

sharisa Joy's Joices and Choices of Autism sharing Worldwide Rainbows of Love, Joy, Hope, Respect and Acceptance

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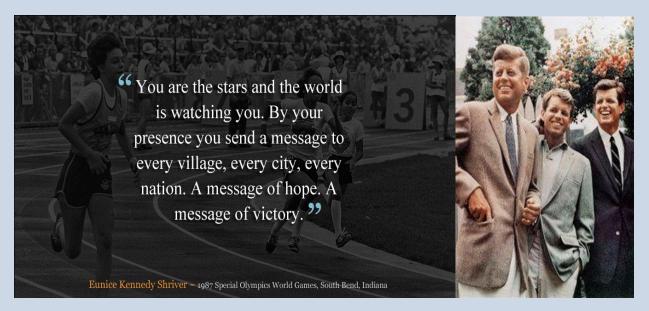
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In the month of August, 2009, The United States of America, and, indeed, the world, lost two great pioneering leaders for equality and human rights. A nation and a world shared love for Eunice Kennedy Shriver and Edward Moore (Ted) Kennedy with an awesome family that suffered losses and tragedies beyond human understanding, beyond anyone's ability to cope and still hope. I dedicate the August issue of "The Voices and Choices of Autism" to this sister and brother and the other fallen members of their family along with the amazing family members who have suffered so much yet done so much, still do so much, yet pledge to do more as long as there remains a cause and a need.



Photos from AP Files and Special Olympics Website





From Eunice Kennedy Shriver:

Special Olympics athletes are spokespersons for freedom itself - they ask for the freedom to live, the freedom to belong, the freedom to contribute, the freedom to have a chance. And, of all the values that unite and inspire us to seek a better world, no value holds a higher place than the value of freedom.

The right to play on any playing field? You have earned it. The right to study in any school? You have earned it. The right to hold a job? You have earned it. The right to be anyone's

neighbor? You have earned it.

In a world where poverty, war, and oppression have dimmed people's hopes, Special Olympic athletes rekindle that hope with their spiritual strength, their excellence, and achievements.

For as we hope for the best in them, hope is reborn in us.

Special Olympians and their families are challenging the common wisdom that says only intellectual achievement is the measure of human life. They have proved that the common wisdom is wrong. Special Olympians and their families-more than one million of them-are proof that the value of human life should be

measured in many ways.

Shriver's family issued a statement upon her death, reading in part, "Inspired by her love of God, her devotion to her family, and her relentless belief in the dignity and worth of every human life, she worked without ceasing — searching, pushing, demanding, hoping for change. She was a living prayer, a living advocate, a living center of power. She set out to change the world and to change us, and she did that and more. She founded the movement that became Special Olympics, the largest movement for accompance and inclusion for neonle with largest movement for acceptance and inclusion for people with intellectual disabilities in the history of the world. Her work transformed the lives of hundreds of millions of people across the globe, and they in turn are her living legacy.'

From Edward M. (Ted) Kennedy:

Integrity is the lifeblood of democracy. Deceit is a poison in its veins.

The commitment I seek is not to outworn views but to old values that will never wear out. Programs may sometimes become obsolete, but the ideal of fairness always endures. Circumstances may change, but the work of compassion must continue. - Democratic National Convention, August 1980

What we have in the United States is not so much a health-

care system as a disease-care system.

We know the future will outlast all of us, but I believe that all of us will live on in the future we make.

The work goes on, the cause endures, the hope still lives

and the dreams shall never die.

My father taught me that even our most profound losses are survivable, and that is — it is what we do with that loss, our ability to transform it into a positive event, that is one of my father's greatest lessons. - Ted Kennedy, Jr.

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To Sharisa Joy, My Daughter and my Friend By Carol Kochmeister

I sat in the cool, darkened hospital room, watching you sleep... or should I say "trying" to sleep amongst the various beeps and buzzes of modern hospital technology. Efficient, kind, and gentle physician's assistants, nurses, nursing assistants and social workers floated in and out of your room doing what they could to make you as comfortable as possible. Some of them were not experienced with the many challenges and triumphs of working with people with autism, but they did their best to understand and include me in their care of you.

There were, however, a few individuals determined to fit you into their notion of the "typical" patient. It was these people with whom I got to shed my cloak of worry and helplessness and step in as your advocate to help with communication and suggest better ways of gaining your cooperation.

I watched the night merge into a yet noisier and brighter dawn. More people floated in and out of your room... doctors, nutritionists, lab techs, laundry, food service and housekeeping staff, and those wonderful transport people who cheerfully and skillfully manipulated your heavy bed down one hallway, up the next, into and out of elevators, up one floor, down three floors, from one invasive medical test to another as I valiantly struggled to keep up.

I sat bleary-eyed trying to understand the meanings of your test results, diagnoses and treatments. Your improvements and setbacks had me on a nightmarish rollercoaster ride of hope, disappointment, more hope, despair, fear and so on... night into day, day into night. Clocks and calendars meant little to me.

It was during a rare quiet moment - just before the cheerful and energetic day shift was to carry us into daytime - when all of a sudden, I heard you hum very clearly the most beautiful melody I had ever heard from you. I am used to hearing shorter musical fragments from you but this magical piece had a clearly defined introduction, middle, and conclusion; it was so clear, sweet and hopeful that tears welled in my eyes and I knew you would be okay.

Your release from the hospital, homecoming, and ongoing recovery have been a huge source of joy, comfort, and relief for your

father, me, and your faithful canine friend Buddy - who stood watch patiently for your return.

There are a multitude of lessons that I have learned from this experience and these, I believe, are the most essential ones:

- 1. It is extremely important to take time to cherish those loving and humorous moments of life... those daily mundane chores can wait!
- 2. You can never tell a person too often that you love them.
- 3. Look beyond your daily existence to the beautiful and often magical moments that music and nature can provide.
- 4. Always embrace and treasure those beloved family members and friends who are on this journey with you, because you can never truly know how much precious travel time you will have.

I love you, Sharisa Joy... MOM!

Don't be fooled by the calendar. There are only as many days in the year as you make use of. - Charles Richards

Pain and suffering are always inevitable for a large intelligence and a deep heart. The really great men must, I think, have great sadness on earth. - Fyodor Dostoevsky

Let the refining and improving of your own life keep you so busy that you have little time to criticize others. - H. Jackson Brown, Jr.

The harder you fight to hold on to specific assumptions, the more likely there's gold in letting go of them. - John Seely Brown

I hope for an America where we can all contend freely and vigorously, but where we will treasure and guard those standards of civility which alone make this nation safe for both democracy and diversity. - From Ted Kennedy's speech "Faith, Truth and Tolerance in America," at Liberty Baptist College in Lynchburg, Va., 10/3/83

It is our responsibility to live in our time - not to look back to the receding shore, but to sail ahead in hope, remembering whence we came, cherishing the values we carry with us, searching out the newer and better world which is the next destination and discovery of the American journey. - Ted Kennedy



Adonya Wong has a diverse professional background and is a veteran of the U.S. Navy. *In My Mind* (Tate Publishing, 2009) creatively explores the inner world of an autistic child - the world no one else can see. From exciting adventures to silly games and conversations with friends, the main character invites readers to see how a child with autism sees the world, and, in turn, how the world often sees him. Adonya's primary motivation for writing such a book stemmed from the most basic recognition that there was a scarcity of literature directed to and written for autistic children. When she is not writing, she heads the community-based nonprofit which she founded, M.O.C.H.A. – Mothers of Color for Holistic Alternatives (www.mochacafe.org).

<u>Living with Alzheimer's While Raising Autism</u> By Adonya Wong A medical diagnosis, of any kind, can be life-altering. A life that once offered some measure of stability would now be forever changed.

In 2005, our family received two blows to our way of living. That April, my son was diagnosed with autism, and a few months later, my grandmother was diagnosed with Alzheimer's.

What is very interesting about the two disorders is they both affect a person's neurodevelopment; however, the effects are experienced at the opposite ends of a person's life. While autism affects the young and how they interact with the world, Alzheimer's typically affects the elderly (over 65) and, ultimately, their interaction with the world outside.

While my son "struggles" with how to communicate his needs in a manner that will be understood by others, my grandmother has simply forgotten who it is she is communicating with. My son and my grandmother are fascinated with one another. He doesn't know what Alzheimer's is nor does she have any knowledge about autism. However, it is obvious to the observer that they "get" one another, that there is a deeper level of knowing. Perhaps it isn't for me to understand. When I watch them, I see purity and innocence; I don't see two people frustrated by the cards dealt them.

Although, my son and I lived out of state for three years and only recently returned, neither is anxious or overwhelmed by the other. Is Alzheimer's autism... in "reverse"? Could this offer an explanation for their intense connection?

Looking for any "similarities" between the two different abilities, I found approximately 1,850,000 search results to read. It didn't exactly make for light reading, but here are a few "similarities" I found in my search that you may also find interesting:

Autism Spectrum Disorder	Alzheimer's Disease
Fastest-growing developmental disability	Diagnoses have increased 10- fold over past decade.
Often unable to handle sensory overload	Often unable to handle sensory overload
Not looked upon as "being present" or "all there".	No longer looked upon as "being present" or "all there".
Disorder has "robbed" individual of a "normal" life	Disease has "robbed" individual of a "normal" life
Individual often fixates on inanimate objects	Individual often fixates on inanimate objects
Repetitive, incoherent, and/or absence of speech	Repetitive, incoherent, and/or absence of speech
Individual has difficulty "reading" social cues.	Individual has difficulty "reading" social cues.
Individual has difficulty with cognition.	Individual has difficulty with cognition.

Of the similarities, a person being seen as not "being present" or "all there" is the one that makes me the most uncomfortable. Just because a person has these disabilities does not imply that they are any less than human. They are still people who deserve to be respected. They are here, and it is society that needs to deal with that reality.

Oftentimes, people only see the disorder/disease and not the person. During conversation, they are spoken of as if they are not physically present; and sadly, are ignored. Additionally, family members have a tendency to feel sorry for themselves because they

now have an individual in their life that doesn't fit into their ideal way of living.

Although I am not the one who was diagnosed with autism, my life has changed as a result of my son's diagnosis. Yet, I do not feel sorry for me nor do I feel sorry for him. I also do not feel sorry for my grandmother.

When I watch them interacting with one another, I do not see two people who are miserable or unhappy in any way. What I see are two people whose brains are wired differently than my own. In spite of their different abilities, they both manage to pull, from within themselves, strength and courage to face each day. I see my son and my grandmother as my sources of inspiration not as burdens or crosses to bear.

In my opinion, society has it all wrong. I believe we must adapt to their way of living, and stop seeing and treating different as if it were abnormal or even a curse.

With the current growth rates for both disabilities, abnormal and different will quickly become the norm.

I have been raising "autism" for over 4 years, and if I were to compare my son's disorder to my grandmother's disease, I would say that autism, for me, is easier to live with.

My grandmother, once the pillar of strength and the foundation of my family, is now a fragile woman desperate to retain her grasp on things.

Her speech, once clear and forceful, has now been reduced to faint mumbling. Memories of her chasing me or my siblings around fill my mind while I watch her shuffle from one spot to another.

My grandmother will not be reduced to "my grandmother with Alzheimer's". I will not let the disease replace my childhood memories of her, not even those memories when she was whoppin' on my hindparts.

Her future is not as promising as my son's. However, at 86, she has lived a life full of adventures as well as "foolishness and mayhem".

Unlike his mind, hers will continue to "betray" her. One day, she will no longer recognize herself as she gazes in the mirror. She, too, will become a stranger.

In the meantime, my uncle will continue to ensure that her remaining days are filled with love and joy, just as I will continue to do the same for my son.

My life, and his, have been touched and changed in ways we could have never imagined. Had it not been for Alzheimer's or autism, neither one of us would have experienced the necessary growth that has made and continues to make us better people with each new day.

"The Anatomy of a Forced Resignation" by Sharisa Joy

I would like to tell you all that I am resigning as President of AutCom, the Autism National Committee as of September 14, 2009, and feel the need to make it clear that I do not endorse this year's conference and in fact will neither presnt at or attend this year's conference because of an incident that started at the beginning of August of this year but has its roots a year ago. What has happened is that two people on the autism Spectrum have been denied admission to this year's conference for the second consecuitve year. The official reason for doing this is that they have a "record" of allegedly "harassing" a couple of the conference presenters via threats on blogs. I want to make it clear that I have looked into this alleged "harassment" with all the resources and information available to me and I see nothing that condones barring them from attendance.

I have been President of AutCom since October, 2007, and in that time have been asked without ever being given past records or documents to learn the by-laws and uphold the mission/goals of AutCom found on their website http://www.autcom.org/about.html and in the by-laws (All Italics added by me):

About AUTCOM The Autism National Committee "AUTCOM is the only autism advocacy organization dedicated to 'Social Justice for All Citizens with Autism' through a shared vision and a commitment to positive approaches. Our organization was founded in 1990 to protect and advance the human rights and civil rights of all persons with autism, Pervasive Developmental Disorder, and related differences of communication and behavior. In the face of social policies of devaluation, which are expressed in the practices of segregation, medicalization, and aversive conditioning, we assert that all individuals are created equal and endowed with certain inalienable rights, and that among these are life, liberty, and the pursuit of rights, and that among these are life, liberty, and the pursuit of

The Committee further believes that the principles of social justice can *only* be upheld through organizational methods which *reflect* those principles. Just as we envision communities based on the *cultivation* and support rather than the control of their members, the Committee encourages its individual members and organizational partners toward self-direction and self-empowerment. We welcome the participation of all family members, people with autism/PDD, caring professionals, and other friends who wish to implement, not debate, the right to self-determination by hearing and heeding the voices of people with autism. We have joined together to provide information, support, networking, We have joined together to provide information, support, networking, advocacy, a strong voice in federal legislation and policy, a newsletter, conferences and trainings, a bookstore, a variety of unique publications, and an ongoing reappraisal of fundamental research and treatment issues in the light of what people with autism themselves find meaningful and respectful."

The by-laws state the following as duties of the president: "Section 4.03 The President shall preside at all meetings of the Board of Directors. Subject to the control of the Board of Directors, the President shall have general supervision of the affairs of AUTCOM and

shall see that the policies and programs adopted or approved by the Board are carried out."

Additionally, the by-laws state: "Section 3.13 Sub-Committees. By resolution adopted by a majority of the whole Board of Directors, sub-committees or temporary committees... may be appointed by the Board of Directors from time to time. A Member or Members appointed to a Sub-committee shall serve as Chair or Co-chairs, as appropriate, of the Sub-committee. Each Sub-committee shall have and exercise such authority in the management of the business and affairs of AUTCOM as the Board of Directors may specify, and shall do so for a length of time which the Board of Directors shall specify. Committee action will be by majority vote. Any action taken by any Sub-committee shall be reported to the Board of Directors by the president thereof and shall be subject to alteration or revocation by the Board of Directors."

So there I sat, trying to uphold these by-laws, when suddenly I received an e-mail on 8/2/09 from the two people who were denied attendance in 2008 and expressed their fear of being excluded again in 2009. I must admit, I was quite frustrated and annoyed when I found out that last year's conference committee had done so without ever clearing it with the board (as mandated by the by-laws) nor made me aware of the situation at that time. It was quite apparent to me that this should NEVER happen in an organization that claims to be committed to full inclusion for "all persons with autism" and "welcome(s) the participation of all... people with autism".

In my belief, any organization that violates its own by-laws and/or mission is poorly administrated and clearly hypocritical; and since I never have been a poor administrator, hypocritical, or one who sides with exclusion in any walk of life (being a PRIME example of inclusion and exclusion myself), I decided the Board needed to discuss this, develop a plan for incidents if they were afraid they'd occur and not exclude anyone without clear, solid and reasonable grounds for doing so.

We had a phone board meeting and discussed the issues at length and although we didn't have a quorum, we seemed to have a consensus and I was told quite clearly to let these two people know they could attend within the boundaries of behavior that I had decided were the minimum of fairness, had shared with these two people, and they had agreed to uphold via e-mail which I shared with the Board of Directors. The text follows with all names omitted, just as I have named no board members other than myself in this article:

"I have posted ... a few times, nearly always strongly disagreeing with ... I have never posted anything there related to Autcom or Autreat. I VERY seldom agree with ... on anything, and just about never about autism. ...is her own person and has very strong opinions but I have

been with her a lot and am sure there is no violence in her. She plans to avoid contact with ... and does not want (is not willing) to confront her or anyone else. She wants to be seen and known. I have read about you on the web, and you have many things in common with ... Her oversuspicion/hypervigilance is the result of decades of institutional abuse that was as bad as can be imagined.

(She) does not own a cellphone and will leave her camera at home. My cellphone does not have a camera, and my camera will stay in my suitcase. Same with audio recorders. There will be no disruption.

(She) needs a trusted support person to attend anything. I went with her to a Michigan DD council meeting where she participated fully and was applauded enthusiastically. I am an aspie myself and am co-manager of an IRC channel that is restricted to those on the autistic spectrum. I am a 58 year old radio broadcast engineer, currently disabled with eye and other problems after working fulltime at radio stations for 35 years. Yes, (she) has been in disputes and strong arguments online, but I am

certain she is no danger to anyone. She is also noticeably calmer than

she was a few years ago.

Can we make solid plans to attend and not worry about ... being turned away...?'

I replied that they could, indeed register and attend (as I was instructed to do by the board) and further asked for proof of diagnoses of autism for both of them. These were sent post-haste... I found it stressful to ask anyone to prove a diagnosis after being challenged myself so many times by others to prove so many things. I subsequently added this proposal to the board and note that a 3/4 vote of a quorum vote was in favor of it:

Conference Policy Proposal sharisajoy Tue Aug 11, 2009 1:38 pm (PDT)

1. Anyone on the spectrum and their assistants if necessary may attend.

2. Others may also attend.

3. Anyone causing disruptions or threatening others physically, verbally or emotionally will be removed from the premises by hotel security and/or local authorities and will forfeit fees paid and any further right to attend this and future conferences.

4. Anyone invading anyone else's chosen personal space will be asked to cease and desist and will be removed as per #3 above if they refuse

5. Anyone who disagrees during a presentation will have to hold their remarks until after the presentation so as not to disrupt the comfort of presenters or interfere with the presentation and the right of the speaker and audience members to a safe atmosphere in which to attend

and learn from what's being presented.

6. Only one warning will be given - if it is not complied with immediately, the person warned will be removed as per #3 above.

7. People wishing a private meeting with any board member or presenter will have to ask that person and be willing to accept a refusal if

8. Any panel presenter disrupting or interfering with another panelist's presentation and time to present will be removed from the

panel.

I believed and still believe this to be a fair and equitable policy, and one that I could live with, that was within our mission and by-laws. I felt that all board members who claimed to support these by-laws and mission would agree. Unfortunately, I was wrong, because over the next two weeks there was an exchange of postings on that board, especially from a couple who hadn't even attended the phone meeting, which I cannot share because of confidentiality rules but can confidently state were characteristic of an ongoing and very nasty level of civil harassment, questioning my honesty, integrity, judgment and right to uphold the by-laws and mission just as I had been charged to do by being elected President of AutCom.

When I questioned lack of involvement, participation and attendance at monthly phone board meetings by some board members (despite the promise they had made and signed on to when they accepted nomination to the board), others defended the missing members by stating simply: "Everyone is a volunteer". In my experiences with volunteerism (which are vast and plentiful), even volunteers do somthing other than merely complain and incite. Many board members seemed to have forgotten I am a volunteer too, even as president, and I wasn't paid to take or accept abuse as a substitute for respect and support. I protested repeatedly being treated this way, asked that the rhetoric and insults cease and desist, consulted a civil rights attorney, and posted statements on the board that showed that the pattern of abuse and level of stress to which I was being subjected was, in fact, defined as harassment in civil laws.

I called an emergency special board meeting for 8/23 and for the first time in recent memory, we actually had a quorum (although, to be quite clear, two members who had the most to say online and had promised they would attend were absent with explanations). At that meeting, I made the following statement:

"I respectfully request that nobody comment until this is read in its entirety and ask for it be entered into the meeting minutes, also in its entirety, so that no one will twist my words, edit them, or interpret them for me I subsequently sent the entire statement to the online Board).

At this time, I would like to make it clear that I will be resigning as President of AutCom and as a member of the board immediately following the September 13th Board call and in advance of the conference. In addition, I will neither present at nor attend the conference. I will never accept another position on this board, will never be a candidate for any position, and will not ever openly choose to oppose the next president and/or any decisions he or she makes. I urge all members of the board to show the new president their support - I have repeatedly suffered from lack of support, constant questioning, subjective accusations and language, challenging of my positions and decisions and motives in upholding the by-laws

and principles of this organization. My successor deserves better, AS DID I, and should receive it. I will, once the new president is chosen, terminate my membership in AutCom along

with all dealings with the organization.

I want you to rest assured this has nothing whatsoever to do with my recent illness - although the stress of being president of such a non-supportive, argumentative group of people who chose to go behind my back and make non-board approved decsions, who showed lack of respect and cordiality to and for me and each other in far too many cases, who failed to attend scheduled meetings as per their promise when they accepted the nomination yet railed against decisions made at those meetings, and who willfully and knowingly violated by-laws and rules of procedure

is enough to make anyone ill.

My mission is to help people, not to discriminate against them. I believed AutCom shared that mission when I joined and when accepted nomination and election to the presidency. I fought against my best instincts not to resign a year ago (when I felt no one was listening to me at an in-person board meeting); if I had known THEN about the exclusion that happened during last year's conference entirely without my knowledge or the Board's approval, I would have immediately done so at that point. I have come to see that I was mistaken in my belief that I and this organization as currently constituted and run by the Board share any common purpose or goal; and I cannot, in all good and sound conscience, continue as the "puppet" president of what I see as an "exclusive" club, or represent or condone decisions and policies that violate human rights and/or allow others to make policy for AutCom or demand that we make and change policy to suit them. Please feel free to choose nominees to replace me in a timely fashion without asking for or receiving input from me in that process. I've nothing more to say to this board today about this as I feel that most of what I've said in the past two years has largely been ignored. I will run the next phone meeting."

This all being said and made crystal clear, I uncategorically state for public knowledge that the reasons for my resigning are related not only to this incident but an ongoing two-year pattern of disrespect, neglect, behind-the-back maneuvering, abusive language and behavior, violating my personal space, maligning my integrity, making me suffer fromhigh stress levels, and refusing to cease and desist when asked politely by both me, my father (who is also a board member and is resigning) and a few caring board members. I will never again allow anyone to subject me or anyone I know to anything like this, and I fervently hope (but doubt) that the new president and board either uphold the by-laws and mission as written and stated or change the by-laws and mission to allow exclusion as a policy!

At that point, I believed there was no more to say or have said to me, yet found two more veiled insults on the Board page and responded as follows on 8/27/09 - to date, only one person has replied and that was via private e-mail rather than on the board!

"To those who have objected to me as president and made it impossible for me every time I did that job according to AutCom by-laws or tried to upholdsections of the by-laws, I tell you

If you wanted a "puppet" president, you should have made that clear before you nominated and elected me... if you were dissatisfied with me not being that, review the past 2 years and see how many times I offered to resign and was pleaded with not to do so.

Last bit of advice: if you expect the next president of AutCom to be a "puppet" president with a set of strings you all can pull to make him/her dance, please let him/her know in advance so he/she can make a truly informed decision before accepting the nomination.

And if you think I have ruined AutCom as President, just say so

clearly and succinctly because a 10 to 1 vote of confidence hardly made that clear, did it?

I am tired of the games, the names, the innuendos, the veiled and not-so-veiled accusations, the questions about my integrity, etc. Open up and let me have your opinions with all the honesty you can muster... feel free, so I can answer you in the exact same wav!

Quotes From Sharisa:

Sometimes rather than deal with the lunatic fringe, It's preferable to cut off the loose ends And hem the garment.

I can no longer be a diamond in a pile of coal dust... I will shine!

> It's another good day to be alive Rather than merely to survive. So here I am, alive and free To be the best me I can be!

A brand new day, a brand new start To do what I may for my soul, mind and heart.

Being busy being me being happy being free; Being gentle being kind being sane with peace of mind. You don't know what you really see When what you think you see is me... Since even stars that shine so brightly Are not what they appear to be!!

Having a simply wonderful day,
See only good things coming my way...
Out with the old, in with the new Time to do what *I* choose to do.

Autism is not merely a part of me It help makes me
Who I am and what I am To remove it would be
To remove the essential part of me.

Labels disable and rarely enable, So take care what you choose To bring to the table.

I am trying to raise people's consciousness, Reduce or eliminate labels, and abolish prejudice -Think I may be taking on TOO MUCH?

I dream of a world without walls and wars!

I want to educate, validate and never discriminate.

Still wondering why so many people find it easier
To pretend they're something they're not
And believe in something they don't
When I have an impossible time
Being duplicitous whatsoever.
The world is a contentious enough place Why would anyone seek to make it more so Can't people on the spectrum
At least unite on something?
I started this magazine and the Yahoo Group
To encourage people, not to "cure" them!

A wall by any other name is still a wall Prejudice and lack of understanding
Are far thicker walls
Than autism to penetrate!

Can a Tree Teach a Child With Autism About Life? By Vinnie Nauheimer©



Every special needs parent and teacher, at one time or another, needs a great visual for teaching lessons about growing up. This is especially true when dealing with students with autism who upon reaching their teens become increasingly aware of the differences between them and their general education counterparts. Just because a student has autism, doesn't mean they won't go through puberty. Nowhere is this more apparent than in the middle school inclusion setting. The schoolyard where I teach presented me with two wonderful gifts: several unique trees and the ability to recognize the powerful visual analogy that could be drawn between the trees, my inclusion students and their future. My administration and a good friend, Kathy, also a Special Ed. teacher, supplied the impetus to write this story. They constantly remind me that successes with special needs children have to be shared so others may be helped.

A wild throw by one of my students brought the trees to my attention. The tennis ball that we were playing with came to rest just below one of As I stood up after the trees. retrieving the ball, it struck me that there was something unusual in front of me. It took me a couple of seconds to figure out that it was the tree. The tree had grown through the fence! There, about seven feet off the ground, the tree had gone through the fence and continued to grow both up and out. As it grew, it enveloped a section of fence that was more than a



foot in diameter. To my amazement, the tree and the fence had become one!

The tree had wrapped itself around its problem and grew through it. Not only the tree in front of me, but several along the fence had enveloped their problem, the fence, and grew out of it to become big trees indistinguishable from those without that problem. Therein lies the beauty of these trees and the wonderful visual they supply for my students. I have had the good fortune of helping several students by creating analogies for them using these wonderful trees. Here are but three:

When Nikeisha became aware that she was a couple of years older than her general education classmates, she became depressed and started to shut down. She was fourteen, about to turn fifteen and still in eighth grade. "I'll be an old lady by time I graduate high school," she would bitterly complain. I used myself as an example by telling her that I didn't graduate college until I was twenty-five, but that meant nothing to her. Nothing anyone could say to her could help her understand that being a couple of years older than her classmates was not going to be a life-altering tragedy. It was easy for everyone to say, but very hard for her to understand.

Remembering the trees, I invited her to look out the window at the trees that grew on the other side of the schoolyard. "What do I have to look at some dumb trees for anyhow?" was her reply. "Because I'm going to show you why some of them are not so dumb," was my reply. Reluctantly, she looked at the trees.

"Nothing but dumb trees," she said sullenly. I asked her to make sure she could see no differences between the trees as we looked down on them. "They're all the same, big dumb trees," was her reply.

I told her they were not the same and at lunchtime I would show her how some of them were a lot like her. "What do you mean they're a lot like me? How can a tree be like me?" The questions came in rapid succession. After lunch, I once again asked her if she saw any



difference in how the trees had grown up and when I knew my point had sunk in, I took her over to the fence and showed her the trees that had grown through the fence.

"Two of these trees are like you," I told her. "They hit the fence when they were young. So have you; only your fence is your age. See, if you get over the fact that you're a little older than your classmates and continue growing like this tree did, when you're an adult no one will know that you were a few years older than your classmates. It's just like you couldn't see any difference in the trees from the window." "You mean when I'm older no one is going to care that I graduated older than the other kids?" she asked. I said: "When you're an adult, no one will know how old you were when you graduated high school just like no one can tell which of these trees grew through the fence and which ones didn't."

Nikeisha didn't change overnight, but each time she started going on about her age, I'd ask her if she needed to look out the window or go down to the schoolyard. After a while, the issue faded and was replaced by the excitement of graduation.

Kenny was a different story. He was a seventh grader who came from another school transitioning from general ed. to my inclusion class. Kenny had been moved from public to private schools and back to public until age thirteen when his needs could no longer be denied. Kenny had been diagnosed with autism early on, but had never been in a Special Ed. class before. This made things twice as hard for him.

As is my custom with new students, I assess them using two or three different measurement tools - fully understanding that on any given day a child with autism can have a bad day. In Kenny's case, both assessments confirmed lower third grade Reading and Comprehension levels. On parent/teachers night, I shared that information with his parents and laid out a plan to help him.

The next morning as I walked by his desk, Kenny blurted out, "I'm so ashamed of my test scores!" Stunned by the outburst, the dejection in his voice, the sadness in his face and the tears welling up in his eyes, I told him this was a conversation the rest of the class didn't need to hear. Out in the hall, Kenny told me that his parents had come home from their meeting with me and shared his reading grade levels with him. I didn't know how this information was relayed to him, but there was no denying how he took it. All he knew was that he was a seventh grader with a third grade reading level. The news of his reading levels was a big blow to his ego. He felt he had to apologize to me for his low reading scores. Many emotions ran through my mind at the same time, but the winning

one was that I had to give this child some hope or risk losing him because his self esteem had been shattered.

So down we went to the schoolyard to visit my favorite trees. "Kenny," I said, "Do you see this tree? When it was your age it had some big problems too. As a matter of fact, they were as big as your problems." "How could they be worse than having a third grade reading level? Trees don't read. They don't do Math. They're just trees!" "You're right!" I said, "but they're special trees because they faced their problems and continued to grow and you can do the same." "What problems do trees have?" he asked again. "See this fence; it was this tree's big problem. The tree had to make a choice, stop growing at the fence or continue to grow. Which choice do you think the tree made, Kenny?" "It wanted to grow," he said. "And what did it grow through, Kenny?" "It grew through the fence, Vinnie." "Yes it did, Kenny, and it grew up through its problem and you can do the same thing. Besides, you have something this tree didn't have; you've got a lot of people who want to help you."

"Kenny, you need to think of yourself as that tree, only your fence is your ability to read. We can help you get through the fence and continue growing just like that tree, but you can't give up." "What happens if I give up, Vinnie?" "Well, if the tree gave up what do you think would have happened to it?" "It wouldn't grow no more?" was the reply. "That's right, Kenny and if you give up, your ability to read won't grow either. Do you want that?" "No Vinnie!" he blurted out. "I don't want that for you either", and for the first time that morning, I saw hope back in Kenny's eyes.

"Kenny, you can be like that tree; just keep growing!"

Every teacher has one of those days when his/her heart is wrenched by the emotional bombshell that one of their students drops on them out of the blue. My saddest one came one year on the last day of classes before the Christmas break. Juan had been acting out because of difficulties he was having at home. Having had a couple of phone conversations with his mom, I knew that his parents were in the process of separating and it was anything but agreeable. Not surprisingly, the more difficult things were at home, the worse Juan's behavior was getting in school.

In the days leading up to the Christmas break, Juan's behavior and sullenness became more pronounced. Wanting him to recognize the causes of his behavior, I asked him to think about why his behavior was spiraling out of control. In typical autistic fashion, I never got a verbal answer. Just before lunch on the last day of class, Juan handed me a note written out on a piece of scrap paper. I asked him what it was and he replied, "You want to know, don't you?" When I replied "Yes", he said, "Here it is."

As the paper unfolded, the words went from the paper to my eyes and took the express to my heart. He had written, "All I want for Christmas is my dad to come home and never abandon his family again." It was obvious that Juan did not understand what was going on at home and a couple of questions confirmed it. Juan knew his father was leaving, but didn't understand why. He needed some support and hope. So down we went to visit the trees.

From across the schoolyard, I asked him if he saw any difference between the tops of the trees. He said "No." As we walked across the schoolyard, I told him that some of the trees had faced severe problems when they were growing up. He dismissed the idea, telling me that trees can't have problems. I told him that all living things can have problems in their lives and the way that they deal with

them determines how well they survive and grow.

"What does this have to do with my dad leaving?" he asked. "You'll see as we get closer," I said. When we got to the fence, I asked him if he noticed anything different about the tree and he said "No." Then I pointed out that the tree grew through the fence. This fact amazed him. Juan asked me dozen "How did it do questions. that?" he asked. I said "The tree didn't want to stop growing." After giving him a moment to absorb what he was looking at, I asked him if he saw anything different about the tree where it went through the fence. responded with the fact that it was thicker.



"It's different from the trees that didn't have to grow through the fence isn't it?" Juan responded positively and I asked him to consider it as a scar from having to go through the pain of growing through the fence. "Do you know what a scar is?" He nodded in the affirmative. Then we stepped away from the trees and looked at the tops again. Once again I asked him if he saw any differences between the trees that grew through the fence and those that didn't. Juan said "No."

"What about the scars?" I asked. He said, "Oh yeah, I forgot about them." "Good," was my reply. Because this is what is happening to you; you are going through a very painful time and it will leave a scar just like going through the fence left a scar on the tree. You will still grow up even though your father doesn't live with you anymore. Your father will always be your father wherever he lives and if he moves out, it doesn't mean that he doesn't love you. You are going have to be like this tree. You have to wrap yourself around the fact that your father is moving out and grow past it."

"Do you think you can do what the tree did?" Juan shook his head and I could see he was still wrestling with what he had just seen. We walked back to the classroom in silence and just as he opened the classroom door, he turned to me and said, "Thanks Vinnie." At that moment, I knew the trees had helped me with another student.

Can a student with autism learn life's lessons from a tree? The answer is a resounding "Yes!" Over the past few years, my trees (and I now consider them my trees) have helped me give hope to several of my inclusion students who were dealing with a variety of problems. Problems have ranged from an acute awareness of being different, to lack of confidence, to being caught up in a bitter divorce. Why are the trees so helpful? One reason is that all of us need a little assurance that things will turn out all right when we're going through tough times and if a "dumb tree" can turn out alright, so can a teenager with problems. Another reason is that they can see that the tree grew up despite its problem and I think that is very reassuring. Are there other great visuals out there that are can be just as effective as these trees? I'm sure there are; we just have to be open to seeing and using them.

Always expect the best and you'll see that the outcome is spontaneously contained in the expectation. - Deepak Chopra

The secret of success in life is for a man to be ready for his opportunity when it comes. - Disraeli

Without freedom from the past, there is no freedom at all, because the mind is never new, fresh, innocent. - Krishnamurti

The real reason your regrets continue to grow is that you keep watering them with "sighs, cries, and whys"! - Guy Finley

He who obtains has little. He who scatters has much. - Lao-Tzu

Using Data Collection and Analysis to Improve Outcomes for Children with Autism Dawn G. Gregg

Data collection is an important component of any school or home-based program for children and teenagers with autism. Data collection has been shown to be vital to understanding whether the educational programs of children with autism are working. It is used to assess a variety of skills and behaviors, and to both create and evaluate intervention strategies [Caldwell, 2007].

Fourteen years ago my son was diagnosed with autism and we began a home applied behavior analysis (ABA) therapy program [see Lovaas & Smith 1988]. We took data for every trial at every therapy session, 30 hours every week. This resulted in mountains of data that we tried to use effectively to guide his therapy programs. Since the data was collected using paper and pencil, however, it was very difficult to perform meaningful long-term data analysis.

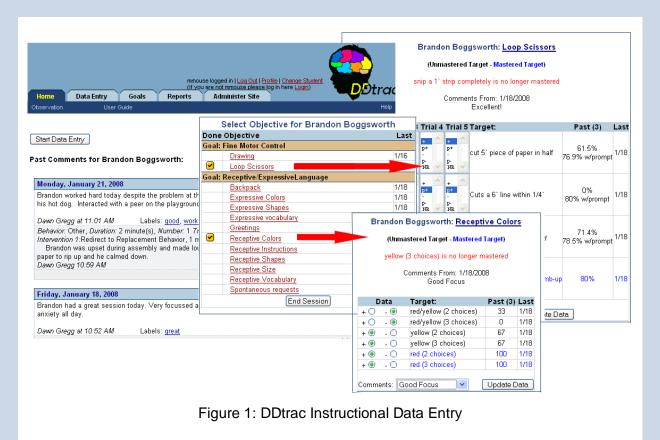
As an information systems professor, I recognized that it would be much more effective to capture my son's therapy data on a computer so that it could be analyzed more completely. In 2002, I decided to utilize my research and computer skills to write a computer program to improve the data collection and analysis task. The first version of my data tracking program significantly enhanced our ability to make meaningful decisions about which of my son's therapy programs were most effective and adjust his therapy accordingly.

A few years ago a group of my graduate and undergraduate students approached me because they wanted to start a company. I suggested commercializing my son's data tracking program and our company, Developing Minds Software, was founded. Today, my son's data tracking application has become DDtrac and it has evolved into a complete special education data tracking tool that can meet the needs of parents, therapists and teachers.

The development of DDtrac has involved evaluating current data collection practices and the data analysis needs of special education teachers and therapists to develop an application that could support all of their data tracking needs and reduce the amount of time required to collect and analyze data. Although it now supports data collection and analysis of data for children (and adults) with all types of disabilities, it continues to support all types of data recommended for documenting the progress of children with autism. DDtrac supports data collection and analysis for instructional objectives and targets, observed social interactions (e.g. for relationship development interventions), behaviors and narrative observations. It supports the collection of quantitative data tied to specific IEP objectives and qualitative data.

Qualitative Data Entry

All of the data entry utilize simple HTML form elements (e.g. checkboxes and dropdown lists) to minimize the amount of time spent on data entry (See Figure 1). The type data that is entered varies depending on the objective. For example, DDtrac includes the ability to record correct/incorrect responses, discrete trial data, the prompts used to elicit a response, or the amount of time



required to complete a task. The behavior input form (Figure 2), allows you to enter a wide variety of quantitative information documenting a behavior episode including the duration of the behavior and the context that resulted in the occurrence of the behavior. DDtrac utilizes web-based data entry forms which allow all data to be validated, reducing the opportunity for errors.

Qualitative Data Entry

Usually children with autism have many people involved in their education and therapy programs. They can receive services in school, in home therapy programs, and in outpatient environments. Consultants from other parts of the country can also be involved in the educational decision making. This can lead to major difficulties in keeping all providers working towards the same goals and modifying instruction to meet the child's changing needs. Even in environments where a child receives all services in the same school, therapists frequently travel between schools and often have limited time to meet and discuss the needs of each child they see.

DDtrac allows teachers, therapists and parents to record narrative comments about what he or she hears, sees, experiences, and thinks in the course of observing the child in a particular context. Since DDtrac is web-based, these comments can be immediately viewed by all people working with the child. This reduces the opportunity for miscommunication between the people involved in the child's education and therapy programs.

Start Date:	1/19/2008	
Start Time:	4:55 PM	
Trigger:	Unknown	
Location:	Therapy room 💌	
List Behaviors:		
Behavior: Head Butting	Duration Behavior: 2 minutes 💌 Number	of Behaviors: 1 💌
Behavior: Kicking	Duration Behavior: 3 minutes V Number	of Behaviors: 3
	Submit Behavior	
Enter the following abo	ut this behavior episode (Only complete if Incide	ent Report is being filed):
Intervention 1:	Redirect to Replacement	
Duration Intervention 1:	2 minutes	Deliavioi
Intervention 2:	Physical Escort/Restraint	~
Duration Intervention 2:	2 minutes	
Others Involved:	Staff V	
Consequence:	Loss of privileges	v
	ere there was injury to the child:	
<u>(</u>	Parts of Face I	njured:
	None Left Eye	^
	Right Eye	
	//\ \\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\	
	Mouth Left Cheek	
	Mouth Left Cheek Right Cheek	
	Mouth Left Cheek Right Cheek Left Ear Right Ear	
	Mouth Left Cheek Right Cheek Left Ear	•
	Mouth Left Cheek Right Cheek Left Ear Right Ear Chin	en

Figure 2: Portion of the Behavior Input Form

Goals, Objectives and Targets

An important characteristic of the education programs of children with autism is that they are highly individualized. Any autism data collection tool must be customizable to meet individual child's needs. DDtrac accomplishes this by allowing three different types of goals, objectives, and targets to be defined: instructional goals, social goals, and behavior goals. The teacher can define goals and objectives from scratch or they can be adapted from model goals that have already been defined in the goal and objective database. Instructional goals, for example, are broken down into goals, objectives, and targets (see Figure 3). The descriptions of these goals, objectives, and targets are designed to clearly define what the child is working on, how instructions are to be given, what response is expected, how progress is to be measured and what level of performance is required for the child to achieve mastery. All of these factors are

Goal Name:	Classroom/School Skills		
Subject/Content Area:	Social Emotional Active: Yes		es
Long-Term Goal:	Jimmy Jefferson will remain on ta	k and work independently.	
	Objective Fellowele		
	Objective: Follow cla	ssroom rules	Active: Yes
Objective:	Follow classroom rules when lead	teacher is not present.	
Instruction:	Do		
Instruction (alt):			
Response:	Student successfully completes t	ask	
Prompts:	None		
Data Collection Type:	Correct/Incorrect	Number of Trials:	1
Date Introduced:	2/26/2009	Date Mastered:	
Mastery Criteria (>=):	Correct	% for Mastery:	80
		# Sessions for Maste	ry: 5
Files	X		
	Follow classroom ru Target Introduced Master Get in line 2/26/2009	ed Comments Active? Yes	
	No Shouting 2/26/2009	Yes	

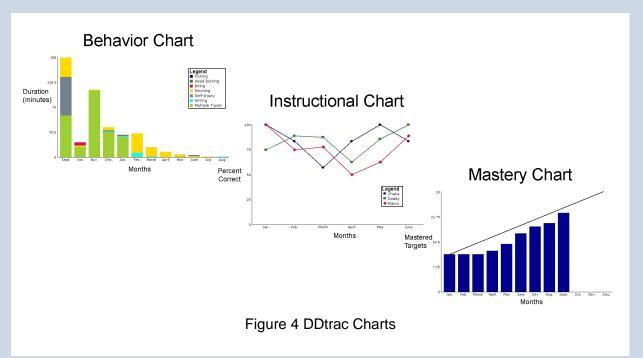
under the control of the teacher or therapist, allowing data collection to be highly individualized and consistent across all of the child's providers.

DDtrac also allows social and behavior goals to be defined and specific behaviors and triggers to be tracked for individual children. The behaviors and triggers that are tracked can be selected from a list of common behavior problems or new behaviors and triggers can be specified based on the child's unique characteristics (e.g. the child has behavior problems when told 'no').

Data Analysis

DDtrac has a number of features that makes it easier for teachers and therapists to meet the intensive needs of children with autism. First, the data tracking portion of DDtrac was designed to highlight the objectives and targets children need to work on most (See Figure 1). Each objective shows the date it was last worked on, as does each individual target. In addition, DDtrac sorts all targets so that the targets that have not been mastered are shown first (in black) followed by targets that are mastered (in blue). This allows you to easily identify which targets need the most work and which only need to be reviewed periodically. Mastery of each target is computed automatically based on the mastery criteria specified in the objective definition.

In addition, DDtrac's reporting and charting features make it easy for teachers and therapists to examine a child's progress and modify objectives and targets to improve learning or behavior outcomes. The reports available in DDtrac include reports summarizing performance on instructional targets, unmastered targets, on mastered targets, on social goals and summarizing



behaviors. The unmastered target report, for example, shows all instructional targets the child has not mastered, when they were introduced, how long they have been worked on, and the number of times they were practiced since they were introduced, and the average performance on the target over the past month.

DDtrac also supports multiple ways of charting a child's progress. The stacked bar behavior chart in Figure 4 shows how individual behaviors contribute to the overall number or duration of behaviors observed for a child. The multiline chart instructional shows how a child is performing on three targets. Finally, the mastery chart shows the rate a child is mastering targets and includes a goal line to help you determine whether the child is on track to meet his or her objective.

Summary

You have choices when it comes to collecting data for an autism therapy program. One of your options is to use DDtrac as your data collection tool. I wrote DDtrac because I felt that I was not making the most of the therapy data I was collecting for my son. There are many things I can do with DDtrac that I could not do with paper data, including:

- Recording changes in interventions, medications or diets so effects of these changes can be assessed with respect to academic progress, socialization and behaviors. Without long term data the effects of these interventions can be missed.
- Easily look up current expectations for a particular drill so everyone is working towards the same goal (you do not want to hear my horror story from before DDtrac when my son's speech therapist at school decided to change his primary means of communication without communicating it to his home therapists or private speech therapist six months lost!).

- Keeping track of standardized assessments given over years so long term changes can be understood.
- Easily check progress from anywhere using a PC or mobile device.

Data collection is essential for all children with special needs, especially those with autism. Daily notes can be used to determine if the child has trouble with something that you might want to rethink for future sessions, or to find things that seem to go well that you can use to make other activities more successful. Quantitative data can be charted to look for emerging trends and help determine future directions [Wallin 2004]. Research shows, when data is taken and used to make informed decisions about the treatments and interventions you use, your child's long term outcomes can be improved [Deno 2003, Safer & Fleischman 2005].

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Dr. Dawn G. Gregg is an Associate Professor of Information Systems at the University of Colorado Denver and cofounder of Developing Minds Software. Her research focuses on how to organize and maintain Web-based content so that it can be used to better meet special education needs. Her work has been published in numerous journals such as MIS Quarterly, Communications of the ACM, and Decision Support Systems.

Ideas are the root of creation. - Ernest Dimnet

There is only one good, knowledge, and one evil, ignorance. - Socrates

There is nothing more frightful than ignorance in action. - Goethe

The greatest lesson in life is to know that even fools are right sometimes. - Winston Churchill

Imagination has always had powers of resurrection that no science can match. - Ingrid Bengis

From Judy Endow:

On July 25, 2009, I participated on a keynote panel entitled The Culture of Autism at Autism Society of America Conference in St. Charles, IL. The panel, consisting of Sondra Williams, Lars Perner and myself with Brenda Myles as moderator, was very well received. Following is the poem I wrote in response to the first question posed to panelists asking about subcultures within a culture of autism, specifically among individuals with classic autism, high-functioning autism and Asperger Syndrome.

Autistic Spectrum: Brown-eyes Blue-eyes

here's hidden curriculum autism style from my vantage point:

when I don't copy and I look like my autie self

I am tolerated in some circles but oftentimes treated like a lovable pet

rarely a part of the real of what's going on

when I do copy and I look like my aspie self

and can be accepted as one

when I am my copy aspie self I am allowed a part

in the real of the world in some circles am less likely to be marginalized

but instead tolerated until

it is time to go home

I can travel in

both worlds of autism

at this point in my life experience

as an autie as an aspie

each a unique experience with vastly different

degrees of separation from the mainstream of society

and from

each other

because within

the population of autistics we have

our own system of separation

the system well known

by the brown-eyed auties

but maybe not so well known by the aspie-eyed blue

the blue-eyed aspie autistics are the fairer of the race while

the brown-eyed autie autistics are lower in class

more unacceptable than the eyes of blue

brown-eyes struggle differently their struggles easier to see

sensory assaults routinely experienced most don't talk like the world-folk do

and even among the brown-eyes

we sort ourselves out in a hierarchy fashion

with the FC users the very darkest of unwittingly true if you can't be a blue

it's preferable to not be the darkest of brown

an FC user furthest away from the aspie-eyed blue

and as

an aspie-eyed blue I think it grossly unfair

all the resources go to the eyes of brown just

because

I look more like the world-folk do I'm expected to

manage all on my own no obvious autie needs seen

yet I'm painfully aware a world-folk I'm not when

I look like I am

no wonder I'm lonely an alien of sorts

often feeling erased having no worldly place

of my own to call home

us blue-eyes we copy the world-folk around us

a ticket to ride

in the mainstream of society

oftentimes negating a part of our real in order to play to swim with them in

their world-folks swimming pool

all of us auties and aspies

brown-eyed and blue have a price to pay

differing costs for differing folks

in our world called autism we each pay

to purchase a ticket to ride

in the land called society whether brown-eyed or blue

Judy Endow July 2009

Where ignorance is our master, there is no possibility of real peace.
- Dalai Lama

You can't depend on your eyes when your imagination is out of focus. - Mark Twain

Where there is an open mind, there will always be a frontier.
- Charles F. Kettering

Fill your paper with the breathings of your heart.

- William Wadsworth

Millions long for immortality who do not know what to do with themselves on a rainy Sunday afternoon. - Susan Ertz

Only those who will risk going too far can possibly find out how far one can go. - T. S. Eliot

Cowardice asks the question, "Is it safe?" Expediency asks the question, "Is it politic?" Vanity asks the question, "Is it popular?" But, conscience asks the question, "Is it right?" And there comes a time when one must take a position that is neither safe, nor politic, nor popular but one must take it because one's conscience tells one that it is right. - Martin Luther King, Jr.

The following is Allison Dix's Account of and narration of a very important meeting she and her husband Shane had with Kevin Rudd, Australian Prime Minister. The Prime Minister is between them in

the photo below.



First, her original letter to the PM:

28 July 2009

The Hon Kevin Rudd PM PO Box 6022 House of Representatives Parliament House Canberra ACT 2600

Dear Prime Minister,

We sincerely thank you for the opportunity to meet with you to discuss what we are doing to enhance the lives of families living with autism in Australia and globally. We congratulate you on your election promise to provide better autism services and on its implementation, while at the same time putting autism on the political agenda.

In March 2009, I founded with my husband's full support, an organisation called Autism Global Network. The organisation was established in honour of our three beautiful children, Kristie (10), Jacob (5) and Aaron (5), who were all diagnosed as being on the autism spectrum in July 2007.

While Australia's official prevalence rate for autism is 1 in 160, which only reflects the rate for children aged between 6 and 12, more alarming figures exist globally. A recent Cambridge University study has found that as many as 1 in 64 children could have autism, due to many children going undiagnosed.

Social inclusion for the whole family is the foundation from which we base our work. As a family, we have personally chosen to embrace autism, to have a positive outlook and to focus on what the children can do, rather than their disability. Based on our own personal experience, we have come to learn that the children can't achieve their full potential unless the whole family's needs are supported.

Our Mission Statement for Autism Global Network accurately summarises what we strive to achieve for our families.

"Autism Global Network is an innovative and dvnamic knowledge, organisation that provides support, care understanding to people dealing with autism to enable enhanced opportunities for social inclusion and quality of life. With our drive and passion, we strive to advocate for the human rights of our families and promote community awareness and inclusion at every opportunity."

Our greatest personal achievements have been a direct result from a 'team effort' that is driven by us. Our support network comprises of us (parents), siblings, support groups, therapists, educators, and medical professionals. This success is almost impossible to achieve because a large percentage of families are already experiencing social exclusion at the time of diagnosis. In addition, many parents, especially the mothers, are suffering from depression due to the extreme behaviours and lifestyle that comes with raising a child on the autism spectrum.

The most significant difference that our Government's could be making to parent's very large stressors is to significantly improve the education system for our children with an autism spectrum disorder. The issues here are endless and of which ultimately leads to the children and their families being excluded from society in almost every way. Many children are being forced to be home schooled because they are not eligible for the special school system, mainstream schools can't cope with their high level needs and there are simply no places available in the limited number of special units.

For our family, schooling is the most significant stressor and will continue to be for many years to come. The State Governments need to do much more to improve the existing education systems and the lives of families living with autism spectrum disorders. Our children deserve the human right to be given a chance of becoming

functioning members of society, where they are employable and therefore pay taxes.

The saddest loss a family living with autism can face, besides the 80-90% divorce rate, is the loss of the family home as a direct result from the extreme medical and therapy bills necessary to give the child any chance of an independent life as an adult.

Our deep belief is that it is possible families can be empowered to implement basic, but effective therapy principles into their everyday life at a much lower cost than the current system and therapy methods indicate. If we were to hire a therapist to provide our three children with the recommended 20 hours a week therapy each at an average cost of \$50 an hour, our gross annual bill would be \$156,000. In addition to this are educational expenses, medical professional consultations, therapy equipment and expensive medications.

Attached to this letter is a summary of the services we currently provide to families living with autism and a business model outlining our future plans.

We are passionate about helping to improve the lives of families living with autism at a national and global level. We hope to achieve this in a proactive manner by working closely with the Federal Ministers for Education and Social Inclusion; Health; Families and Community Services; to achieve positive and cost effective outcomes. We invite your Ministers to contact us any time.

We also want to bring to your attention the wonderful support we have been given by Tony Zappia, Member for Makin. Tony is the chief patron of our Rainbow Land Play Time family support group where we currently run a playgroup for the whole family on a Saturday.

Thank you again for the great honour of meeting with you today and we very much look forward to more meetings in the future.

Yours sincerely, Allison Dix Autism Global Network



Allison's Account of the Actual Meeting:

Our one on one meeting with the Prime Minister after the Cabinet Meeting/Public Forum was a once in a lifetime experience. We were very lucky to have been chosen for a meeting and were very excited to have the opportunity to represent the autism community.

The PM was very warm and made us feel comfortable talking to him about what we want to see happen in the future to improve autism services and to get better outcomes. He was very attentive and had genuine concern for our personal situation having three children on the autism Spectrum. Kristie who has Asperger's Syndrome is 10 and our twin sons, Jacob and Aaron, who have autism spectrum disorder, just turned 5.

What impressed me the most was that every Minister was committed to following up on the issues raised at the Cabinet meeting. The same applied when we met with the PM. He acknowledged the issues we raised about the Helping Children with Autism package, including therapy not being accessible enough to the children and the very long waiting lists. The PM then invited Bill Shorten, the Parliamentary Secretary for Disabilities and Children's Services, to have a separate meeting with us where he recognised that there is a lot more that can be done to help families by providing more services. We were extremely grateful because we were given a lot more time than the allocated 10 minutes and were appreciative of the time taken to listen to our concerns.

My personal view is that having autism on the political agenda and The Helping Children with Autism Package was a major win for families like mine at the last election. Through the family business 'Autism Global Network', we would love to work with the Government in an advocacy role to get more much needed services for families living with autism.

Bill Shorten brought to our attention that he is working to make early intervention funding more flexible and to add more providers to the list. I was told that FaHCSIA has been pursuing this for a while, especially with regard to getting more providers on the panel.

I was also given assurances from Bill Shorten that he will help the Rainbow Land Play Time (Playgroup for families living with autism and development delay) committee explore ways to apply for funding through the proper processes because he recognises that the playgroup model is a good idea but hasn't received any funding to date because it doesn't fit existing criteria.

Funding for children with autism over the age of seven is a significant issue for a lot of families, but I believe the Government has certainly recognised that it is a problem and that this issue is being looked into.

Because of the time constraints, the Helping Children with Autism Package was the only issue we had time to discuss. We hope to discuss the significant issues around education for children with special needs with the Government in the not too distant future.

CONTACT ALLISON and READ MORE at:

http://www.rainbowmomsurvival.blogspot.com/

WE CAN MAKE A DIFFERENCE! - Sharisa Joy

Sometimes I sit and wonder why
The flow of life goes rushing by
And some folks never do a thing
While I can laugh and I can sing
And write about what's in my soul
That makes me special, free and whole.
- Sharisa

Courage is not the towering oak that sees storms come and go; it is the fragile blossom that opens in the snow.

- Alice Mackenzie Swaim

Enjoying success requires the ability to adapt. Only by being open to change will you get the most from your talent.
- Nolan Ryan

We must cut our coat according to our cloth, and adapt ourselves to changing circumstances. - William Ralph Inge (1860-1954)

Adapt or perish, now as ever, is nature's inexorable imperative. - H. G. Wells

Battle not with monsters, lest ye become a monster, and if you gaze into the abyss, the abyss gazes also into you. - Nietzsche

Leaders are more powerful role models when they learn than when they teach. - Rosabeth Moss Kantor

A man will be imprisoned in a room with a door that's unlocked and opens inwards; as long as it does not occur to him to pull rather than push. - Ludwig Wittgenstein

Every achiever that I have ever met says, "My life turned around when I began to believe in me." - Dr. Robert Schuller

We are more ready to try the untried when what we do is inconsequential. Hence, the remarkable fact that many inventions had their birth as toys. - Eric Hoffer

"Outcast Horse" by my friend Jessie, 13, who has Asperger's and lives in New Zealand Part 2 of Serialization

Three Choosen Ones

She first walked over to Seal, who she called "WaiRua" which meant "A Free Spirit", and loaded her onto the truck. Loco started wondering if he would never see her again and started pacing up and down the big metal fence with Belinda's beady little eyes watching him then she walked towards him. "Easy boy, easy, nobody is gonna harm you." With that she clipped the lead onto the halter - all horses were now wearing one - and led him up the truck; it brought back dark memories for Loco. He remembered when his mother and he had once been led onto this when he was a few weeks old and taken to a loud noisy place, and he had gotten lost and hadn't been found for a whole day. He didn't want to go up, but he knew his mother was inside so he walked bravely up one shaky step at a time. When he was up, he was placed in a little stall next to Seal and he gave her a friendly snort and got a whinny back. The last of the three horses Belinda chose was one of the yearlings, a soft mouse grey with a white snip. "Beautiful filly!" one of the men commented. "Yea, she'll do well in breeding," Greg said. "Nah, I'm gonna keep this girl for jumping cross country," Belinda said with a little grin while loading the rest of the horses on.

The Sales

It had been almost a year that the small bunch had been together and Loco had been hoping it would be the way he lived the rest of his life, but instead he had been chased, trapped and loved by a girl about the same age as Kattie. He didn't mind, he was just happy to be with Seal but he also knew something really different was about to happen - he could feel it in his gut. The truck moved slowly forward and the horses all let out a small snort and some stomped their hooves once or twice. It smelt, felt and sounded different to Loco and he was scared; but was reasured when Seal gave him a little whinny as if seeing his thoughts clearly. Loco stood quietly the rest of the way, and when they stopped he started making a big deal and drawing a lot of attention to their truck. He was rearing, bucking, pawing at the metal bars and snorting loudly. Lots of people closed in outside and all wanted to see what the big deal was. They stood outside waiting for the back to be dropped and when it was there was an admiring silence from the crowd, as they set their eyes on the three at the front. "Who wouldn't pay alot for that bunch!" one of them said. Belinda came up and stood with her hands on her hips. "If you don't mind people, I would like to get these horses out in time before the bidding starts, and the three in front aren't for sale so get your greedy eyes off!" Everyone backed off and the seven men all

went in to help unload the horses. In the end, only three horses were left in the truck - Seal, Loco and the small but beautiful grey filly whose name was Soot. The three were lead out and put in a corral that had been attached to the side of the truck, and they watched as their friends were auctioned off one by one. Soon the strawberry roan stallion was led past by a stocky and angry looking man, and when he stopped to try nuzzle them the man whipped him. He pulled back and got whipped again, and that was the last Loco would see of his new old friend. They watched as the rest of their friends were rammed into trailers before being driven off and then they just stood there watching where all the cars had exited - at least they still had each other...

The Trip

The three got loaded onto the truck yet again and everything was packed up. They had a bigger area for each of them now as the rest of the horses had gone. The truck launched and they were off. It was no short trip the horses were on, it was sopposedly going to take at the least a day and a half; so they got fresh water and a huge slab of meadow hay each morning and night. The trip took three-and-a-half days because the men and Belinda stopped everynight and stayed at a hotel so they could rest. During that time, the horses were let loose with the other guests' horses and it didn't take long to catch them in the morning. Each day they stopped at least five to six times for five minutes to let the horses out and stretch their legs. Belinda adored Soot and although she didn't show it, that was going to be her new favourite hunter. After the three-and-a-half days they were home, and Loco was expecting some huge mansion and a humongous stable for the horses, but what they saw surprised both Seal and Loco from the life they lived before freedom.

The Cottage

Soot wasn't at all surprised, she had been born wild and that was the only life she knew; so when she saw the house that looked like the small one in the middle of the field she wasn't the least interested - she just wanted this stupid rope off her so she could go meet the other horses and graze a little. Seal gazed at the tiny house. It was a bit bigger than the one in the field that they had in the wild with Dan, but she also remembered the huge house she lived at as a foal where she was mistreated by a little girl. She pulled back a little, banging into Loco who was grazing. He shied, starled by the sudden hit to his side and looked at his mother whose face looked worried and a little scared. He turned and looked at the house and he was surprised a lot! First off, it was tiny compared to the HUGE mansion he used to live in and there was NO stable! I mean the closest thing to a stable was the covered little shed in the

paddock that kept the rain off them. He looked and nickered at Seal and then continued eating - that was all he could think to do at the moment because he was starving!

Black Saddle

The next thing Loco knew was that Seal and he were locked in the small shed along with the pretty filly named Soot. The only thing Loco could think of was he had fallen asleep and somehow, in some strange way the people must have gotten him in here. He wasn't worried; he knew the girl was good, and besides he had his mother and a small filly that had become his friend along this strange trip. But still "better keep on the safe side" was all he was thinking as he ducked in behind Seal and the filly named Soot. What seemed like hours later, Belinda came back with three lead ropes and clipped one onto each of the horse's halters, and then they were led out. Loco breathed the fresh air and went crazy, not to try get loose but enjoying being outside and on a loose lead. Belinda let all three go and they galloped the paddock five times before the pace showed signs it was slowing down. They slept in that paddock with the other strange unknown horses and ponies that night, and in the morning Loco had a lead clipped on him again and he was led to a post and tied. When Belinda left, Seal came up and nuzzled him over the fence and stayed by him until Belinda came back with a big black saddle. When Loco saw that he really did go crazy! He was pulling at the post and making the lead stretch for all it was worth, but that post didn't move nor the lead break so he just stayed with the lead pulled tight as Belinda put the saddle on his back and did up the girth. Loco wasn't going to take it. When Belinda was pulling the girth tight, he bucked for his freedom and that of Seal and Soot, for his safety, and just for the fun of bucking that little bit more. When he felt the saddle slide, he let up and stood still, staring at the girl who had fallen over and was watching him calm down. Belinda stood had fallen over and was watching him calm down. Belinda stood up and went to his back. "You have no problem with me near your back, huh, fella" she said as she leaned on him and took her feet off the ground putting full weight on his back. "Neither do you care much if you have someone on your back." She then put her feet on the ground, grabbed a handful of mane, and catapulted herself up, sat sternly on his back, and gave Loco a few taps just to see if he knew what to do. When she tapped, Loco went forward and when she pulled the lead rope to one side, he went that way and the same for the other. "You have no problem at all being ridden and you know what you are doing, don't you boy?" Belinda asked as she jumped onto the flat surface again. "So why don't you like the saddle, Loco? It's the most comfortable saddle you can buy and I use it especially for breaking em' in and testing them." She walked around and picked up the saddle that was still on the ground and placed it on his back, and everything was still. She reached under and gently pulled the girth up so to make sure it didn't touch his belly. Then quick as you can blink your eye, she had it done up and Loco bucked again and again. "Get it off your back!" was all he could think. "You don't want to go through the pain you had before with the saddle!" So he bucked till he tired and then he stopped breathing hard and opened his nostrils to get the air he needed. "Now, now, Loco, I didn't think you would acttually live up to your name but now I see you do!" Belinda laughed; and while he was still catching his breath, she climbed up into the saddle and Loco didn't even know she was there!

The Forest Ride

When she felt him breathing normally again, she gripped the reins and tapped gently with her feet. Loco was tired but he wanted the saddle off! "Get it off get it off!" was his thought, but his front legs just wobbled when he tried to put weight on them and so he just walked on as told. When Belinda believed he was fine and would not buck, she circled once more round the corral and headed out the gate and up the path that led into the forest. As soon as Loco saw they were heading out into a wide open space with no gates or fences, leads or halters, his ears perked up and his neck arched. He had a plan that he had used many a time with Kattie and it worked like a charm everytime. As Belinda thought he was finally getting the use of the saddle and being ridden, she put him into a high lope. "This is it!" Loco thought. "Just find a tree and buck!" Belinda felt his back arch and knew what was coming, so she held onto the front of the saddle. As soon as Loco saw a good tree, he let out a huge buck and galloped towards the tree. Belinda, who had held on, regained her balance quickly and steered him away before her leg hit the tree knocking her out of the saddle and pulled Loco to a stop. "You must have had a real bad experience boy, cos that would've really hurt!" Belinda said with shock and a little shake in her voice. Loco just replied by shaking his head and putting it down to scratch his long bay leg. Then Belinda turned him around and put him on a jog back to the small cottage that now seemed considerably bigger than it did when they first arrived.

Seal's Time To Shine

Seal didn't realise until she was tied to the very post Loco was the day before that she hadn't been ridden in seven years! And she didn't want to be ridden again. In the time she had been out with the wild bunch, she had learnt tricks only the smartest and wisest of horses knew; and with one of them, she pulled off, the rope broke and she jogged back over to her son and friend. When Belinda came out with the bucket of grain she was going to feed Seal and found her garzing in the paddock she just laughed. "You silly old mare, thinking I am going to get on that rare back of yours! You're too old now - by the looks of your skinny little legs and yellow cracked teeth - you'd be about 21 years old and your son as I think he is looks three!

Poor old girl must've been old enough when you had him," Belinda said as she caught the trailing rope that was clipped on Seal. "Now c'mon, I want to fatten you up, I want you to live long enough to see your son become a famous racer. I know you both have the spirit for it, but with the rough play they use nowadays you'd break down halfway, old girl," Belinda said tying Seal up again and leaning on the post watching her and looking her over. "Well... Seal, you have a perfect back still, and your legs hold you long enough on a full-out run around the paddock a few times..." Belinda was starting to think of racing Seal once at the track. "Nah nah, better not - I don't want to have one of the best lookers put down because of a broken leg or missing hoof!" She laughed a little and then looked her over again and without realising it, she was walking towards the tack shed and came out with the same gear that was on Loco yesterday. Hearing the clinking of the gear, Loco looked up and trotted to the fence line, pretty much begging to be ridden. "Now now, let your poor old mother have a turn, she needs the exercise!" Belinda slipped the saddle on whilst Seal was eating; and then when she was done, slipped the bridle over and placed the bit gently in her mouth. "If you've had it rougher than little Loco over there, then you will be impossible to ride!" she commented, putting on her chaps, climbing into the saddle and unclipping the lead shank. "Yah!" she yelled, digging her heels into Seal's sides and feeling her gather up under her and then taking Seal's sides and feeling her gather up under her and then taking off. "That's the girl! Don't wear yourself out!" she yelled, but the wind just whipped away her words. "Damn, that mare can sure run!" whispered an excited Greg watching from the window. The lady of the house came over. "And y'all sure she is safe up-top that nightmare?" she questioned cautiously, then walked off before awaiting her reply. When they were done, Belinda whipped off the saddle and saw the damage. Seal's sides were layered in sweat and her sides were heaving tring to get air. "What'd I tell you at the beginning, old girl?!" Belinda cried in alarm and ran off to get the accessories needed.

<u>SealSlime</u>

Seal was know known as SealSlime to the family, and the reason was after she was cleaned up after that one ride she was still fine - so they entered her in a real Thoroughbred race and had to have a racing name. They thought about it for three days, and half an hour before the race they were just about to resign when Greg blurted out "SealSlime!" Belinda and the men just laughed and the attendant raised an eyebrow, then wrote her down as number seven. "There you go, with such a hard time getting her in and choosing a name, she'd better do well," said Greg. "Now on ya get and go out to the parading area, we will be there soon." With that, Belinda climbed into the specially made racing saddle and jogged Seal out to the parading area.

[TO BE CONTINUED NEXT MONTH]

LABELS ASIDE By: Jennifer A. Peterson

My son was given the diagnostic label of Autism nearly four years ago. Upon this revelation, I quickly came to see endless similarities between him and myself, as it pertains to our neurologic status. I mostly identify with Asperger's Syndrome. A part of me curses the timing of the DSM additions in 1994 and how I felt chastised by classmates and family members for not acting "normal". At the time, there was no logical explanation for my deficits in executive function, odd sensitivities I had to quash for the sake of escaping ridicule, or shyness that was mistaken for aloofness. Much of life during my college years was sink-or-swim, where many hard life lessons were learned without the benefit of a safety net afforded by disability-related services.

Labels in and of themselves are morally neutral. The rub lies in which school of thought one identifies with. On one hand, families and service providers may put off labeling a person in the hopes of catching up on deficient skills. In essence, this is a gamble on the affected person's future. Labels can have a benefit of securing services and describe a way for someone to belong to a group, if that is their desire.

Sure, there were labels bestowed upon me: weird, lazy, odd, silly, stuck-up or what have you. It has taken a couple of decades, but my life is now relatively comfortable reality I can function within. My years of schooling are behind me and any ill reputation I once had is now wiped clean. In the adult

world, as in the online world, nobody is the wiser.

My behaviors or lack of comprehension of verbal instruction can be explained away by the fact that my young children require more attention at times. Writing is my preferred mode of communication as I do not have to calculate timing, tone of voice, the other person's mood or other variables that trip me up in face-to-face conversation. Of course, there are my special interests to contend with. Over time, I have learned to either keep them to myself or join online groups dedicated to

expounding on these topics.

I have the need to regularly close myself off from the world for a while. There are instances when interaction with people and putting up with sensory overload is unavoidably overwhelming. For example, I find it literally painful to look at bright blue and red contrasted together. (Do you know how many toys are given these colors for the sake of "stimulating a child's brain"? Part of me used to think that toy manufacturers had a Machiavellian slant with that particular color scheme.) Living in old college dormitories and apartments were necessary evils as I heard every sound that carried through the structure. I experienced many a meltdown from this alone.

Sometimes, planning and finding motivation to just get it done are enough stress within themselves to throw me into a fit of anxiety. I have spent more time fixating on an incomplete task than it actually takes to finish the job. Using a day planner and to-do lists have been invaluable aids in prioritizing what

needs to be done.

Other times, I am thankful for not having a label. I have the unwitting ability to prove the "experts" wrong. Without one, I can challenge their beliefs. In the world of the undiagnosed, self-determination is a given; not something to fight tooth and nail or fight bureaucratic red tape for. Yes, I am an adult who can live independently and function within society. I have a college degree. What's this? I even have children and have been called a "good mother" by some. Before starting a family, I held down a career. It is devilishly satisfying to declare that I can promote hope to others who have a place on the autism spectrum. Nobody — not even I — could predict that one day I would give guest lectures in college classes. I would have laughed if someone told me years ago that my confidence in my own abilities would be built up to maintain my family and advocate for my childrens' health and educational needs. The future for my son and others like him is riddled with hope that they can live their dreams and contribute to their community.

Most of this personal success started with taking a risk and stretching the rubber band of my comfort zone. Part of it comes from the admonishment to "act normal" or "fake it till you make it". Okay, so I tried and worked! Most of the time, I can pass with flying colors. At the end of the day though, it is still an act. I rely on people like my husband to let me be myself without ridicule or the impression that I'm not trying hard enough. Like many of the self-diagnosed, there are moments of self-doubt that taunt me. Our experience is validated when we read the likes of Tony Attwood, Shana Nichols and Liane Holliday Willey. We have also been flat-out disbelieved by those closest to us and are reminded of the negative attitudes of others in our earlier years. Sometimes though, glaring moments of validation happen, like when we nearly have a meltdown during a simple trip to the grocery store.

So, what is my label? Take your pick: spouse, mother, Chief Operations Officer of my family, Special Education advocate, author, teacher, occasional daredevil and Aspie. I am all of these. People on the Autism spectrum can, have and will apply these labels to their lives. This happens every day and more than what is reported in scientific journals. The support and belief that we have the same right to life's possibilities as

neurotypicals do is what makes this possible.

There is no off position on the genius switch! - Unknown

Only put off until tomorrow what you are willing to die having left undone. - Pablo Picasso

Be willing to abandon your old ideas if someone comes up with something new and better. - Brian Tracy

Imagination is everything. It is the preview of life's coming attractions. - Einstein

WHEN AUTISM MEETS LOVE by Ashley Weis

I was ten years old when I found out my sister had autism spectrum disorder. Seven years later, I began working with children with disabilities. That's when Alex entered my life.

I worked at a nearby swim school, teaching children to swim. When I put up a flyer to teach kids with disabilities, it didn't take long to develop a packed schedule. Every child I taught impacted my heart in some way, but not like Alex.

When he entered the pool area, every instructor turned their head. I could see their minds forming thoughts like, "This kid learning to swim? I don't think so." Honestly, I thought the same thing.

Strapped to a wheelchair, he entered with his arms twisted under his chin and his legs dangling from the chair. When I approached him, I noticed his eyes focused somewhere behind me.

His grandmother chimed in, "Alex is brain damaged, paralyzed on one side of his body, blind, and deaf in one ear."

"Wow," I thought, smiling up at him.

Lowering him into the pool - with his grandmother's help - I wondered if I'd ever be able to teach him to swim. During our first lesson, I decided to simply play with him and get him used to me and the water.

After his lesson, his grandmother explained that she didn't expect him to learn to swim, she just wanted him to enjoy the pool. That's also when she explained that Alex was severely handicapped because his parents found out he had autism when he was very young. Apparently, they couldn't handle the news.

Alex's parents threw him and beat him, eventually causing brain damage, paralysis on the left side of his body, blindness, and deafness in one ear. Why? Because they couldn't handle autism. I worked with dozens of children with autism, but never encountered something so heartbreaking.

When Alex left the pool that day I found myself fighting back tears, wondering how someone could do that to their child. Images of Alex stayed with me all day. His smile inspired me. After all he had been through, his smile never disappeared.

As the following lesson came closer, I grew excited to see him again. When he arrived, I took him into the deeper water where he couldn't stand, constantly reminding him of what I was doing so he wouldn't get anxious. I spent the duration of the lesson trying to get him comfortable lying on his back in the water.

We floated around the pool with my arms supporting him and I began to talk to him about love.

I asked, "Alex, do you know that I love you?"

His eyes lit up and he responded to the best of his ability, "Yes."

I can recall asking him during one of the last lessons if he knew he was loved. When he replied, "I am loved," my heart raced. "Severely handicapped: with a terrible past, Alex knew he was loved.

Over the next few weeks, he became acclimated to me and started to touch my face to "see" what I look like, but more importantly, he learned to float on his back.

One day after talking, laughing, and splashing around with Alex he gave me a hug and tried to say, "I love you."

That very same day, he swam on his back from one side of the pool to the other... a miracle I never thought possible. To this day, I believe that the more Alex knew he was loved and accepted, the more he believed in himself.

Maybe I'm wrong, but I think his motivation to swim came purely from love. He knew he was loved, and the more he knew that... the more he believed in himself. If only his parents could have known that. If only Alex would have been able to see the water he splashed in.

He couldn't, though. Alex wasn't like the other children at swim lessons. He didn't walk into the pool room swinging by his dad's hand. He wheeled in - his parents long gone from his life. But he smiled a lot more than the other children.

Since my sister's birth, I have had a growing passion for children with autism. When others stare in annoyance at a child in the grocery store having a temper tantrum, I want to help them. But Alex taught me that autism isn't just about helping. It's not just about potty training, learning speech, and behaving in public.

It's about love.

He taught me to love... to look past the disability and see the heart of the child... to stop trying to do something, and be something: an example of love in the lives of children with autism.

Alex entered my life and changed it. He showed me that there is a purpose in everything, including autism. And that's love. Regardless of the circumstances, regardless of the pain - just love.

Since then, I have worked with several more spectrum children, and what I have found with each one is the more they know they are loved, the more they accomplish and the more they believe in themselves. Love goes a long way. It changes people, hearts, and lives.

Beyond the textbooks and training is something much deeper: love. To work with an autistic child and hear them say, "I am loved," is my passion.

When Alex entered my life, I thought I would help him, maybe change his life. What I didn't realize is that he entered the pool that day to change my life - to show me love.

When an autistic child (or any child) meets love, their world is changed forever. They are more motivated and accomplish much more. Alex, a brain-damaged, paralyzed, blind, autistic child, learned to swim... something that, most likely, would have never happened if I focused too much on teaching.

Now, whenever I work with autistic children, my foremost goal is not to increase their speech, develop better social skills, or get them potty-trained - it's to have them walk away able to feel, or say, "I am loved."

Always expect the best and you'll see that the outcome is spontaneously contained in the expectation. - Deepak Chopra

The Eye Contact Issue By: Brian R. King, LCSW Asperger's Ambassador, Social Worker, Consultant, Speaker, Author; www.ImAnAspie.com

Neurotypicals (the average person) are seemingly bending over backwards at the notion that eye contact is an essential aspect of socialization. If that is the case, then by their logic blind people can't have meaningful social interaction either. The fact of the matter is that many Aspies don't use their eyes to socialize the same way neurotypicals do.

I've heard some Neurotypicals say that without eye contact you can't tell if a person is listening to you. My response is "Have you ever heard of asking?" A person can look at you and not be paying attention. In fact, forcing an Aspie who resists eye contact to make eye contact with you can often give you the opposite of what you want. Let me explain. Using myself, the comments I've received from other Aspies as well as several professionals have allowed me to identify at least three main reasons why some Aspies resist eye contact.

The first reason is sensory, usually due to light sensitivity. In a brightly lit room, having your eyes at eye level exposes them to the light which can be painful. Therefore, averting your eyes downward makes it easier to be in the room and avoid the light. Additionally, some Aspies have explained that some people have brighter complexions which make their faces difficult to look at in a brightly lit room.

The second reason is a matter of cognitive processing, specifically unitasking versus multitasking. Aspies are famous for their ability to give their undivided attention to a single task for long periods of time. They may, however, have an extremely difficult time with a task that requires them to repeatedly shift their attention from one thing to another. This challenge with multitasking can be seen with children who freeze up in a room with multiple things happening because it requires their brains to account for multiple streams of information through all of their senses simultaneously.

Therefore, for a unitasking brain, when having a conversation with someone, listening and looking are separate tasks. Which means for many Aspies (including myself) they can look at you or listen to you but they can't do both. Please understand this when demanding someone make eye contact with you. They're not doing it to be difficult or evasive; they're doing what works for them.

The third reason for resisting eye contact is emotional. Considering that eye contact is a way of connecting with people, a way of communicating emotion and allowing oneself to be vulnerable with another person, is it a wonder why many Aspies would avoid it?

With different degrees of social anxiety, Aspies can be very emotionally guarded, insecure and sometimes defensive in social situations and avoiding eye contact is in one small way a means of self preservation in an emotionally threatening environment.

There are ways to determine which of these three areas the most likely case is for the Aspie in your life.

If it is sensory, you will likely see improved eye contact in a more sensory-friendly environment which is quieter and more dimly lit. If a processing issue, they may look towards the eyes of someone they're observing but avert their eyes when interacting with someone they're either speaking to or who is speaking to them because it demands more attention to hear the person and maximize comprehension.

If it's emotional you'll see improvement in eye contact with those with whom they're comfortable, one on one, most often a close family member. However, there are times such as with myself, in which it can be all three reasons.

For the longest time, I made myself make eye contact because I was always scolded in school for not paying attention and was told that looking forward or looking at the person talking to you was the solution. Of course, I found social interactions that much more uncomfortable, I was always missing things my teachers were saying, etc.

Sometimes while looking someone in the eye, I would find myself studying a person's iris which can have a fascinating pattern; which then, of course, causes me to lose track of what they're saying. When I learned of my Aspiness and sensory sensitivities as an adult and the toll eye contact was taking on me, I made the decision to be more respectful of myself and no longer cause myself such undo suffering by making myself make eye contact. Yes, there was a backlash at my place of employment as people told me how if I was able to do it before I should do it again. Others told me it was unprofessional to avoid eye contact.

In the minds of my former coworkers, it was more important for me to socialize on their terms even if it was at my expense. You wonder why Aspies avoid socializing when the bar is held inflexibly high at times. Nowadays, I avoid eye contact entirely when in one time interactions such as the grocery store. My eye contact is sporadic when interacting with clients. When having a lengthy conversation with someone who doesn't know me that well, I'll use a variety of disclaimers.

If the room is bright, I'll mention how bright the lights are so it makes sense that I'm turning my eyes away. If it's more of a unitasking issue you can simply say "It's easier for me to think about what you're saying if I look away and focus on listening." If it's emotional, you can simply say you're shy when meeting new people.

The more I force myself to make eye contact, the more difficult socialization becomes. My eyes begin hurting if I look too long, usually less than a minute. In longer conversations requiring a lot of eye contact, I begin to get a headache. More often than not, I become distracted by my discomfort and begin wondering when the conversation will end instead of listening. In short, no eye contact is better for myself and the speaker if listening is to take place.

However you choose to handle the eye contact issue, I implore the Neurotypicals of the world to give us a break and ideally drop the issue altogether. When interacting with Aspies, rely more on words for communication and less on nonverbal interaction such as your eyes, and I assure you that you'll have much fuller communication with us.

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A loving heart is the truest wisdom. - Dickens

Don't say you don't have enough time. You have exactly the same number of hours per day that were given to Helen Keller, Pasteur, Michelangelo, Mother Teresa, Leonardo da Vinci, Thomas Jefferson, and Albert Einstein. - H. Jackson Brown, Jr.

It takes a thousand voices to tell a single story.

- Native American Proverb

Can Figurative Language Skills be Taught to People with Autism? By Kathie Harrington, M.A., CCC-SLP http://blog.kathiesworld.com/

As people on the autism spectrum (ASD) grow in so many ways, the area of figurative language, idioms, sarcasm, jokes, has always been a complex and arduous area for them to understand as well as for professionals and parents to teach. Whichever side of the table you are on, it isn't easy.

As a speech-language pathologist (SLP) and the mother of a grown son with "high functioning autism", I've always felt that my son, Doug, has received the most speech therapy introduced to any human being in the civilized world! Within that focus of language has, of course, been figurative language skills by the bucket loads. I wasn't sure if it was ever going to stick in Doug's noggin that everything that is said can't be taken literally. As ASD people grow older, the demand for the understanding of this kind of language intensifies in the work environment, among peers, in movies, and anywhere that life takes them. When they miss the cues in life, that life passes them by.

I have wonderful news for all of you parents, employers, speech pathologists, psychologists, brothers, sisters, aunts, uncles, grandparents, etc. PEOPLE WITH "HIGH FUNCTIONING AUTISM" and ASPERGERS DO EVENTUALLY LEARN FIGURATIVE LANGUAGE SKILLS! They are not only capable of learning them and understanding them, but using them and creating new ones on their own.

I know first-hand how important it is to start by "planting seeds" of figurative language in the fertile area of the brains of children with autism. We must start early by giving our children choices which enable them to make decisions and to be independent as they grow older. We need to laugh with them and ask "what's silly about that?" (e.g., "I went to the post office to pick up some milk today" or "That kitten just barked at me"). This will give them the ability to see humor, understand language, and learn that words can change meaning. We teach individual idioms such as "it's raining cats and dogs", but we don't have to teach every idiom in the English language. Generalization can and will prevail.

Today, my son, Doug, who is 37 years of age, works full time on the Las Vegas Strip at the premiere Five-Star, Five-Diamond Resort, "The Wynn Las Vegas". He not only understands his fellow workers, he jokes with them, teases them, and uses idioms all of the time. He creates his own idioms in describing his day to his family.

Communication is THE most important aspect of a person's life. Yes, as a mother and SLP I may have waited a long time to see that figurative language shine and thrive in my son, but the journey has been worth it. After all, "life is just a bowl of cherries."

A Page of Quotations and Wisdom:

The virtue lies in the struggle, not in the prize. - Milnes

Good instincts usually tell you what to do long before your head has figured it out. - Michael Burke

If you have much, give of your wealth; if you have little, give of your heart. - Arab Proverb

A child's education should begin at least one hundred years before he is born. - Oliver Wendell Holmes, Sr., poet, novelist, essayist & physician (1809-94)

We must adjust to changing times and still hold to unchanging principles. - Jimmy Carter

Every action in our lives touches on some chord that will vibrate in eternity. - Edwin Hubbel Chapin

If you believe tomorrow holds the answer to all of your problems, I want to remind you that's what you said yesterday. - Bob Perks

A great pleasure in life is in doing the things which people say you can not! - Yuvraj

This is the true joy in life, the being used for a purpose recognized by yourself as a mighty one; the being thoroughly worn out before you are thrown on the scrap heap. - George Bernard Shaw

I believe I found the missing link between animal and civilized man. It is us. - Konrad Lorenz, ethologist, Nobel laureate (1903-89)

We can escape the prison of our own beliefs and enter the Palace of Possibilities when we allow ourselves to be astonished by everything. - Gary Craig

Losers see thunderstorms, winners see rainbows; losers see icy streets, winners put on their ice skates! - Denis Waitley

Why do people accept the opinions of others about themselves as truth? Who is going to live the rest of your life anyway? Now THAT is TRUTH! - Doug Firebaugh

An Announcement and Request from Shana Nichols, Ph.D.

Hi everyone,

It has been great hearing everyone's response to our book Girls Growing Up on the Autism Spectrum What Parents and Professionals Should Know about the Pre-Teen and Teenage Years and in particular, we've been receiving requests for a companion guide for the girls themselves. So, we've started working on one!

We are seeking advice, suggestions, comments etc. from girls, teens, and women with ASDs on all the topics in our first book including:

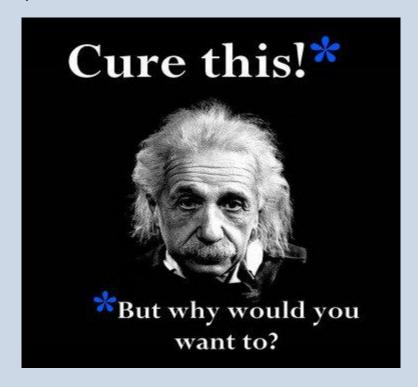
- 1. what it's like being a female with AS
- 2. strengths and interests
- 3. handling adolescence and puberty
- 4. menstruation
- 5. fashion
- 6. hygiene and grooming
- 7. social skills and frienships and bullying
- 8. sexuality and dating
- 9. mental health, self-esteem
- 10. personal safety
- 11. gender, media, culture, society expectations

Also, poetry or drawings!

I can be reached through email if you are interested: drshananichols@gmail.com

Thanks! Look forward to hearing from you,

Shana Nichols, Ph.D.



<u>Time For Einstein</u>:
Only a life lived for others is a life worthwhile.

True religion is real living; living with all one's soul, with all one's goodness and righteousness.

Peace cannot be kept by force. It can only be achieved by understanding.

The man who regards his own life and that of his fellow creatures as meaningless is not merely unfortunate but almost disqualified for life.

When the solution is simple, God is answering.

The most beautiful thing we can experience is the mysterious; it is the source of all true art and science.

Science without religion is lame. Religion without science is blind.

I want to know God's thoughts; the rest are details.

AUTISM FROM THE INSIDE OUT by Sharisa Joy Kochmeister January 26, 2008 revised 8-09

In a news story, the following was reported:

"Genetic flaw appears to increase risk of autism" Updated Wed. Jan. 9 2008 5:04 PM ET CTV.ca News Staff: "Researchers have made an important discovery in the search for answers in the mystery of autism. They've identified a genetic flaw that appears to increase one's susceptibility to the condition. The researchers found that a segment of chromosome 16 is either missing or duplicated in about one per cent of individuals with autism or related disorders.

That may not sound like much, but the study's senior author, Dr. Mark Daly, of the Massachusetts General Hospital Center for Human Genetic Research, tells CTV News that those people who have this chromosomal abnormality have 'a very, very high risk of autism.' In fact, kids with the chromosomal abnormality have a 100-fold increased chance of developing autism than kids without it.

What's more, the researchers found that the gene flaw does not appear to be inherited. In the autistic kids the researchers identified who had the flaw, none of their parents had it as well.

'This tells us this is a spontaneously rising mutation,' says Daly.

Dr. Steven Scherer, a senior scientist in Genetics & Genome Biology at Toronto's Hospital for Sick Children says that will come as good news to many parents of autistic children. 'We can actually tell the families – it's not your fault. It's just something that happens randomly, a genetic roll of the dice,' he says.

I actually shrieked when I read this AND AM STILL AGHAST MORE THAN A YEAR LATER!!! How dare they assume that a gene mutation is a "flaw" or a bad thing that needs fixing when evolutionary theory and history both tell us that good mutations improve the species while bad mutations are eliminated via natural selection? Darwin must have spun in his grave, as did Einstein, Edison, Van Gogh, Da Vinci and countless other genetically flawed mutant geniuses! To me this kind of bias compares with things such renowned geniuses as Hitler and Mengele believed. Perhaps civilization needs us "mutants" to fix what's so clearly wrong with this planet and the attitudinally challenged "non-mutants" who inhabit and control it! Their track record, after all, is not so good, to put it QUITE mildly.

Before we talk about "curing" autism, maybe we need to figure out what it is and how we define it! In my point of view, autism is a mystery - a dilemma - a puzzle - an enigma - a conundrum - a curse - a gift - NOT a "disease" in need of a "cure"! This is why I

repeatedly argue that we should "CURE MEAT and TREAT PEOPLE!" I do NOT have a DISEASE – I have DIS-abilities as well as ABILITIES that cause UNEASE – generally to others more than to myself!

People need to study autism, communication, neurology, intelligence, etc., before DARING to assume and presume they know of what they speak. I am a former user of Facilitated Communication (FC), an admittedly controversial technique, who became an independent typist after three years of being facilitated. Over time, I went from being considered profoundly retarded, severely autistic and unable to learn with no hope of ever communicating to having my IQ test at a genius level, graduating high school with honors, having an Associates degree with honors from a community college and a dual Bachelor's degree from an esteemed university with honors, being a published author and composer and in-demand presenter at conferences and colleges AND HERE I AM TODAY! I just also happen to USE the augmentative communication device known as a Lightwriter and other devices and can assure you they are not only very valid and accepted devices, but often also very expensive pieces of equipment that Medicaid and insurance pay for as a medical necessity and school districts pay for as an educational aid. Therefore, I say to those who doubt to please do some real research and keep an open mind or you fail to give people who most deserve and need it the benefit of the doubt.

In my case, my abilities were tested and documented by courtordered, school district, and psychologist blind testing and I still have NEVER stated that FC works for EVERYBODY – NOTHING works for EVERYBODY – a simple pill can poison one as easily as treat one's illness – but I DO resent the implication that it works for NOBODY!

If you went into a situation where "incredulity" and doubt would only allow and even guarantee failure, what do you think the result might be? If you were forced to prove yourself, your intelligence, your sentience and your credibility by non-believers and skeptics, would that make it easier or harder? Have you ever even remotely considered that the person you try to deny might not LIKE you or feel comfortable sharing with you, and/or might have picked up on your "incredulity" and doubt and obvious negative bias – I certainly pick up on it whenever I encounter it.

Lastly, if I and other FC users and former FC users have graduated with honors from colleges and universities and have degrees in various areas of study and have been appointed to state boards,

been invited to the White House by the President, won advocacy awards, spoken at many professional conferences as presenters & keynote speakers, serve as adviser to medical and professional and disability organizations, are published author, performed composer, gifted artists and scientists and educators, consultants and communications trainers, and have testified as EXPERT witnesses before Congressional Committees and state legislatures and attorneys general, did we "scam" them all into trusting us and believing in us or perhaps do they value us for our clear expertise in autism and other disabilities? Please feel free to discuss, challenge, comment, prognosticate, pontificate, define, etc.

The bottom line for me is that what we need to truly celebrate in life is life itself and its diversity... the hope and joy that is part of being human... what I call the "Evolution Revolution"! Challenges are not obstacles unless one allows them to be and accepts them as such – and even if most of my life has far too often felt like an "obstacle course", I am glad to have risen to the challenges, leaped the barriers, climbed the walls, walked the tightropes, conquered the chasms, and learned to embrace my autism and its gifts along with any inconveniences! So, PLEASE, "cure" my epilepsy, "cure" my cerebral palsy, "cure" whatever causes me horrific physical and emotional pain, BUT treat the person I am –don't dare to talk of "curing" my autism or ME! I am, after all, what I am meant to be – and if I can accept YOU for who you are, I expect no less. One has to accept oneself if one desires the acceptance of others!

I truly enjoy expressing my feelings via poetry, so here's a poem:

CHALLENGED

Copyright Sharisa Joy Kochmeister 1-9-08

It's a challenging world
In which we live
With challenging people
And challenging ways -

And I hope to remember it
Fondly with humor
When I look back on it
One of these days!

AUTISM: Learning From Each Other by
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It has been more than 30 years since the enactment of Public Law 94-142, the landmark legislation guaranteeing a "free and appropriate" education for handicapped children. At the time, I was a fifth year elementary school teacher in a "regular" public school classroom, the students of which spanned academic, emotional, and social continuums ranging from the mainstream to what today would be considered impaired. There was virtually nothing in the way of specialized programs, classrooms or services. But with the new law came a surge of funding for special accommodations. It was exhilarating.

Over the years, the terminology has changed with the shifting winds of political correctness. CRMD or "children with retarded mental development" morphed into cognitively impaired and then **Emotionally handicapped became** developmentally challenged. with "severely emotionally disturbed." SED, Academically delayed was redefined as LD, "learning disabled." The term special education itself went through an evolutionary process, with one common current definition being ESE, "exceptional student education." But the designation of the one handicapping condition that did not change, simply because until somewhat recently it was seldom seldom referenced, touched upon in educational, psychological or health care circles, is autism.

Reflecting upon a 40 year career in education, which included classroom, counseling, research, and administrative experiences in regular and special settings, in both the public and private domains, it's apparent to me that no other condition has not only been so overlooked, so swept under the rug, but also so misdiagnosed. And at the risk of taking umbrage with a great deal of dedicated and well meaning individuals whose lives have been touched in one way or another by autism, I do not believe that the absolute number or percentage of children with autism has increased over the years. Previously, they were simply grouped within an all-inclusive definition of special needs children. Over the years, however, as the acknowledged autism spectrum expanded from high to low functioning, so did the numbers.

I recall one particular incident that would serve as my own personal template for the ignorance associated with autism, and incredibly it came from a professional in the field. I was chairing a committee meeting, the purpose of which was an annual evaluation of a child in an autistic class. After observing the child, a visiting psychologist insisted that she was retarded and wanted her placed in a CRMD setting. After all, she could not speak, made little or no eve contact, was behavioral, and displayed certain unusual physical movements that seemed to have no apparent external stimuli. At that point I stopped the meeting, went to the classroom and brought the young girl back into the room along with a rather large and challenging jigsaw puzzle. I scattered the pieces on the table, and the girl proceeded to assemble them with lightning speed. finished, I asked the psychologist whether this was "normal" behavior for a "retarded" child, whether there was a severe cognitive delay here, or whether this was a different, yet sophisticated skill set of a bright individual. Needless to say, the reevaluation did not end with CRMD eligibility, rather with a continuation of autism. But looking back, I cannot imagine how many autistic children were so misdiagnosed, so mislabeled, and eventually placed in inappropriate settings.

I was given a more universal perspective about autism and the wall of apprehension surrounding it in my capacity as an intake coordinator for a large non-public organization servicing children and young adults with a wide range of disabilities. description involved observing potential clients and interviewing family members in order to develop case histories. Finally, I would make a recommendation for placement in the most appropriate least restrictive setting. Many parents vehemently rejected an eligibility of autism, regardless of how apparent it was; the diagnosis was simply too stigmatizing, too fear-filled. Privately, I referred to it as the "A" word. Given that resistance to signing off on a diagnosis and placement, the number of defined autism cases was kept statistically In time, however, with the recognition of a broader-based definition of autism and a more enlightened public, that ignominious The diagnosis was no longer so intolerable, increasing the number of documented cases. In fact, a sea change has recently occurred, with many parents now embracing the eligibility, since it comes with an array of services critical to the effective treatment of those falling within the spectrum.

It is interesting that after what I thought was my permanent retirement, I was asked to come back for another full-time job in

education, that of a teacher. By accepting the assignment, I had gone full circle, starting in the classroom and then moving through the administrative/supervisory hierarchy. Reconnecting with the grassroots educative process turned out to be a good place to be. I was assigned to a class of six autistic children, all of whom were non-verbal and considered to be on the lower end of the functioning continuum. I was in the room with four teacher aides and a full-time behaviorist. These were very talented professionals and it quickly dawned on me that we were a family of twelve. R.D. Laing, the British psychiatrist who was influential in the sixties and seventies, came to mind. He encouraged therapists to "live" with their clients in a therapeutic environment. I learned to live with those children. And rather than the more traditional instructional model in which the teacher seeks to bring the autistic student into his or her "normal" world, my goal became one of sharing worlds. I tried to think, live and interact autistically while, at the same time, encouraging the children to think, live and interact "non-autistically. In time, I found this melding of worlds to be the most effective way of reaching each other.

At its core, autism is a communication disorder; and as of late, there is a great deal of activity directed at finding a cure. I am not sure about a particular path to take concerning this endeavor but, if in treating its symptoms, there may be the seeds of a cure, then two-way communication between the autistic and those close to them could point to a long awaited breakthrough.

* * * * *

BTO:

Howard Karlitz is a teacher and administrator who has been deeply involved in both special and regular education for more than 40 years. Additionally, he has taught courses in education, organizational psychology, research methods and counseling at the college level and has been extensively published. He earned a Bachelors Degree at Queens College in New York, a Master of Science Degree at the City University of New York, and a Masters and Doctor of Education Degree at Teachers College, Columbia University.

* * * * *

The Art of Being Van Gogh:

As we advance in life it becomes more and more difficult, but in fighting the difficulties the inmost strength of the heart is developed.

Conscience is a man's compass.

Do not quench your inspiration and your imagination; do not become the slave of your model.

Even the knowledge of my own fallibility cannot keep me from making mistakes. Only when I fall do I get up again.

For my part I know nothing with any certainty, but the sight of the stars makes me dream.

Great things are done by a series of small things brought together.

Happiness... it lies in the joy of achievement, in the thrill of creative effort.

How can I be useful, of what service can I be? There is something inside me, what can it be?

I dream of painting and then I paint my dream.

I experience a period of frightening clarity in those moments when nature is so beautiful. I am no longer sure of myself, and the paintings appear as in a dream.

I feel that there is nothing more truly artistic than to love people.

I often think that the night is more alive and more richly colored than the day.

I put my heart and my soul into my work, and have lost my mind in the process.

I see drawings and pictures in the poorest of huts and the dirtiest of corners.

I wish they would only take me as I am.

If one is master of one thing and understands one thing well, one has at the same time, insight into and understanding of many things. If you hear a voice within you say "you cannot paint," then by all means paint, and that voice will be silenced.

It is better to be high-spirited even though one makes more mistakes, than to be narrow-minded and all too prudent.

In spite of everything I shall rise again: I will take up my pencil, which I have forsaken in my great discouragement, and I will go on with my drawing.

It is not the language of painters but the language of nature which one should listen to, the feeling for the things themselves, for reality is more important than the feeling for pictures.

Love always brings difficulties, that is true, but the good side of it is that it gives energy.

One must work and dare if one really wants to live.

Love many things, for therein lies the true strength, and whosoever loves much performs much, and can accomplish much, and what is done in love is done well.

Love is something eternal. The aspect may change, but not the essence.

One may have a blazing hearth in one's soul and yet no one ever come to sit by it.

Passersby see only a wisp of smoke from the chimney and continue on the way.

Paintings have a life of their own that derives from the painter's soul.

Poetry surrounds us everywhere, but putting it on paper is, alas, not so easy as looking at it.

The fishermen know that the sea is dangerous and the storm terrible, but they have never found these dangers sufficient reason for remaining ashore.

The more I think about it, the more I realize there is nothing more artistic that to love others.

The way to know life is to love many things.

What would life be if we had no courage to attempt anything?

What, indeed? - Sharisa Joy

Instead of noblemen, let us have noble villages of men. - Thoreau

Why don't you want to do what you know you should do? The reason is that you're in conflict with yourself. - Tom Hopkins

Growing old is mandatory; growing up is optional. - Chili Davis

Yesterday's home runs don't win today's games. - Babe Ruth

There is only now to do what you dreamed a lifetime to begin. There are no more excuses and no better time. - Bob Perks

Imitate until you emulate; match and surpass those who launched you. It's the highest form of thankfulness. - Mark Victor Hansen

The world is full of poetry. The air is living with its spirit; and the waves dance to the music of its melodies, and sparkle in its brightness. - Percival

The ability to adapt is everything! - Denis Waitley

Chantelle Jary "is a happy mum of 2 remarkable boys. One is called Jackson (who is confirmed as living on the spectrum), aged 3 years and 10 months and the other is Hunter, who is 19 months old and adorable beyond belief (but cheeky cheeky cheeky). Chantelle is married to Andrew and we all live in Kurrajong, NSW, Australia."

Autism Mum by Chantelle Jary

Jackson was assessed developmentally and diagnosed with moderate Autism in August last year and also had a severe speech and language delay and a global developmental delay. Chantelle is pleased to report that within a year, Jackson is now testing as having no speech and language delay and no developmental delay but is still within the lovely, colourful, quirky, diverse and spectacular Autism Spectrum criteria.

Jackson is a happy member of our family and it is our aim to help him remain that way..... Who he is and..... Happy."

Here I sit and wonder where my son's "fidget" could possibly be and quietly panic about our visit to preschool this afternoon to watch him do a singalong performance with his "peers." By "fidget", I mean his little wooden fidget toy he likes to hold and caress when he feels anxious and likes to keep in his pocket at all times for this very purpose. It's missing. By singalong performance, I mean the songs he has been learning at preschool which are to be performed by the children in a special end of term show for the parents and grannies. My son will not be performing in that one. The one I am going to today is a "pretend" performance and I am the only parent in attendance so Jackson is less likely to feel anxious and have a meltdown. The "real" performance is next week and Jackson will be sitting out of that one and instead having quiet time in a different part of the preschool with his teacher's aide. By "peers", I mean the other children in his class. You know, the "typical" or in less politically correct terminology, the "normal" kids, the same age as my son. Which part of this opening paragraph hurts my heart the least I wonder now, in addition to wondering where that damn fidget could possibly be?

My son has Autism. These days it's known as Autism Spectrum Disorder. I don't like that term. Why disorder? I've been doing a whole lot of reading lately and thinking disorder is not really fair. I'm starting to think difference is so much lovelier than disorder but really it's all just semantics when you get down to how it's viewed, regardless of the official label stamped upon my child's head or the official box he is shoved kicking and screaming into each day... We

like, "living on the spectrum." Nice. It sounds colourful, mysterious and quite unique. It's perfect for my boy. It sums him up. We also like, "quirky." That's succinct and ambiguous all at the same time. That also fits my boy.

The reason I ponder the semantics is this. Imagine being highly intelligent, aware, bright and desperate for social contact and relationship-connectedness but confused about how to achieve this every minute of your waking life. Imagine knowing exactly what you want and how you want to acquire it, but being continuously told your approach is wrong. Imagine telling people exactly how you feel, think and what's on your mind, only to be "corrected" and expected to conform to being something else which is unnatural and neurologically uncomfortable for you. ALL OF THE TIME. Imagine. Then imagine you grow up being told you are disordered or disabled. Can you imagine? I can but it hurts. It hurts me in that damned heart again.

Here is my long-term struggle. How do I raise my boy with inner confidence, self love and pride in his uniqueness? This is probably a question every parent asks themselves. How do I make my child happy? That's the short version of the same question I think. There in itself is another quandary. What on earth is "happy"? My happy is a wide social circle, lots of outings, catching up with friends all the time, hustle bustle, noise, music, food, laughter, spontanaiety, change, go go go... That's happy for me. Me. Everyone's happy is different but when you find yourself with a child of neurological difference, suddenly everyone is apparently much happier being the same... This is what the experts think. At least that's what I think they think. I'm so confused now, I'm really not sure what anvone thinks. If fitting into this so called "real world" will make my child happy, I'm all for it. But we get back to happiness being different for everyone including my special child of neurological difference. My version of happy would be a nightmare for my child.

hustle bustle, food, people, change... Oh my God!!! Change! Not happy at all for Jackson. He seems most comfortable when things are the same, routine and predictable. My version of happy seems not to be his at all. Apparently though, the "real world" is unpredictable, hustle bustle, noise, people, etc. He must get used to the real world. He really must learn to conform. He is bright and "high-functioning", which incidentally is yet another label I detest, as it's so cold. Lacking. Inadequate. To describe people's level of functioning as the essence of how they are living their life is quite insulting I think. What the hell do they mean by functioning? I have come to realise they mean how well he fakes being "normal" out there in that real world again. The level of his functioning and

ability to pass off as "normal" in a social scene is supposed to be what will lead him to emotional happiness. I am not so convinced.

The decisions ahead of this family fill me with angst. What is the best course to take, how do we decide which of the numerous therapies available out there will promote improved communication abilities, foster self confidence and keep the integrity of Jackson's differently functioning soul intact? Is there even such a therapy out there and exactly what are we "therapizing" this divine child for? Which aspects of his personality and soul *require* therapy in the first place?

If it was up to me, I'd put him in a protective bubble and never expose him to the harsh "real world" the experts keep telling me he must be prepared for. I'd home school him and surround him with only like-minded people and peers. He'd never have to face being teased in the playground, feeling stupid after a less than understanding person, or worse, a teacher, belittles him. He would never ever experience self-loathing or the pain of knowing he does not quite fit into the rest of the crowd. He would only ever be celebrated and applauded for his difference, his courage, his abilities and his strengths. If it was up to me, this is the perfect "real world" I would build for him.

Easy. So if I feel this way, why don't I make it happen this way? What happens when I'm gone? Who will keep up this charade for him? Who will create the perfect world and keep him safe like I can? The concept reminds me of the Jim Carrey movie, "The Truman Show." A completely scripted and staged world of perfection and happiness but no amount of altered perfect reality made Truman happy in the end and it was impossible to maintain anyway.

The true reality is that there is no one who can keep him completely protected and safe in the emotional sense. Not even me. This world does not and cannot exist no matter how much I would like it to. I guess emotional strength and safety comes from emotional growth, lessons learned, experience shared. I guess we all have to live through challenges and even pain to understand and appreciate the achievement of overcoming them.

So does this mean I have to "normalise" him and send him out to typical school and teach him to fake it until he makes it? Maybe. I live hoping not. I live hoping that there is a happy medium to be found. Perhaps it has not been found by anyone else yet and it's up to me to find it or create this medium. Perhaps I can trust in myself, my instincts and my beautiful boy to make this happy medium our reality.

In the meantime, I try out different early intervention approaches always thinking in the back of my mind I am not even sure we

should be intervening anyway. My current reality is that we must jump through set hoops to receive support, funding and help. Boxes must be ticked, forms must be signed and professionals need to be called in for intervention so we can continue to receive support for a little boy who admittedly does need some help feeling comfortable and secure in any reality. Make no mistake though, I don't think my boy fits in any ticked box and it's my mission to make sure his "intervention" is approached in a rather left of centre manner with this in mind. We still jump through the hoops, we sign the forms and we play the support game for now. I try to intervene in the least damaging and the least soul-altering way whilst working with his difference, not trying to save him from it. I don't think it's wise to adopt the attitude to change my child. I simply want to support him. With this in mind, we are attempting a not so traditional approach to finding our own happy medium.

I still take him to speech therapy to help him improve his perceptive language skills but have made it clear the therapist needs to work outside the usual speech pathology box. He is not made to sit down for half an hour of structured table work - a task that he has no chance at succeeding at at this point. To sit anywhere and complete a half hour task would be difficult for any three year old boy but a three year old boy with attention span difficulties and anxiety issues makes this expectation impossible to achieve, in my opinion. Is it so difficult to set our children up for success? I do not think so. Surely, we can find a more flexible approach which will motivate our children to try for success and then go on and achieve it. We do not attempt the desk work anymore. Instead, Jackson is almost "training the trainer" in learning a different approach that suits him; and together, the therapist and I work on language whilst playing with Jackson with items he is interested in. I am the one who receives the speech homework instead of Jackson to assist him developmentally at home.

We do occupational therapy; but again, I found a clinic that specialises in a child-centred approach and that works on his sensory defensiveness, his relationship building skills, his emerging ability to self-regulate so as to avoid meltdown and his ability to connect with people; and they do not focus on the traditional fine motor "problems" like his pencil grip. Is this the right course of action? I don't know. I do know that I think his ability to interact with another person and share a moment of his happiness with them whilst learning to build relationships and connections seems like a more important goal than correct pencil grip and learning to place pegs on a board to assist fine motor skills. My goals for Jackson's preschool was not to focus so much on him learning to write his

name (a skill I am sure he will master in his own time), cut with scissors or that damned pencil grip hang up again.

The goals we set for the preschool were all about teaching my special boy to ask a friend to play with him, to show him how to approach a game and join in gracefully, if he wants to. Apparently my approach and goal-setting standards are not the "norm" but isn't that kind of the point? Have we not worked out by now my boy is not this so called "norm" either? Is this not what the diagnosis of his perceived "disorder" is all about? Why tick the box and stamp him differently, if he is then just expected to fit into the "normal box" anyway? Sitting on the mat for extended periods of time in complete meltdown mode whilst other kids wriggle about or the ceiling fan overhead whirrs annoyingly above him, distracting him from any ability to concentrate on a story or a song when he is in sensory overload are no longer ordeals I care for my child to go through daily. Instead, the preschool came up with a small group for Jackson to do stories and music. He invites two friends to accompany him to a less overwhelming space in the preschool and they read an interactive story with Jackson's teacher's aide. With support and a bit of lateral thinking I am slowly becoming more hopeful the happy medium is out there to be discovered.

I have said many times that I do not wish to change my son. He is perfect. I would love to change the world he is growing up in, though. I realise I probably sound naive and unrealistic. Reality in my neurotypical "real world" does not interest me anymore anyway. My boy has taught me to look at reality differently. He has taught me the only true reality is my overwhelming and all-consuming love for this incredible individual. He has taught me it is my job to educate others to accept and embrace difference. He has taught me I am capable of raising him and his brother with a strength I only recently realised I had. He has taught me to find joy where I would never have believed it was possible to find. The singalong at preschool was joyful. We found the fidget and he sung happily alongside his "normal" peers. We found the happy medium with Jackson's help and guidance. Do I still mourn for his future and the uncertainty of which are the right decisions? Do I still have bad days and wonder what his reality will be? Of course!

The difference now is I accept difference. I accept it and I embrace it. My quirky Jackson living on his colourful spectrum taught me this. I am still worried for his future and his own experience of reality out there in that "real world" he must enter at some stage but I am also excited to find more joy along the way.

He is one hell of a kid.

Chantelle and Her Boys ©











Thinking In Abstracts - Thoughts of Giants:

Isaaac Newton:

I keep the subject of my inquiry constantly before me, and wait till the first dawning opens gradually, by little and little, into a full and clear light.

If I have ever made any valuable discoveries, it has been owing more to patient attention, than to any other talent.

Tact is the knack of making a point without making an enemy.

I do not know what I may appear to the world; but to myself I seem to have been only like a boy playing on the seashore, and diverting myself in now and then finding a smoother pebble or a prettier shell than ordinary, whilst the great ocean of truth lay all undiscovered before me.

If I have seen further it is by standing on the shoulders of giants.

- Newton, Letter to Robert Hooke, February 5, 1675

DaVinci, Notebooks (c. 1500):

Obstacles cannot crush me. Every obstacle yields to stern resolve. He who is fixed to a star does not change his mind.

Jules Verne:

Anything one man can imagine, other men can make real.

Whatever one man is capable of conceiving, other men will be able to achieve.

Travel enables us to enrich our lives with new experiences, to enjoy and to be educated, to learn respect for foreign cultures, to establish friendships, and above all to contribute to international cooperation and peace throughout the world.

Science... is made up of mistakes, but they are mistakes which it is useful to make, because they lead little by little to the truth.

Others:

Life has an expiration date and every day in the present is a present. - Anon

When you were born, you were crying and everyone around you was smiling. Live your life so that at the end, you're the one who is smiling and everyone around you is crying. - Anon

Whenever catching sight of others, look on them with an open, loving heart. - Patrul Rinpoche

Poetry is the overflowing of the Soul. - Henry Theodore Tuckerman

From The Inventive Mind of Edison:

I never perfected an invention that I did not think about in terms of the service it might give others... I find out what the world needs, then I proceed to invent....

I readily absorb ideas from every source, frequently starting where the last person left off.

Genius is one per cent inspiration and ninety-nine-percent perspiration. Accordingly, a "genius" is often merely a talented person who has done all of his or her homework.

The first requisite for success is to develop the ability to focus and apply your mental and physical energies to the problem at hand - without growing weary. Because such thinking is often difficult, there seems to be no limit to which some people will go to avoid the effort and labor that is associated with it....

Inspiration can be found in a pile of junk. Sometimes, you can put it together with a good imagination and invent something.

Our schools are not teaching students to think. It is astonishing how many young people have difficulty in putting their brains definitely and systematically to work....

Personally, I enjoy working about 18 hours a day. Besides the shortcatnaps I take each day, I average about four to five hours of sleep per night.

If we all did the things we are really capable of doing, we would literally astound ourselves....

I have far more respect for the person with a single idea who gets there than for the person with a thousand ideas who does nothing.... Unfortunately, there seems to be far more opportunity out there than ability.... We should remember that good fortune often happens when opportunity meets with preparation.

Surprises and reverses can serve as an incentive for great accomplishment. There are no rules here, we're just trying to accomplish something.

The only time I really become discouraged is when I think of all the things I would like to do and the little time I have in which to do them.

The thing I lose patience with the most is the clock. Its hands move too fast.

Time is really the only capital that any human being has and the thing that he can least afford to waste or lose...

The doctor of the future will give no medicine, but will interest his patients in the care of the human body, in diet, and in the cause and prevention of disease.

From his neck down a man is worth a couple of dollars a day, from his neck up he is worth anything that his brain can produce.

Whatever the mind of man creates, should be controlled by man's character.

Someday, man will harness the rise and fall of the tides, imprison the power of the sun, and release atomic power.

I am both pleased but astonished by the fact that mankind has not yet begun to use all the means and devices that are available for destruction. I hope that such weapons are never manufactured in quantity.

The dove is my emblem.... I want to save and advance human life, not destroy it.... I am proud of the fact that I never invented weapons to kill....

To me, the idea and expectation that the day is slowly and surely coming when we will be able to honestly say we are our brother's keeper and not his oppressor is very beautiful.

Until man duplicates a blade of grass, nature can laugh at his socalled scientific knowledge....

It's obvious that we don't know one millionth of one percent about anything.

We have merely scratched the surface of the store of knowledge which will come to us. I believe that we are now, a-tremble on the verge of vast discoveries - discoveries so wondrously important they will upset the present trend of human thought and start it along completely new lines.

If parents pass enthusiasm along to their children, they will leave them an estate of incalculable value....

Life's most soothing things are a child's goodnight and sweet music....

Even though I am nearly deaf, I seem to be gifted with a kind of inner hearing which enables me to detect sounds and noises that the listeners do not perceive.

And Others:

Good thoughts bear good fruit, bad thoughts bear bad fruit - and each of us is a gardener. - Unknown

Doubt yourself and you doubt everything you see. Judge yourself and you see judges everywhere. But if you listen to the sound of your own voice, you can rise above doubt and judgment. And you can see forever. - Nancy Lopez

All real education is the architecture of the soul. - William J. Bennett

Jane Strauss - Bio/Resume janestrauss@janesprints.com

I first picked up a camera in the late 1960s on the East Coast, when at the age of 15, I learned to shoot and develop 35 mm black and white film. I've been enamored of graphic arts ever after. Since then, I have tried to be practical, pursued multiple academic courses of study, relocated to the Twin Cities in the mid-1970s, raised a family, worked with community organizations, nonprofits, and in the practice of law, before returning to my first love, art. As a digital photographer, I am largely self-taught, only beginning to work at that craft in 2004, after my eldest daughter had become an artist and teacher in the medium.

My art flows from who I am, a person placed on the autistic spectrum in midlife who has often wondered why I see detail many folks miss. I look at the trees and the forest, and see the geometric shapes between and within them. I wait for the animals to settle, and come right up to them for a look. I notice small details and parts of things that for the usual person blend in with their surroundings. I look up to the sky when many would look down or straight ahead. I focus on reflections. Once images are digitized, I use Photoshop to crop, enlarge and adjust them to reflect what I saw, rarely using other aspects unless they substantially strengthen the primary image, or provide a strongly-contrasting accompanying image.

Recognition

Richard Owen, MD Award, Photography, Sister Kenny International Art Show, 2009

Honorable Mention, Photography, Sister Kenny International Art Show, 2008

Several blue ribbons, Hennepin County Fair 2006

Sweepstakes award for County fair photography, Hennepin County Fair, 2006

Multiple Blue, one Purple ribbon Hennepin County Fair, 2005

Show Locations to date:

Solo:

Gallery and Public

- Bohlander Arts Gallery, Minneapolis 2008-09
- The Warren, Minneapolis 2007
- Thrivent Financial Skyway Gallery, Minneapolis 2007, 2009
- St. Paul Art Crawl 2009

- Minneapolis City Hall, 2009
- Patrick's Cabaret, Minneapolis 2006
- Theatre in the Round, Minneapolis 2005
- St. Paul Jewish Community Center 2007
- Washburn Library, Minneapolis 2007
- Bottineau Library, Minneapolis 2006
- Theatre in the Round, Minneapolis 2005
- LOLA Art Crawl 2009
- "Flow" Northside Art Crawl 2006-09

Corporate

- Allina Clinic Woodbury, MN 2009
- Hartford Insurance Company, Woodbury, MN 2006,07,08,09
- Health Partners, Woodbury, MN 2007
- K&S Conservatory, Woodbury, MN 2007, 2008
- Main St. Bank, Woodbury 2006, 07,.08
- Marathon Oil Headquarters, St. Paul Park 2008 2009
- Park State Bank, Minneapolis 2006
- South Point Community Acupuncture, Minneapolis 2009
- Woodwinds Health Campus, Woodbury, MN 2009

Cafes and Eateries

- A Fine Grind, St. Paul, MN 2009
- Anodyne at 43rd, Minneapolis 2006
- Bryn Mawr Coffee Shop, Minneapolis 2009
- Caffe Tempo, Minneapolis 2006
- Cuppa Java, Minneapolis 2009
- Dunn Brothers Coffee various from 2006-2009
- Harvest Moon Coffee, St. Louis Park, MN 2007, 2009
- Jitters showcase, Minneapolis 2006. 07
- Luna Blu Coffee Company, Rogers, MN 2006 -07
- Pizza Luce, Minneapolis 2005, 2008
- Rudie's Coffeehouse, St. Paul, MN 2006
- The Beanery, an Internet Café, Aitkin, MN 2006
- Tillie's Bean, Minneapolis 2006, 2008
- Trotter's Café, St. Paul 2006, 2008

Duo or Group:

Galleries and Public Space

- Altered Esthetic Gallery, Minneapolis, MN , several shows, 2007-09
- Center for Independent Artists West Gallery Minneapolis* 2007
- Center for Independent Artists: Frinj of the Frinj, Minneapolis 2005
- Emerging Artists Outside Illinois, Liz Long Gallery, Chicago, IL 2009

- Gallery on the Fly, Uptown Minneapolis Art Fair 2005
- "Gone Fishing" Outsiders and Others Gallery, Minneapolis, 2006
- Jaques Art Center, Aitkin, MN 2006
- King George's Market, Belfast, N. Ireland, UK (by invitation) 2005
- LA Center for Digital Art: Snap to Grid: 2005
- NAC Group show at Northway Trust, Minneapolis 2006
- "FLOW" NAC Group Show 2006-08
- Minneapolis Foundation- NAC Group show
- NAC Group Show, North Point Health and Wellness Center Gallery 2007
- NAC Group Show, Hennepin County Government Center 2007
- Salon 300, Hopkins, MN 2007-08
- "From the Attic," SMG Gallery, Minneapolis
- "ACEOs Art Trading Cards" SMG Gallery, Minneapolis 2007
- Sister Kenny Institute, Minneapolis 2008-09
- Turning Mobility 3, Auckland, NZ (by invitation) 2006 Cafes and Eateries
- A Fine Grind * 2007
- Artist's Grind, St. Paul, MN 2007-09
- With Altered Aesthetic Gallery "Minnesota 150 Show" Black Dog Café & Wine Bar, St Paul 2008
- Chocolate Spoon, White Bear Lake
- Dunn Brothers, Edina (with Mina Blyly-Strauss) 2009
- Fresh Grounds Coffee house, St. Paul 2008-09
- Gingko Coffeehouse, St. Paul* 2006, 2008
- White Rock Coffee, St. Paul
- *with Cher Fields, Acrylicist)

Ongoing Displays at

- Eddy's Café, Minneapolis
- Sovereign Grounds Coffee Shop, 813 E. 48th Street, Minneapolis, 55409
- Village Social Services West Broadway, Minneapolis.

Web Presences:

www.janesprints.com (sales through this site)

http://janesprints.mosaicglobe.com www.disabledartistsnetwork.net

www.auties.org

www.janesprints.com

SOUARE PEG ADVOCACY

Square Peg Advocacy has its origins in Jane Strauss' training as a teacher, attorney, and administrator and her experience as a teacher, and advocate, a square peg who has never comfortably fit any round holes, and a parent of children who followed that same pattern. As she saw attitudes in both the medical and educational settings that even she, with an extensive background in law, health, and education, sometimes found daunting, she considered making her services available to others.

She has over two decades' experience as a disability rights advocate, researcher, educator, parent, and consultant. She has walked in your footsteps, or close and strongly believes in every child's right to learn skills that will maximize independence and build on his or her unique strengths.

It's lovely to know that the world can't interfere with the inside of your head. - Frank McCourt

Opportunities are like sunrises - if you wait too long, you miss them. - William Arthur Ward

Slow down and enjoy life. It's not only the scenery you miss by going too fast - you also miss the sense of where you are going and why. - Eddie Cantor

Happiness comes when your work and words are of benefit to yourself and others. - Buddha

Those who are firm, enduring, simple and unpretentious are the nearest to virtue. - Confucius

Change the way you look at things and the things you look at change. - Dr. Wayne Dyer

Strength does not come from physical capacity. It comes from an indomitable will. - Gandhi

If the average person realized the power he wields over his life and destiny, he would live in a perpetual state of wonder and thanksgiving. - Earl Nightingale

Calmness is the cradle of power. - Josiah Gilbert Holland

<u>www.brighttots.com</u> <u>Developmental Disorders</u> <u>Autisn</u>

Our goal at Bright Tots is to help those who are not as familiar with the different types of developmental delays, as well as those who are. We offer resources on child development and special needs; articles on disabilities, diagnosis, treatments and other concerns. Bright Tots also provides a guideline on how to choose the right toys for enhancing developmental skills.

A DIFFERENT WAY TO LEARN The Child's Perspective By: Tracey Spiro

Special Education/ABA Teacher

Capture my MOTIVATION to LEARN!

• I LOVE to be reinforced, but the usual "social reinforcers" may not be meaningful to me in the beginning.

I am a Visual Learner

- My visual "channel" is stronger than my auditory "channel".
- Visual and concrete experiences help me UNDERSTAND the meaning of my experiences.

I Prefer Consistent, Predictable and Organized Routines

- Keep it the same RIGHT FROM THE START
- When things change, please SHOW ME WHAT TO EXPECT

I Understand and Process my environment in a unique way

- Sometimes, I organize and remember things in "CHUNKS" or "Wholes" and have a hard time understanding that the separate "parts" mean.
- It's sometimes hard for me to learn by watching what others around me are doing and saying.
- Since I'm not always sure what the "important" information is in my experiences, I sometimes focus on small "bits" of information that may not even be relevant.
- I almost always have a hard time processing auditory information. For me to understand, please SHOW me what you mean!
- I'm not a fan of "multi-tasking". It's hard for me to attend to information coming from several "Channels" at the same time.

One thing at a time please!

• I learn best when skills are broken down into "bite-sized" pieces.

Relationship Entrapment by Alyson Bradley

Those on the spectrum and parents with children on the spectrum: despite what you may or may not have read, there is real hope for everyone, our differences often seem extreme to some and the "norm" to others, but we are all born uniquely different and need to allow for and remember that. The problem is often that enforced conformity and trying to be and act in ways that are not natural to us simply does not work. For any relationship, we need to first fully understand, accept and be able to allow and help others understand our differences and who we are as individuals.

The downside at times is simply by being ourselves because of lack of real awareness in the world causes our invisible differences to lead others to misinterpret who we are, label us wrongly, even discriminate against us. Those on the spectrum, if not embraced from birth, often lack self-esteem and it can be so easy to become paranoid and think there is something wrong with us. We may think we will never be able to have relationships, often settling for second best or anyone... this of course is so wrong, as it can lead to all sorts of abuse and

complications in relationships.

Among the problems are far too often society's interpretations on how relationships should be and, at times, our own feeling that we need to have relationships because we know no better and so go along with everyone else's terms. This often does not work for us, but then how are we to know?! What often happens next when things do not seem right is that we may become insecure in who we are as individuals and wonder why we are different; extremity in a way brings to light what can happen at various levels of stereotypes of how everyone should be. There is no blame, but a history of years of invisible difference often open for general discussion more than truly understood; open to all sorts of wrong information and fad treatments. It's also a puzzle to many with nowhere to turn and wanting to do the right thing, we often get it horridly wrong!

The complexities of how we do or do not connect, so many things we question ourselves, far too often are left unsaid and unanswered; that void of not knowing eats away at self-esteem. This is a heavy burden for a small child; when others smile we look away, avoiding a life we feel disconnected with. A child reaching out and being crushed at every turn is horrendous, like we tread on thin ice, wanting to be accepted; but so often our naivete leads to others taking advantage, abuse and rejection. This may seem far-fetched, but to the mind of a misunderstood child it's devastating and the damage starts! Maybe for you that understand, this seems extreme; but many still have no

clue, many still suffer in silence.

The support and comfort often does not come; at times we even get told off instead of being praised, so we simply withdraw into our own worlds, away from the constant reality that we simply do not fit! Often we so want to be understood and simply embraced for who we are but instead get seen as awkward, difficult children whose misunderstood emotions mean we

cry inside, as often our voices go unheard. Parents often have no clue yet discipline us, and enforced conformity starts. What choice does a child have? Eventually, we give in. A pathway of self-destruction and pretense starts, a part of self is slowly lost and in a way stolen from us; and the false fixed smile may look real, but eyes say it all, fixed firmly to the floor,

saddened within. Safety screens start to close down.

We start out in life like everyone else, as small children with many dreams and hopes; but our paths are much more complex - like crossing a sea of glass barefoot - the harder we try, the more we get hurt, our attempts of being heard often are rejected and the answer is yet again, "That's not what children should do or say!" We find often what we are asked to do feels wrong for us, but our small truths are lost as just words, with often no clue why. We simply have no idea why our efforts are rejected, why we are not heard, understood or accepted; so we remove ourselves and watch endless videos and films and feel and want so much to be like those other happy children, people... life, of course, not so simple - but growing up maybe we feel it should be and in our minds to be allowed we will try anything and in an attempt to get things so, so right wanting to please maybe we compromise yet a little more of self.

Next come whispers and labels: disturbed child, sent to exile, discarded, others not to talk about, some may feel sorry for you, even call you the unthinkable... but in reality, the invisibility of real self starts to be apparent, differences are yours alone and <u>no one</u> seems to understand. The lonely journey begins and any recognition and/or affection in our naivete is better than none - at our lowest moments like a disused rage. Like everyone else, we often only want what others have, want bullying to go away and hurt to stop. We start to respond to any kindness; of course often we are just being taken advantage of and do not know any better, especially when we may feel no one, including our own parents at times understands. Of course, many parents try so hard; but our disconnect and differences in communication can mean we feel no one really listens, so let me

explain more.

A child rejected by life itself (well so they think), is confused and as they see it, instead of others trying to understand, others let them down and try to enforce conformity. Of course, parents often just do what they feel is best but can only be guided by stereotyped visions of what *should* be. They are often wrongly informed or simply act unintentionally because of lack of real information from those with lived experience; some do not understand there is, in fact, a whole different neurological way of being. I guess parents often do not know their child can be any other way. Let me put it another way as an Aspergian parent - if I was to enforce my non-autistic child to be and act like me, an autistic individual, that would be wrong, of course, so why not the other way around?!

This is where I add a warning: as an Aspergian child who was often extremely naive, and lacked confidence in self, I was easier prey and led astray. Unfortunately, my intelligence or maybe my misunderstood emotions helped me cover up to the

outsider that there was anything wrong. Anyway, this piece of writing just sets the screen for what can happen in relationships and why; so for now, parents, I will leave you with previous thoughts to think about. But the consequences of not allowing a child to be embraced for the individual they are can lead to a lifetime of battles and challenges before the individual finds true self like I did.

Young adults are the Aspergians I am most concerned for, the ones pushed to the edge of life itself, so it's time to speak about real situations, be very real, because the consequences are harder to deal with. We can all smile behind polite curtains and pretend life is ok, hiding what deep down we know is wrong. I am not saying this is anyone's mistake alone, there are varied reasons and often misinformation is continuous. Those in the most need often get rejected, labeled as odd and weird, and are often broken from being exposed to a society that simply is unable to understand or does not want to listen. This takes away part of the individual, which in turn leads to frustration, anger, confusion, chaos and a path of isolation, alienation and unthinkable consequences, but we continue to allow it to happen!

What happens when a spectrum teenager feels totally at odds with life and society can show up in various ways - the obvious is removing themselves from what they see as unbearable for a while to ease pain by taking various substances. They also could overeat or undereati; but whatever spectrum individuals tend to do to hide emotions may not be understood by others as obsessive. This can be dangerous; and sadly, places of support often do not really cater to obsessive tendencies of Aspergians. Treatment such as AA may not work, because if we no longer do one thing another obsession may easily take hold. A factor that needs mentioning is that those in need that do not get help and are pushed to the edge of society (often by society itself) can become suicidal; for teenagers especially, it can be a real danger point, and sadly there is so little help for this age group that is probably the most in need.

Relationships often do not work for Aspergians because they have only learned average neurotypical ways growing up and these simply may not apply and work for them. This can cause all sorts of problems. In attempts to be like everyone else, they can fall into the wrong crowd, get in trouble, and get addicted to alcohol, drugs, food or whatever their obsession is in order to take away the focus of pain. While individuals with Aspergers may comprehend feelings of others, they often lack ability to express this knowledge without prompting. This does not have to be the case, of course, because for those embraced from birth this simply rarely happens.

But growing up and entering the world of relationships, with pressure from peers and realizing it simply does not seem to work for us, we force ourselves into situations that can make us extremely awkward and don't fully understand ourselves emotionally. Lack of self-esteem often leads many into what I call relationship entrapment. Often, we are so pleased to have any relationship, do not like change and lack self belief; so we

put up with so much more than we need to, yet are often very genuine and honest and can be taken advantage of. We need to teach our children they are entitled to relationships on their terms; but sadly, within the wider world of disability, diversity and difference, relationships outside the "norm" are often frowned upon. Maybe it's time for society in general to re-think and wake up; there are many diversities and differences

and maybe we all need to be a little more open-minded.

I think acceptance of individual differences has to come from you first and those that do not face up to who they are, become frustrated from lack of fulfillment of self. I guess the main thing is not so much labels but all within each family accepting our differences and remembering no one can express emotions on tap like others may want. I guess we all need to teach our children to know of the many diversities and differences in this world and that there is more than one way of showing and doing many things. For acceptance in society, that has to start with education from all adults and to simply remember we can all learn from each other, as I feel we should celebrate diversity and difference, not stress over it. With understanding comes awareness, comes acceptance....

Sometimes, I have found that when we judge others it is for the right reason; and at times I have to look on how I impact on others. My family accepts my differences and knows that's the way I am because I have always reinforced my love for them in my own way however rejected I have felt. They recognize I have my own issues and want what may never exist for me; but I am still learning to communicate my differences, as being diagnosed is one thing, but understanding self all over again takes time.

I guess I am the same person as I was before diagnosis; but as I continue on my journey, I am changing and realize that for some around me that may never happen or happen at a different pace. In the meantime, I have had to learn to communicate and continue to remind those around me that saying things once never works, people fall back into old habits, and maybe my words are not what others expect, as many Aspies show rather than say. If we do not communicate well, there are other ways to communicate, e-mail or whatever; this works well with my Aspie son at times.

Each of us is a unique individual on or off the spectrum; what defines me as an autistic adult are my neurological differences, the way I am and interact in the world. If I was blind, I could not pretend not to be - who would that benefit - pretending to not be autistic would be like going back in time with my differences invisible to many; so I need to acknowledge so that others and myself understand. As for me, not telling a child or adult the reasons for their differences is wrong to me and can only lead to sadness, longterm resentment and a future of complications. Our differences may be invisible to some, but I feel we should not hide them; otherwise it's like a shameful secret!



Me and my 2 boys

Just to add - I am an Aspie mother with 2 beautiful sons, the older also on the spectrum and have been with my husband nearly 20 years. There is no reason Aspergians can not be mothers, be married, be happy - the only thing that held me back for years was self. I was brought up all wrong, misunderstood by many including self for years, but I survived my teens somehow - far from easy. But even when I discovered Aspergers not so long ago (as diagnosed later in life), first brilliant - it helped explain so much, then lots to face up to, a change that cannot happen overnight, but highly recommended. As now I understand self, I can explain things to my husband and family that I never could before. Not only do I feel I have grown as a person - it has helped and strengthened my family so much. Maybe we all need to be a little more open-minded!

For more on relationship advice Aspergers Parallel Planet web site (forum) - www.asplanet.info:
Unconventional relationships never easy - mix in some ASD traits, expect the unexpected:
http://asplanet.info/index.php?option=com_content&task=view&id=1
00&Itemid=146

Ignorance breeds monsters to fill up the vacancies of the soul that are unoccupied by the verities of knowledge. - Horace Mann

Man's greatness lies in his power of thought.
- Blaise Pascal, French mathematician & theologian, 1623-62

Spectacular achievements are always preceded by unspectacular preparation. - Roger Staubach

It is better to be prepared for an opportunity and not have one than to have an opportunity and not be prepared. - Whitney Young, Jr.

In the midst of movement and chaos, keep stillness inside of you. - Deepak Chopra

Dreams by Jessie

The mare's small hooves thunder over the ground, Her swift movements smooth and without sound. She flared her nostrils and galloped on, All the while listening to the owls' night-time song, You hang on to her silky mane so tight, The rhythm and beat of her hooves makes the night seem right, Both her mane and your hair blowing back in the cold night's breeze, As you hold her silk mane and she gallops on with ease, The stretch seems endless along the beach, Stars are the only thing you both aim to reach, With the full moon shining oh so bright, She gathers up and leaps into the empty night, The small weight of you on her back, Though her swift pace will never lack, Soaring gracefully over the calm-smooth sea, You know this is where you're both meant to be, Her mane flowing and your hair blown back, She's never known feeling of cold hard tack, Her eyes are like marbles and her coat a bright star, You know this ride could never go too far, Your eyes flash open as the sun appears, Releasing all your inside fears. The ride starts at the sun's set. And ends again at the sun's get, So leaping from the sky to the sandy beaches below, It's time for this ride to end and you to go, So with a single kiss on the head and a nicker in your ear, You close your eyes and all you can hear, The hooves running towards the sea, She'll always be here and free. With a single blink, you're back in your own bed, "I can't wait for tomorrow's dream" sings your sleepy head.

Shades of Normal by Elizabeth Brown

This deals with my journey as a mother coming to terms with the diagnosis of my child with Asperger Syndrome.

A diagnostic label is not easy for any parent to swallow. When it's Asperger's Syndrome, a higher functioning form of autism, it may take years of painstaking research and advocating, seeking some plausible answer, some description that sounds like a match.

When you arrive, and you hear the diagnosis, Asperger Syndrome, you have to decide what you think about it, how your child possibly could possess this innate difference identified as a syndrome. It sounds strange and unnatural. You wonder if it's real and true, or based on a subjective opinion of doctors that collectively agree on a set of symptoms. You hear the backlash, the critics, who proclaim that we are pathologizing typical behavior, assigning labels indiscriminately. You hear that an autism diagnosis is nonexistent, fabricated by parents and doctors and spurred on by pharmaceutical companies and others in the medical field trying to profit off this new spectrum disorder. Tragically, you believe some it and remain, as I have, conflicted and

What is the truth? How do I help my son?

Eventually, you realize the truth. Your child needs help. You consider your options. If it was 20 years ago, there wouldn't be as many. He'd be misunderstood, identified as emotionally disturbed or socially maladjusted. It would be disastrous.

There are positives to his diagnosis, I've concluded. But I have to go back to the beginning; reminding myself, frequently, that my son could not handle kindergarten, that it was not the staff, and that he was not singled out and persecuted. It was that he could not read the cues or discern the expectations. He was not bad or insubordinate. Nevertheless, even now, four years later, I consider it might be different, more positive, if he was just given more freedom to be himself and the staff was better educated and made more of an effort to see the real problem.

One can't look back, so I move forward.

Reality: I've been there, in the trenches, at the round table, with the team and the charts and tallied scores of noncompliance, aggression to environment, outbursts, unsafe behavior, failure to transition, bolting and hiding, and I've cringed each time my son has been objectified with the use of harsh language flavored in negative tones. How does he stand a chance against the round table, the collective team? How do I?

I've become averse to shaping techniques and earned points and functional behavior assessments and, especially, the data collection: the note taking, the observations; as if my son were some creature that fell from the sky, a specimen to be studied. I'm convinced he notices it too and feels the disregard for his being.

I do not find reason to celebrate that we received a diagnosis, a 25 page clinical report that discusses my son and his social deficits associated with Asperger Syndrome. It is a moot point at this time. I want peace for my son. Now that he's older and has become more aware, he does too. He does not want to be singled out and he does not want to be given special accommodations, or preferences, or short buses. Instead, he wants to feel accepted and normal and part of society.

You continue, walking a fine line between acceptance and dismissal of the diagnosis. You watch as your child, too, tries to find a place. One day, at the close of school last year, my son came home and decided he wanted create a documentary on Asperger Syndrome. We filmed it (one of his interests). He insisted I be a part of it. I was proud and impressed. We laughed and enjoyed the process. It had to be perfect, so it took a few hours. We did it and then that was that. But mostly, other than that moment, we don't discuss it. I've concluded that my son will accept being an Aspie as long as he is accepted by others for his talents. If not, he will reject it and parts of himself as well.

Truthfully, despite a lengthy and detailed report that cites social deficits, he is not a loner nor does he want to be. He has his quirks and intense interests, but he always wants to share with others. He loves people and connecting. From the time he was small, he'd engage anyone in conversation, say hello just to see them smile. I am convinced that the school environment itself has made my son anxious and self-conscious and has resulted in the need to have a label and supports. Paradoxically, as he gets older, it is the special education and stigma he wants to avoid. Minus the demands of school, he functions quite well. He has an insatiable curiosity and his questions have always made me pause: "Can we survive without the moon?" he asked me just the other day.

I'm left with the nagging questions that haunt many parents of high functioning kids who are quirky and single minded: Where does my child fit in? What is the right learning environment besides home? My son is not disabled. On the contrary, he is gifted and unique and he has taught me how to be patient and curious and reminded me to stop and smell the roses. His insights are way beyond what I would expect from a child of ten years. He has shown me the different shades of normal.

For now, I will continue to advocate for my son's right to be completely accepted and tolerated as a ten-year old boy with enormous strengths, very able in mind and body. He functions best when he is appreciated. When he is at his worst and he loses his enthusiasm, I see it in his face, in his mannerisms, and I know he has been treated as a boy with a disorder. The older he gets the wiser and more vocal he becomes. Therefore, I will listen to him when he demands to be taken out of special education because he feels it is a "conspiracy" and he wants out. I will consider that he feels stigmatized and is not being treated fairly. I will consider including him at the round table, at the PPT, so that he can voice his opinion. I will dismiss any notion that he is, somehow, disabled or deficient. I will not refer to him as an Aspie, or expect him to accept his diagnosis. It will be his decision to reach out to other likeminded people.

It is not perfect or linear or in any way mainstream, the journey I've been taking alongside my son; but it is a spiritual quest to somehow improve a society that marks its citizens and brands them typical or atypical. It is a mission to be heard, to be acknowledged and to be accepted, freely, without restraint or discrimination.

People who are unable to motivate themselves must be content with mediocrity, no matter how impressive their other talents.

- Andrew Carnegie

I have found that if you love life, life will love you back.

- Arthur Rubinstein

Everyone wishes to have truth on his side, but not everyone wishes to be on the side of truth.

- Richard Whately, English logician/theologian, 1787-1863

There are no extra pieces in the universe. Everyone is here because he or she has a place to fill, and every piece must fit itself into the big jigsaw puzzle. - Deepak Chopra

It is man that makes truth great, not truth that makes man great.

- Confucius

Courage is not the towering oak that sees storms come and go; it is the fragile blossom that opens in the snow. - Alice Mackenzie Swaim

When it is dark enough, you can see the stars. - Charles A. Beard

Dr. Bill Frea, Ph.D. has started a new series of parent tip sheets on various autism-related topics. A most recent one offers ideas for back to school strategies for children with autism and their families. This information is provided by Autism Spectrum Therapies (AST), an agency providing autism services to individuals and families. More information about AST can be found on their website at www.autismtherapies.com.



Back to School Strategies for Children with Autism

Getting ready for the new school year can be a hectic and exciting time. However, for children with autism, all this change can feel overwhelming.

Here are some suggestions for how to help ease your child's back-to-school anxieties:

Scope out the school and classroom in advance. If your child is going into a new classroom, visit it at least once before the first day of school. If transition has been a struggle in the past, consider taking as much time as your child needs to explore the classroom. Make it as much fun as possible, playing in each of the new areas.

Check out seat assignments. For older children, ask the teacher if a seat assignment has been made. Do some enjoyable activities in that seat. If familiar classmates will be in the room, show where they will be sitting, too.

Rehearse new activities. Find out from the teacher what new activities are planned. Then, prepare your child by performing, practicing, and talking about them. This rehearsal will reduce anxiety when the new activities come up in the first week of school.

Anticipate sensory overload. The noise and chaos of a typical classroom can sometimes be a bit much to handle. Establish a plan for what to do in this situation – perhaps there is a quiet room where your child can "take a break" for a short time.

Volunteer in the classroom. Most teachers welcome assistance from parents. Your presence may be a source of comfort to your

Going to school can pose many challenges for children with autism, as well as countless opportunities for building crucial social, language, and academic skills. Be positive and

child during those challenging first weeks. encouraging, and your child will be off to a great year!

For more Information, visit www.autismtherapies.com or call (866) AST-1520

This information is provided by Autism Spectrum Therapies (AST), an agency providing autism services to individuals and families. More information about AST can be found on their website at www.autismtherapies.com.

Turning Adversity into Opportunity By James Wallis Martin JB Metrics Ltd, Director www.ibmetrics.com

Is the glass half full or half empty? For those of us with autism, the glass is twice the size necessary for the amount of liquid. Although humans like to box people as either group A or group B, invariably there is a group of us that are neither A or B (to make matters more difficult, it doesn't mean we are C either!) Although it can be hard for most of society to handle us or figure us out, it is this difference that is also our opportunity to provide a different "Weltausblick" - literally translates to "World view" (but means much more in German).

I was diagnosed in my late thirties with Asperger's, and only because my first daughter was diagnosed, the youngest child in New Zealand at 21 months old, with more obvious signs of autism than me. I have never seen it as an advantage/disadvantage; rather I saw it as a point of difference which gave me opportunities to excel as a genius in some areas (like mathematics, logic, and pattern recognition) and explained why I just didn't get other areas (like human emotions, social behaviour, and was physically coordinated). The diagnosis didn't change who I am, but it helped those around me understand I wasn't trying to be difficult, different, or plain weird; rather I was wired differently and therefore have a very different "Weltausblick" than 99.9% of the human population. Most people see the negative in being autistic and spend literally tens or hundreds of thousands of dollars trying to "cure" their autistic children. Why is it then, that everyone hopes their child grows up to be the next Einstein, DaVinci, or Shakespeare and does not see that part of what made them able to have different "Weltausblick" was their autism added to the opportunity to focus on the areas in which they were strong and have others compensate where they just "didn't get it".

I played card games at the age of 16 months, did 2000 piece puzzles at the age of two, spoke three languages at the age of three, wrote my first software program at seven on a mainframe, taught computer courses to university graduates at thirteen and started university at fifteen. However, I usually felt alone in a crowd, didn't get jokes and often was part of other people's jokes, and was "celibate by popular mandate", as I had the raging hormones of a typical fifteen year old teenager but the social ability of a polite ten year old surrounded by fellow twenty year old classmates.

I was fortunate to have an amazing first love at nineteen for seven years who taught me to understand emotions, learn that when people pass by and say "How are you doing?" that they are not actually asking nor wanting any other answer than "Fine, how are you doing?", and that when she storms out after a "lover's quarrel" that I am supposed to follow her rather than go back to working on my computer.

The advantage of not knowing how to court or date meant that getting into a committed relationship only took a couple hours, becoming life mates with my wife only took three days, and conceiving our first child took eight more days (more to do with fertility than autism). The awkwardness of social interaction for an autistic person also opens an opportunity to shortcut around the usual social games and be honest from day one (since we usually make terrible poker players).

The challenge lies in creating a good support network of friends, partners, and colleagues who can compensate or work around my shortcomings and allow me to focus and channel my strengths. I was extremely successful in Silicon Valley because I was able to solve problems in a third of the time at half the cost while having a colleague handle all the political wrangling (and fallout sometimes from my logical, but emotionally insensitive solutions). I had an amazing business analyst who taught me to wait for the person asking a question to finish their question, look like I am thinking about it for several seconds thereafter rather than give the correct answer (after analyzing hundreds of possible outcomes) before the person has finished the first sentence of their question. Without her "translating" what I was trying to say, I would not have gotten acceptance for what I was trying to accomplish and would not have had the amazing success I had.

With the right people (and with the right amount of patience) providing a support network, the adversity of autism is easily compensated by the opportunities the autistic mind provides not only us as individuals, but what we can contribute with our different "Weltausblick" to the advancement and achievement of humanity.

An aim in life is the only fortune worth the finding; and it is not to be found in foreign lands, but in the heart itself.

- Robert Louis Stevenson

Do not look to the ground for your next step. Greatness lies with those who look to the horizon. - Norwegian Proverb

Some day I'm going to escape. I really am. I guess it's

just going to take a little bit longer than I anticipated.

Maybe I should back up a bit. You see, I've got this barely understood disorder called autism, and no, I'm no Rain Man. I think that movie did more disservice to people like me than actual good. Sure, it was only a movie, but now everybody expects me to be able to "count cards" while going to Vegas or do other stupid human tricks on Letterman or some weird crap like that.

In point of fact, I was fairly "normal" until about age two or so. I did all the stuff that most babies and toddlers go through -creeping, crawling, walking, talking, pooping, the list goes on and on. But four days after my 2nd birthday, I got a hellacious fever (my mom says that I stayed at 103 degrees for something like two and a half days) and that's when the proverbial bottom dropped out. I no longer wanted to play with other kids, loud noises freaked me out big time, incandescent lights looked like supernovae all of a sudden, and I also just stopped talking. Verbosity just seemed kind of redundant when I could carry on whole conversations in my head. Who needed

people when I had myself?

My parents, naturally, freaked out and lamented the loss of their "old" son. Mom in particular went through years of self-guilt trips, blaming herself for "not getting Brandon to the doctor in time." Boy, if she only knew that the fever itself was simply the catalyst that sparked the fuse that was just waiting to go off at any moment. From the moment I was conceived, my genetic outlay had provided a time bomb just waiting to go off. Anything could have done it, really. Vaccines. Red food coloring. Sunspots. Cell phones. If you can think of a reason, you're probably right in what could have caused it. All the king's men and all the king's horses (i.e. the doctors) didn't have a clue in the world. All they had was a label and an "I'm very sorry Mr. and Mrs. Rothman. Better luck next time!"

Of course, my parents were in complete denial for the first year or so and they toted me around to just about every major hospital and clinic that the United States had to offer. And, of course, they were sent back home with usually the same response as when they received my initial diagnosis, except sometimes their ears were cruelly perked up when they heard false hopes of: "He may grow out of it" or "There's this promising new treatment at so-and-so university that you may want to check out"; all to no avail. I never did "grow out of it," and the leads they followed at these universities or special clinics were often part of immensely long longitudinal studies where the results wouldn't be known until I was nearly twenty-two.

So, back home to Bridgeport, Indiana we would go, Mom and Dad usually more depressed than ever and me continually retreating into my own world that was forming more and more dimensions every day. You see, that's what all the doctors and

specialists and teachers could never quite get - here they were, along with my parents and family feeling sorry as heck for me that I was virtually cut off from the world and not able to interact with anybody, when in reality, I had all the interaction I could ever possibly hope to have. Don't get me wrong. I still loved my parents and my two older brothers and whatever other family member that I had contact with; it's just that instead of willingly giving them a kiss or a hug or even a simple hello, I would involve them in my own world in ways they couldn't possibly imagine.

Take my two older brothers, Mike and Jacob, for example. Those guys were probably the sweetest brothers you could ever hope to have. They tried to interact with me, get me to do stuff with them, you name it, long after they (and long before my parents were willing to admit it) realized I just wasn't going to be your typical, "normal" brother. They took me on long walks through the woods, defended my honor (almost violently sometimes) when other kids called me "retard" and other crap like that, read to me, etc, etc. What they never realized is I was also able to take them on wonderful adventures that rivaled those I saw in the wonderful Star Wars or Indiana Jones movies. The sad part is they never even had a clue what they were involved with and how could they - it was all in my head and I could never tell them word one about what I was able to do for them. To this day, I still make up wild yarns with them as my costars in movies Hollywood could only dream about.

That's pretty much how it went until I "graduated" from high school. I use the term very loosely because they changed education law around so much that in order to actually "graduated". I had to pass stupid tosts that a good third of the

"graduate," I had to pass stupid tests that a good third of the non-special education population could never even hope to pass. On June 6th of some year, they sent me home with my very own "Certificate of Attendance" that proved that I showed up to Bridgeport High four years in a row and didn't cause too much trouble. I imagine the paper it was printed on, along with its declaration, was probably worth less than a cup of coffee at

your local McDonald's Luxury Lounge.

Since I was pretty much nonverbal most of my life except for a few words grunted out here and there, my vocational options were pretty severely limited. Fortunately, Mom and Dad were able to keep me at home after high school; and with some help from some not-for-profit organization in town, they even got me a job bagging cookies on an assembly line making minimum wage for a job that would make most go out of their mind from sheer boredom.

Not me, though. My mind is pretty much all I have, and believe you me, those hours spent on the factory floor at the Kooligan Kookie plant were some of my best ever. Not only was I getting paid to do what most would, by any stretch of the imagination, consider to be the most menial of tasks, but I was also, for what it's worth, getting paid to live the most outlandish fantasies just about any human could ever dream up.
Trust me, when I first got there (and before other disabled individuals started showing up (more on that later) I would

often look up from my task to the faces of some of my fellow coworkers and you could just tell that if offered to put a bullet through their brain to end the mindless droning of their work they would take the gun in a proverbial heartbeat. Me, I would just fade out, like a cloud does the sun on a hot, summer day, and Boom! there I was, back either flying around some made-up galaxy or filling the shoes of some superhero that I had dreamt of back when I was six. And they called me the unlucky one for having this disability known as autism. Ha! At least I could very well escape from whatever situation I was in whenever I wanted.

But I couldn't, really, which brings me back to my opening point I posited at the beginning of this tale. As much as I could escape within the confines of my own brain (and boy did I love it when I did), there was always one place that I never could reach, and that was the land of Human Contact. My emotions have always been too scattered to label what I feel as either frustrated, disappointed, or even outright apathetic about the whole situation. Sure, I've felt the whole gamut of human feeling, and I've even tried expressing as such to my family from time to time. Usually, however, the whole of the situation was usually conflated into some disgusting display of hand-waving and tears and I would feel so sorry for my parents or my brothers who would try so desperately to understand just what the heck I was feeling or trying to communicate... all to no avail. Either they thought I wanted some toy I couldn't get to or had some mysterious ailment I couldn't tell them about (which often led to many unnecessary trips to the doctor) or was acting out because that's what people like me did. Yeah, you could say I was frustrated, but probably the single greatest emotion I've felt in this regard is disappointment that my own family, as much as they love me and try to understand me, cannot seem to figure me out. I don't really blame them, but they just seem to assume that since I can't communicate my higher-level needs, I don't have any.

For example, little do they know that despite being secluded in a classroom for many years with other students that were barely aware of their own existence, I was able to teach myself to read on a much higher level than most of my teachers ever thought possible. Many a time I would sneak into my parents' library (they loved the classics) and pore over its many volumes of great literature - Joyce, Dickens, Tolstoy, Kafka - the list goes on and on. One of my favorites was Finnegans Wake, a novel that has baffled many for nearly a century. I ate that stuff up like a newly-made hot fudge sundae from Dairy Queen. Honestly, I couldn't see what the big deal was really. His stream-of-consciousness work, along with Faulkner's, provided me with hours of joy that rivaled even my

own mind's.

It was shortly after discovering these authors that I thought to myself, hey, why couldn't $\it I$ write my own stuff and get it published. I mean, if Joyce and Faulkner could come up with stuff like this, then certainly someone like $\it me$ had just as

much right to produce his own work and disseminate it to the

world at large.

Ah, but here was where rubber of reality hit the proverbial road. As much as my mind allowed me to access these previously written great works of literature, when it came to transcribing my own thoughts and ideas down into the so-called world of reality, I was met with instant frustration.

You see, throughout my years at school I had been taught how to write my name and my ABCs and even my address and phone number. But when my teachers attempted to get me to write even the simplest of sentences, "Johnny rode his bike to school 'for example, all that would come out would be something today," following the state of the state of

Fjjiiei jjd skkk keei djjei do.

Sure, it did look like something that would fit in neatly within the pages of *Finnegans Wake*, but as far as attempting to get any of my teachers to understand what I had written, forget I mean, it made *perfect* sense to me; but to everyone else on the planet, it might as well have been the text from some alien from planet Incommunicadia. My teachers, God love 'em, would sense my frustration as I tried to delineate out my reams of ideas and thoughts onto first paper then a computer and then a myriad of other assistive technology devices that were brought in to help. All through my middle school years I would either cry or crumple up my papers; sometimes, I stamped my feet or slapped my head trying to force my visions out of my teeming brain. By the time I had hit high school, by the grace of God, I can only imagine, a calm epiphany had settled over me and I realized that no matter how hard the teachers and their assistants tried and no matter how much I screamed or erupted into paroxysms, there was no earthly way that I was going to deliver my conceptions, beliefs, or any other neurological

goings-on into some tabula rasa anybody could really understand.

And you know what, in moments of blatant conceit, I would often feel sorry for everyone else *other* than me, if for no other reason than *they* were the ones not able to share in the joy of what I had been able to so easily create within the confines of my mind; but was, nonetheless, destined to stay forever, so it seemed, locked away like some long-forgotten prisoner of war. Again, in vain appraisal of my mental tomes, I knew that I had created strings of words, phrases, chapters, and entire novels that would quickly be snatched up by any literary agent worth his or her salt. I felt similar to the protagonist of Johnny Got His Gun, Joe Bonham. Joe was the unfortunate remainder of wartime violence and had the bad luck to have a shell explode near him, yet, inconceivably, survive. Except Joe's survival meant spending however many days God granted him in a hospital without any limbs and no face, which meant no communication whatsoever with the outside world (until he futilely learns much later on to use Morse code with his head).

Sure, I had all my limbs and I could even communicate my basic needs, but on a comparable level to Joe Bonham, I could not relate what I truly wanted to relate, which were the millions upon millions of complex and varied thoughts that went through my head every single day. I might as well have been locked up in a limbless body with no face because that was exactly how I felt some days, especially at school when my noble teachers were ushering forth their own blood, sweat, and tears just for me to be able to produce a simple five-word sentence and all they would get would be:

Fjjiiei jjd skkk keei djjei do.

I doubt Joyce or Faulkner ever had it this bad. Even if they were misunderstood by millions, at least they could get their thoughts down on paper vis-à-vis their hand or a typewriter or something. Me, I was stuck with an audience of one. Eternally.

To Be Continued in the September Issue!

The radical of one century is the conservative of the next. The radical invents the views. When he has worn them out the conservative adopts them.

- Mark Twain (1835-1910), Notebook, 1935

A man will be imprisoned in a room with a door that's unlocked and opens inwards; as long as it does not occur to him to pull rather than push. - Ludwig Wittgenstein

Who breaks the thread, the one who pulls, the one who holds on?
- James Richardson, poet, professor (b. 1950)

Where there is love, there is life. - Gandhi

If I were asked to give what I consider the single most useful bit of advice for all humanity it would be this: Expect trouble as an inevitable part of life and when it comes, hold you head high, look it squarely in eye and say, "I will be bigger than you. You cannot defeat me." - Ann Landers

Life is too short to spend your precious time trying to convince a person who wants to live in gloom and doom otherwise. Give lifting that person your best show, but don't hang around long enough for his or her bad attitude to pull you down. Instead, surround yourself with optimistic people. - Zig Ziglar

If instead of a flower, or even a gem, we should cast the gift of a loving thought into the heart of a friend; that would be giving as the angels give. - George MacDonald, Scottish poet, 1824-1905

The way is not in the sky. The way is in the heart. - Buddha

A Poem by Ondrea Marisa Robinson

My heart is broken,
Because someone stole what was dear to me,
But I am not going to be down,
Because things can be replaced.

My hands are broken,
Because I'm not typing my life away.
But I am not going to be down,
Because my story will be told again.

My eye is broken,
Because I'm not capturing other people and their lives.
But I am not going to be down,
Because I will paint many pictures soon.

Even though I may seem broken inside of me,
I know I won't be down, because God wants me to get up.
And He wants me to stay up and rise up to the top
So I can share my testimony with others.

The weakest living creature, by concentrating his powers on a single object, can accomplish something. The strongest, by dispensing his over many, may fail to accomplish anything. The drop, by continually falling, bores its passage through the hardest rock. The hasty torrent rushes over it with hideous uproar, and leaves no trace behind.

- Thomas Carlyle, essayist & historian (1795-1881)

We live in a wonderful world that is full of beauty, charm and adventure. There is no end to the adventures that we can have if only we seek them with our eyes open. - Nehru

No person was ever honored for what they received. Honor has been the reward for what they gave. - Calvin Coolidge

I've learned that you shouldn't go through life with a catcher's mitt on both hands; you need to be able to throw some things back.

- Maya Angelou

Power consists in one's capacity to link his will with the purpose of others, to lead by reason and a gift of cooperation.

- Woodrow Wilson



Helping All Children Learn to be Buddies By Amanda Gray

What is Learn to be Buddies?

Learn to be Buddies is the name I chose for the series of picture books I am writing, but it has grown to be much more.

The theme of Learn to be Buddies is resilience and the development of social skills. The picture books are written for children aged between 3 and 6 years. They use realistic pictures and true-to-life storylines to demonstrate specific values or social skills in a fun and engaging way. In short, they are like social stories (for more about social stories visit http://www.thegraycenter.org)

Dave is Brave

Dave is Brave is the first book in the series and has just been published. It tells the story of Dave as he defends himself and his friends from Golly, who is being a bully.

"Golly was a bully when
He didn't act like a friend
He'd ride around and knock kids down.
He didn't care he wouldn't share..."

But Dave was brave... and he had had enough.

"He made a stand, held up his hand, put up his head and said... 'STOP!'"

Golly then realises what he has been doing. He says, "Sorry"... and they all play happily together.

But wait, there's more...

But Learn to be Buddies is more than just books. With Dave is Brave there will be an increasing number of additional products to help parents and teachers educate their children about the key social skills contained in the book.

Currently there are four activity plans available for *Dave is Brave*. These include a series of questions for discussion on a social theme and some ideas for behaviour management or reinforcement of the new skill in the child's daily routine.

Then there is a music CD where I narrate the story. The second track is Luke Reed performing a song I wrote to reinforce the key themes addressed in the activity plans. It is called *Be Brave*.

I have also developed two games. The *Feelings Game* is a set of cards sold on disk for parents and teachers to print. These cards represent different emotions and can be used to play memory or snap. The How are You Feeling?! Board Game is also on disk. This game aims to help children learn about appropriate responses to certain feelings.

About Me

All this came from my two passions: supporting children with behavioural and social difficulties and their families, and

writing.

I trained and worked as a special education and early childhood teacher. While I loved teaching, I always longed to use my love of reading and writing. I went back to University to study for a PhD. On this study I began research into the support systems available to families of children with behaviour and social difficulties.

Unfortunately, due to chronic ill health, I have not yet been able to complete this research. However, I have managed to maintain my treasured teaching position at the University of Newcastle. And I have now found time to write... thus *Learn to be* Buddies was born.

Breaking into the Blogging World
An additional branch of Learn to be Buddies is blogging about behaviour at www.learn2bebuddies.blogspot.com. I focus on discussing behaviour management strategies for teachers and parents, as well as promoting understanding of the needs of children with different abilities.

Each month I write on a theme. Themes I have covered to date include "Why aren't you listening? Disobedience or Distraction?" This included discussion of difficulties children may have in hearing, processing, understanding or remembering requests. This covered explanations of difficulties faced by children with Autism, Down Syndrome, ADHD and more.

Other themes I discussed were bullying, resilience and aggression. Each theme is closely related to the issues

addressed in Dave is Brave.

MV Hope for the Future

My desire is not to get rich or famous. Instead, it is to make a difference in the lives of those who really need it. especially hope to help teachers understand and support children with disabilities more effectively in inclusive classrooms. And I also want to help families feel more confident and supported when dealing with the issue of behaviour and social development. If you want to know more, visit www.learn2bebuddies.com.au.

You might also want to drop in and comment on www.learn2bebuddies.blogspot.com, especially if you want to ask a question or give me a topic for discussion for the monthly Ask *Amanda* column.

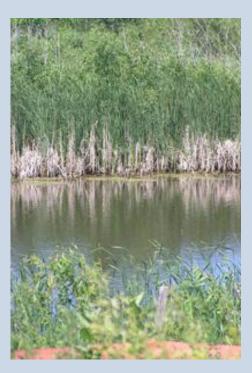
I look forward to connecting with you, and hope what I have written is helpful.

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Autism Arts All In the Family By Jane Strauss with Mina Blyly-Strauss

In my nuclear (which is not to say explosive) family we seem to have both significant autism and significant artistry. My Aspie brother is a professional violist, one acknowledged odd duck of a great uncle was a painter, two of my daughters, labeled in childhood with speech and language delays and autistic like behaviors are artists, my younger son, with a PDD label, has finally gotten the hang of using a pencil and draws and paints in tempera at every opportunity, telling people he will BE an artist, and my older son, a classic Geek, is a Martial Artist.





Mina Blyly-Strauss "Reflections" Jane Strauss "Reflections"

For years, one of my mentors, Enid, has been telling me that the reason my now 26 year old daughter Mina and I conflicted so years ago was because we were too much alike. Mina, of course, insists that she is in no way like me. It is purely coincidental that she is a teacher (and I have been), licensed in Social Studies and Special Ed (and my background is law and public administration, with emphasis on disability rights and all my electives while in the Ed. Program in developmental Psych and Special Ed) and she and I are both artists. Our art is radically different, though we use the same tools, cameras, computers, and printers. (Hey, I am a PC person, and she uses exclusively Apple) For me, Photoshop is a darkroom, and for Mina it is an easel. I photograph things that the neurotypical may miss seeing and she layers photo images into eye candy. Her visual interpretation of reality is

phenomenal. And she uses it (and her persistence AKA stubbornness) to teach art to secondary students with special needs in a Level 4 EBD program in our local school District - the same District which denied her help as a preschooler and elementary age child.







Mina Blyly-Strauss "Kiddie Midway"

When Mina was small, she was one of those girls who slipped through the larger autistiscreen of the 80s by dint of being a female. She spoke early, but her conversation was stereotyped: "The____ goes to the ____ house, has rice cereal and goes to sleep" was a story told about nearly anything Mina happened to see while we were out and about. She was literal in her interpretations of language and objects: When a tester at an early childhood assessment program showed her a Barbie shoe and asked what it was, Mina stated it was a piece of plastic. This was not surprising, as I had no high heels and she had no Barbie dolls or their accoutrements. The tester of course thought her unable to identify a shoe.



"Quilt" Mina



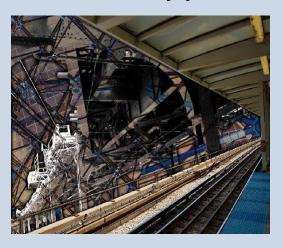
"Dreamworld"

Jane

Her sensory integration was iffy, fine and gross motor skills delayed relative to the typical, motor planning a challenge, and as the oldest of four kids born in 5-1/2 years (Yes, I *know*

what causes this) she was bossy and often aggressive. Both as a baby and now she was and is easily overwhelmed when compelled to interact in large groups over extended times. And, oh yes, she rocked and flapped, though not as much as her next younger sister. But she was a girl, and along with both siblings who were old enough for the local Autism program to observe, she got the label of "Autistic like behaviors", and later became the Poster child for Oppositional Defiant Disorder. None of this was sufficient to get any early intervention however. Contrast that with a few years ago, when Mina worked in the 4 year old assessment program for our schools, and she bemoaned the fact that the majority of kids going through the program were labeled initially as on the Spectrum, though in Mina's opinion 4 of five had a different issue. (And she, like me, is a *good* spectrum spotter.)

"Trains" Mina Blyly-Strauss



"Elevated" Jane Strauss



When Mina started Kindergarten, she already knew that she wanted to work in film and video. However, she could only do that kind of thing through the "Gifted and Talented" program in school. It being school, "giftedness" was defined by how neatly and colorfully the student could draw many things based on a circle. And Mina did not work that way... plus had failed every single gross and fine motor item on the "kindergarten readiness" testing. I was furious, as she had gotten past her initial stereotyped speech and was spinning tales verbally that showed a real command of imagination, and had showed giftedness in a number of other areas as long as she did not have to write or use a pencil. By first grade, it was clear that school was not doing her justice so I began teaching her and the other kids at home, and continued for six years. By second grade, it was clear that her command of spelling and language were difficult, that some perceptual issues were still there, and the person from the schools interpreted Mina's assessment as "the kind of kid who does far better in grad school than in the Primary grades" - and how right he was! Mina started learning from and working with a group that taught youth skills in videography and

digital photography when she was 14, and has been teaching others, curating exhibits, and making art ever since.





"Skylines" Mina Blyly-Strauss

"Foshay" Jane Strauss

Many of Mina's and my images are on similar topics or of similar appearance. For Mother's Day, at a local coffeeshop, I developed a joint exhibit with similar subjects juxtaposed. The images in this article were drawn from that show, with similar colors, subjects, and completely different execution. Mina adds together details to form a whole, while I pick out the details from the whole.

Websites:

Mina: http://www.mnartists.org/artistHome.do?rid=111165

Jane: http://www.janesprints.com

Awareness is like a staircase: each step brings you up one more level, and the farther you ascend, the more you can see.
- Peggy McColl

The cyclone derives its powers from a calm center. So does a person. - Norman Vincent Peale

Power is so characteristically calm, that calmness in itself has the aspect of strength. - Edward G. Bulwer-Lytton

Silence is the severest criticism.
- Charles Buxton, brewer, philanthropist, writer & politician

Judge me all you want, but keep the verdict to yourself. - Anon

The strongest principle of growth lies in the human choice. - George Eliot

A Model Program for College Students on the Spectrum:

College can Be Hard. Do You Struggle With:

- > starting a conversation
- keeping conversations going
- > planning for upcoming events
- > getting stuck on special interests
- > getting social cues
- > keeping friends
- understanding jokes



Come join our Social Outreach Network

When: Wednesday, October 7th 2009 at 7 pm
Please call Jennifer Gibson at SDC for more details
(530)752-3184

Social Outreach Group

<u>jgibson@ucdavis.edu</u> (530)752-3184 The Gifts of Autism Webpage by Lori Gahana Shayew

Have autism? Know someone who does? Want to learn more? I'd like to invite you to an uplifting Autism group I started on Facebook, called "The Gifts of Autism". Our group attracts people from around the globe where we share positive stories, experiences, friendship, support, videos, articles and a whole lot more. Our members include everyone under the sun. Point your mouse here to join us: http://www.facebook.com/group.php?gid=47468152956

Look forward to meeting you there.



The Gifts of Autism

A positive look at Autism. Stories, experiences, support, and positive ways we see Autism in our lives. Please feel free to post your own topics. This is our group.

I had rather take my chance that some traitors will escape detection than spread abroad a spirit of general suspicion and distrust, which accepts rumor and gossip in place of undismayed and unintimidated inquiry. - Learned Hand, jurist (1872-1961)

Virtue is nothing else but action in accordance with the laws of one's own nature. - Baruch Spinoza (1632-77)

Beware of those who do nothing constructive with their precious few moments on this earth, for they seek to squander your allotted time with the same reckless abandon. - Guy Finley

A person should set his goals as early as he can and devote all his energy and talent to getting there. With enough effort, he may achieve it. Or he may find something that is even more rewarding. But in the end, no matter what the outcome, he will know he has been alive. - Walt Disney

You should set goals beyond your reach so you always have something to live for. - Ted Turner

Few things are harder to put up with than a good example. - Mark Twain

A man who works with his hands is a laborer; a man who works with his hands and his brain is a craftsman; but a man who works with his hands and his brain and his heart is an artist. - Louis Nizer

Too often we give our children answers to remember rather than problems to solve. - Roger Lewin

Life is a sort of splendid torch which I have hold of for the moment, and I want to make it burn as brightly as possible before handing it over to future generations.

- George Bernard Shaw

Education is hanging around until you've caught on. - Robert Frost

The road to happiness lies in two simple principles: find what it is that interests you and that you can do well, and when you find it put your whole soul into it - every bit of energy and ambition and natural ability you have. - John D. Rockefeller III

Americans are incredibly impatient. Someone once said that the shortest period of time in America is the time between when the light turns green and when you hear the first horn honk.

– Jim Rohn

Wisdom is the reward you get for a lifetime of listening when you'd have preferred to talk. - Doug Larson

To be sensitive is to feel the thoughts and hearts of others as only you would want yours felt. - Unknown

Love is a better master than duty. - Einstein

To succeed... you need to find something to hold on to, something to motivate you, something to inspire you. - Tony Dorsett

This is the nature of genius, to be able to grasp the knowable even when no one else recognizes that it is present. - Deepak Chopra

Ideals are like stars; you will not succeed in touching them with your hands, but like the seafaring man on the desert of waters, you choose them as your guides, and following them you reach_your destiny.

- Carl Schurz, German born American politician, 1829-1906

Anyone who thinks the sky is the limit, has limited imagination. - Anon

What signifies knowing the Names, if you know not the Natures of things. - Benjamin Franklin

And the trouble is, if you don't risk anything, you risk even more. - Erica Jong

Most of us tend to suffer from "agenda anxiety," the feeling that what we want to say to others is more important than what we think they might want to say to us. - Nido Qubein

Forgiveness is the attribute of the strong. - Gandhi