interests with the challenged child. She finds that even a “faked” friendship can help that child at the center of the circle to develop social skills! Further, taking part in a circle assists those children to better understand people with different personalities and needs.

These children in a circle of friends, she recommends about ten children per circle are tasked with speaking to the challenged child: even a few short sentences, each day. They should take the special child to lunch weekly or bi - weekly. They let adults know if there is anything appropriate (whether they see bullying of the central child, or notice that child behaving in inappropriate ways). They are the special child’s cheerleaders. She reports that the children whom she has so engaged as friends enjoy the task.

She likes to have meetings with parents of the special children and of parents of children within the circle. Not many meetings, people soon become disenchanted with those. During these meetings the child should not be present, as that child’s needs and strengths and challenges must be discussed directly.

She spoke about involving all school personnel, including bus drivers and janitors in the effort, because there are not enough teachers to go around. In essence, she would educate as many school employees as possible as to the special needs of some students and therefore create an environment for those children. Much of what she said was in relation to purely practical issues of implementation such as having lunches at meetings as people whether children or teachers are more like to come to the meeting if there is free food. Some one person in the school (in this case her) has to take the lead, others will follow.

She wants to include the child into as much typicality as possible and to include as many people around that child as possible in that effort. Include children, include parents, include school teaching and non teaching staff. What she said was so not - magickal, so simple, and I think that it could do a lot of good for the special students whether auties or other non typical children. A big point that she took pains to drive home was that by including she means that as much as possible the special child should not be placed into special classes; they will in that class model each other’s behaviours. Simple stuff, but common sense. She has good results.

A few specific points: 1. Use time well, 2. Appoint a leader to set schedules, 3. Rotate leaders so that they do not get burned out, 4. Get feedback, see how the system is actually running, 5. Do not get hung up on theory, always ask: “How did it work?” I liked her ideas - a lot.

DAY FOUR
Saturday, 12 July

“Digestive Enzyme Supplementation, Hope or Hype”
Presented by: Dennis Houston

Dennis' credentials - in short form - are as follows. He has been an NIH funded researcher. In 1997 he quit that to become a researcher for an enzyme company. He was asked to research autism and enzymes: can enzymes be used to assist in an autistic person's gluten and or casein sensitivities. Can perhaps the GFCF diet be replaced with enzymes? When the company at which he worked did not want to press this line of research as far as he wished to go, he quit and started his own company: *Houston Nutricuticals, Incorporated*. And we must remember that he does then have a dog in this fight.

This man impressed me. He was not only knowledgeable about the topic that he presented; when he spoke about digestion he was as excited as a rock hound talking of a geode he had found. I had no idea that anyone could develop a near autistic obsession with digestion!

Here is his talk short. Not only can a person's digestion tract be incapable of completely digesting proteins such as gluten and casein; an autistic person's incomplete digestion can actually render digestive products of those two specific proteins as opiates! Therefore, we are talking about far more than a sour stomach or IBS, autistic behaviours can be exacerbated by these digestion products. He went on and on about very specific digestive steps and enzymes and where in a protein these enzymes make their cuts in molecular structure by way of catalytic action. But let us get on with his conclusions.

The obvious action to take with an autistic person with gluten and or casein trouble is the GFCF diet. However, in some cases (He stressed that: *in some cases*), proper enzymes may be able to allow the person may be able to consume regular food, if enzymes are added to the diet. He stated also that enzymes may be used as a diagnostic tool: they work immediately - so if one sees a change in their child very quickly with enzymes, than that child probably does have a gluten and or casein problem. He stated too, as a caution, that for a person with celiac disease do not even think of replacing a special diet with enzymes!

All in all, I thought he knew well what he spoke of, and that enzymes may help an autistic person face life. I came home and ordered some. I will have to try them again - I personally noticed no change. Oh well, he did say that the product would not work for everyone. If I was raising an autistic child, I would certainly try this, it is fairly inexpensive and has no known side effects.

DAY FOUR
Saturday, 12 July

“Preparing for Success in Adult Life for People with Autism”
Presented by Stephen Shore, EdD

Yes, I went to another of Stephen's talks.

This talk was about the issues facing a reasonably well functioning autistic facing

adulthood. (Let me add here that I wonder about these labels of high and moderate and low functioning. I probably seem plenty high functioning to someone outside my mind and soul. I am fifty four, I have no retirement, take vacations about every twenty years, only in the past decade or so have had friends, run a business because I find it so difficult to get a job; impossible to get a good job; and impossible to keep jobs. I have so many alone nights. My mind and stomach churn at the prospect of a new client. And back to the central issue of it all, the simplest of all social rewards: money: I do not live in a house literally the size of a garden shed in a friend's backyard because of my great success. Fact is that I make it, barely. I want to see a whole crop of younger auties of all stripes do so much better than have I!)

He dealt with issues such as finding job types that use one's strengths and do not trigger so many social or sensory issues. There are such jobs out there, and the autistic individual must think realistically in assessing himself. There is a time for self advocacy. Speak up, an employer just might be willing to do a few things to accommodate a good employee, but you will not know that unless you speak up. We have large assets and equally large liabilities, work with the former and around the latter. You know, so much of all that can make autistic life better is so simple and well known. As I ponder autism and life I think of the lyrics: "You've got to. . . Accentuate the positive. . . Eliminate the negative." Yes, and since I know what sort of human I am I can face me honestly and with understanding. Simple but true for all, autistic or not.

He suggests that as the child matures he should be involved in planning his IEP as a step to self determination. He states that even as that person ages that he will still need family support. And he brought up a few organizations:

- Autism Resource Center
- Talk Autism
- Grasp Autism Today
- Ladders.org

And then the last real session I attended was over. Wonderful, the sharing of information.

DAY FOUR
Saturday, 12 July

"Town Hall"

This was not actually a presentation. Rather, this meeting had a room devoted to an autistic person's get together. Indeed, here the NeuroTypical people were referred to as "guests". The talk was informal. I knew I wanted to go there, but has some timing issues as I worked about health issues that I will not mention (No problem: just scheduling: too much information!). and so I arrived late to the session.

As I walked in, a woman who was moderating the group told of a chair I could have. Just

then, however, was a voice: “Or you could sit on the floor.” Was Stephen Shore! So I sat on the floor. There was a pleasant round robin and free flowing conversation going on. As I entered there were issues in regards diagnostic standards for autism. The conversation was quite thoughtful.

For the most part, I forget specifics here because I sat (and as Stephen pointed out: rocked) in a wonderfully natural atmosphere. Some of the things I learned at the conference were specific and learned by way of specific remarks made by specific presenters. Other learnings I had were far more amorphous. I noted few specifics in this get together. Mostly I just took in the gestalt of a gathering of so many *literally* like minded people. It was wonderful. What would a bunch of people; social illiterates all, do together? Exactly as we did. We spoke carefully and with consideration and moderation, and were as much in agreement about the topics covered as one might expect like minded people to be.

I do recall that one point mentioned there was that the town hall for us, for us, was a good thing and should be longer next conference. And I recall the one thing I said there. I pointed out that I am self diagnosed, and have neither the need nor the cash to get an official; but that I have known me for a long time, that autism is experiential in nature anyway, and that I did not need to have my diagnosis confirmed by someone who is not autistic but who has read a book. Two men, middle aged and seated together; each with the notation of therapist on his name tag heard and they nodded with smiles. I may not see eyes, but I do see smiles. I saw two goodly ones right there and then. One of my major issues in regards the entire spectrum is civil rights. To me, that means that we who are must be involved in the definition of our condition. There is hope. I saw it and felt it at the 2008 ASA National Conference.

Then time for the trip home. I had never been to such a conference before. If I ever go to another such function I will check the time it is expected to be over and probably leave that afternoon or evening. Instead, I was there until the next morning when my flight home was scheduled to leave. I noticed that the conference center emptied of autistic people and those who care about us very quickly.

So the next morn I arose and prepared to leave the hotel for the airport and then home. I was ready for a boring - and we all hope air travel will be boring - trip home. At the airport I now knew the drill pretty well and had been in this airport before and knew something of its physical layout. So I went through the steps and took many real steps and found myself at gate seven, awaiting *Delta Airlines* flight 58 departing at 1400.

And since even though I was somewhat up on the airport drill, but manifestly still me, I got up every twenty minutes to make sure certain that I was still in the right place. And time and time again I was. But then there was a difference. The red LED display showed a departure of 1830 for *Delta Airlines* flight 058. What dies this mean? Oooooom!

I strolled to the *Delta* desk and asked if flight 58 was the same as 058, and why the difference in departure times. I was told that yes, 058 and 58 were the same and that it was merely a delay. So I sat back down and waited to wait even longer. Then I heard an announcement over the Tannoy. *Delta* flight 58 has been cancelled. Please all passengers of flight 58 go to the telephones and call the *Delta* whatever the heck it was. So I replaced book and bins into my bag, and tidied up my local squalor and padded over to the phones where I was third in line for one of six telephones. The persons there had apparently spoken about this much into the phones: “HI, I am a passenger on flight fifty eight from Orlando to Atlanta.” and then had been put on hold.

And on hold and on hold. I did not want to talk on a phone anyway. I want to see a real live person. And I really, really wanted to see a real live person right then. This trip was my first time on an airline in twenty years. It was the first time ever I had flown to a place without a friend who knew the ground on the far end of the flight. I had barely become accustomed to airline travel at its best, and now faced a major and unexpected change in my plans and one that placed me into unknown waters. Ya’ kno’ some of the autie stereotypes have some degree of truth behind them. I was more than nervous. And the initial people to the phone remained on indefinite hold.

After approximately forty minutes I heard a *Delta* guy speaking to two women in another line awaiting their turn on another of the six phones. He said to them quietly that they did not have to wait for a telephone, but could proceed to the *Delta* ticket desk. I was thinking: “Why is he whispering this to two women in one line? This ought be on the bleeding public address system.” But alas, it seemed that *Delta Airlines* has never cancelled a flight before ever in its August history, and was quite without specific methods to deal with the problem. (Are Aspies allowed to be sarcastic?)

So I then walked over to that man and asked: “Did you just say that we can go to the ticket counter rather than stand here for a telephone?”, and was told yes. And I asked then if the ticket window so mentioned was the one at which I had obtained my boarding pass. Yes again. And so then I grabbed my carry on bags and took off back so very far and using one monorail to that ticket desk. There I found one terrifying line.

As I stood in this line I was gradually assaulted by the sound of loud air handlers, a rhythmically squeaking piece of baggage handling equipment, the muffled murmurs of human voices in displeasure, hot humid Florida air coming through the nearby doors to the outside and as hotted and humidited by approximately ten million unhappy people in the line. And time passed. Lots of time passed. The line moved perhaps ten feet in more than an hour. The line was grinding my gears. I remained in the line as the little stress gauge in my head moved from the yellow arc well into the red. My then boyfriend emailed me that I ought leave the line. But could I leave the line?

If I leave the line will I be shipwrecked here in Orlando where I have no house, no friends, no income, and surely will starve for a time before being consumed by a large alligator?

What can I do? And I tarried in the line and began to melt.

Then I spied a *Delta* guy in not only a shirt and tie, but in a suit. So I asked the person adjacent to me to watch my bags a moment and sped to the Delta suit guy and asked can I leave the line, or will this mess up Delta or their procedures or my ability to return home? He said that I could indeed leave the line. So I grabbed my carry on bags from my position in line and took off for a part of the airport far away from the line of infinite misery. I found a *Sbarro* and bought a slice of anodyne pizza and a Dr. Pepper. Then I walked, pacing up and back the mall. I bought some chocolate. And then I found a place to sit in on a decently comfy bench near a fountain.

And waiting there was not fun as I knew of the essential problem that had placed me there rather than in the air, in a pressurized sardine can en route home. But I stayed because the line, and I did look at it periodically, was still there and still long and still slower than two dead snails.

Then finally it was actually shortening. So I re entered it. By now people were no longer murmuring in tones of anger. Their resentment has passed into resignation, and now were laughs. They were the laughs of the condemned to be certain, but laughs still. And I stayed in line, now sitting on the floor sometimes as the long standing earlier had given me a back ache. And I was still very melty. Then it was my turn to speak to the goddess at the ticket window! I have been received! Salvation at last! It was now 2100, the flight had been cancelled prior to 1400. I had been in the red arc of my capability in life for a loooooong time.

And I thought in that last minute and so I approached the window of benevolent action and said to the woman in attendance pretty much this: "Hi. I am autistic and just leaving the national conference here. I have been in a place of great stress for several hours. I am suffering several large sensory problems and other issues at this time. I will ask you to speak very simply to me. I will take notes. I will ask questions. I may need you to repeat statements." She treated me like a total moron! GOOD! By then, I was a total bloody moron. My brain had left my cranium hours earlier to take up residence in my secondary control center - located safely in my left butt cheek. She made it easy, I took notes. And then I was off to a shuttle to take me to the Quality Inn with a voucher for the night.

I arrived there somewhat after 2130. I checked in and found my room. I bought a single bottle of Heineken and returned to my room. I watched some TV. I drank my beer - I so rarely do consume any alcohol. I called my sister. I found that if I sat on the end of the bed and bounced my legs ever so little, that at resonant frequency I soon obtained at least one foot altitude above the bed. And I prepared for the morning. I really did not want to miss my flight.

That flight was not on Delta, but on a competing airline. It was early - early enough to pruch some potential issues with a probably - but - not - certainly - related ASD problem: the ever feared IBS. I felt that if I blew off this flight that I may be stranded here in Orlando for ever. So I set my watch to wake me at 0400, then I set the clock in my Grundig G5 to wake me at the Arizona time equivalent to 0400 local. And I set the room's clock radio to wake me at 0400.

Then I went to the office once more to request a wake up call at 0400. I had to be sure.

Then to sleep, a fitful sleep. I awoke at 0330 and could not go back to sleep. So I cancelled the alarm on my watch, the Grundig, the clock radio, and waited for the wake up call as I began my preparations to leave. At 0400 the “continental breakfast” (packaged bagels and such) was available in the office. So I got a bagel and returned to my roof to light the coffee maker. Then a shower and the shuttle and to the airport. This day there were no major tornadic storms over Atlanta as had caused the previous day’s cancellations. Wait. Check the gate and flight number and departure times a few times. And on the aircraft. It was an airbus A - 300 series. I do not like their flight controls. A Boeing pilot can always override the airplane’s judgements, an Airbus driver cannot. Further, there is a question of the VSTAB’s strength at attachment to the tail cone.

But all went well on the flight. Was as boring as a Boeing. As loud too. But this aircraft was set up for longer flights, and indeed ran from Orlando to Phoenix non stop. Due to its intended use, it had far more room between the seats. More comfortable. The movie was “Whatever it was for Neverland” Peter Pan creeps me out and so I did not watch. Was done with my books. Slept a bit. The aircraft landed in Phoenix without special events (such as avionics malfunctions and separating VSTABs), good. All I had to do now was await my ride back to Williams. Spent most of the day lounging in the mundane boredom of Sky Harbor. I had done it!

A fine adventure, all in all. And I learned a lot at the conference. I hope this typing of it is comprehensible and of use. Thank you to the Autism Society of America for such a good event, and to my local chapter for sending me there. Oh yes, and thank you for bring me back home too.

Laura Nagle