Sharisa Joy's Voices and Choices of Autism - Sharing Worldwide Rainbows of Love, Joy, Hope, Respect and Acceptance

We could all learn more
and make this a world of
peace, hope and joy.

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My mind is filled with awe and delight
all day long and half the night. - Sharisa Joy

Not being able to speak
is not the same as having nothing to say. - Anne McDonald

Then there are those who don't shut up,
yet never say anything meaningful. - Sharisa Joy

Warning: Additional Poetry & Quotations May be Found Anywhere!

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It's not that I'm so smart,
it's just that I stay with problems longer. - Einstein

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Hatred is so counter-productive -
we need to make it counter-intuitive!

I have many words of wisdom and wit
If one could just make sense of it.

All my words are always right,
Though they may differ day from night.

It is up to me to heal my soul;
It all is under my control.

If I had a mind to tell you what's on my mind,
You'd be required to tell what's on yours;
But the depths of my mind
Are so unfathomable,
I fear some might drown in the riptides.

The things that I find are on my mind
Are not the thoughts of someone who’s blind
To the world around that's so insane
Or how it feels to a weary brain,
Soul and spirit that yearn to be free
From chains that bind and shackle me.

Have you ever *really* noticed people around you?
Have you wondered what's inside?
Have you wondered if the faces you see
Merely mask the ones they choose to hide?

On my mind are many things:
Poets, painters, frogs and kings;
Goddesses in flowing gowns,
Wearing shiny diamond crowns.

Flattery will get you nowhere
With someone who doesn't care
About the words you type and say
As much as wisdoms that we share.

Words unless they're real are empty,
Words unless they feel are cold,
People may try to exempt me,
But feelings are truly more precious than gold.

There’s so much in my mind that I try not to mind
What's on my mind as long as others don't mind
Waiting while I try to unwind
The ties that bind my busy mind.

I think it's far easier to be something different from what you appear - look at the world, its people and their behaviors and tell me what you would define as "normal". I want to be me, could do with less disabilities but am playing the hand I've been dealt the best I can and thank the universe for giving me a father, grandparents, a sister, a brother-in-law, a “stepmother” who's the Mom I always wished I had, good friends, and others who understand my differences are what make me uniquely ME!

Sharisa Joy Revised 7-5-09 - To My Father:

In my life that’s too often confusing and vexing,
And far too frequently filled with grief,
Anxiety, sorrow, and perplexing
Pain and panic beyond belief;
All the times when I’ve feared that I shall never
Free my sad truths from all the lies,
One thing shined crystalline clear forever -
The love I see in your deep, dark eyes.

It’s my strongest shelter against a storm,
It blocks out icy and fills me with warm
Tender, gentle and all that’s alive;
In my emptiest moments, it helped me survive
The horrible pain and panic and fear
That sought to devour me year after year.

You taught me to think, to care, to hope
To learn and grow, love and cope.
You never gave up, so neither did I,
Even when I felt I should surrender or die.

You’re much more than parent, teacher or friend,
More than gold at my rainbow’s end,
More than I ever could possibly say -
You’re light, sound and life I cling to each day.

So I’ll keep doing all
You’ve taught me to do -
That’s the truest of gifts
I can offer to you!

No sensible decision can be made any longer without taking into account not only the world as it is, but the world as it will be.
- Isaac Asimov

Perseverance is not a long race;
it is many short races one after the other.
- Walter Elliot (1842-1928)

Life is not easy for any of us. But what of that?
We must have perseverance and above all confidence in ourselves.
We must believe that we are gifted for something,
and that this thing, at whatever cost, must be attained.
- Marie Curie (1867-1934)

In the June Premiere Issue, we were fortunate to present an excerpt from *Paper Words, Discovering and Living With My Autism* by Judy Endow. Due for release July 2009 through Autism Asperger Publishing Company www.asperger.net – here is another one!

As far back as I can remember, I knew I was “different.” Over the years, a smorgasbord of psychiatric labels have been used to describe my differences. At the time of this writing, I have been living with my autism label for nearly a decade. I now understand that it is highly unlikely I ever really had any of the mental illnesses that were attributed to me. Instead, I have had since birth what is now known by the medical profession as a neurologically based disorder of the brain called autism.

I thought that after so many years, there was nothing as wonderful as getting a label that finally fit! I immediately became a sponge, absorbing information about autism, reading everything I could. I was glad to have kept much of my poetry from the years before I received the autism diagnosis, as the poems accurately reflect so many aspects of autistic life. At the time I penned the poems, I wrote about what was inside me as a way to try to understand myself and my experience in and of the world around me. Little did I know these poems would ever hold any interest to anyone other than me.

It was extremely liberating to finally be able to understand the movies in my head as an autistic style of thinking rather than a mental illness, a nervous breakdown or being possessed by demons. And now that much of my yester-years have been sorted out, I have become aware of the privilege of being able to move into the future of my life. For so many years until receiving my autism label, during times in my life when my differences would show, I always looked towards that day in the future when I would no longer have the so-called mental or demonic problems. Now I know better. Now IS that future!

So, come along
once again

and travel with me
as walking
hand in hand

together we
survey this
new road

called Today

as I begin
to embrace
my autism

loving the
“real” of me

just as I am …

learning to live
comfortably with

the autism of me
in my Now

No Druthers

If she had

her druthers,

would she

rather be

a part of

world commonality?

Not really.

She’s content

in being

who she is

inside

her own skin,
walking around

in the world

outside her,

often bumping up

against differences

causing her

to sift for sameness

to make a match

with the insides

of another,

knowing that

at least one

universal difference

for each person

is known –

accounting

for individuality

in that world-sea sameness

to which

we all cling to

for life

while supporting

diversity’s greatness,

but secretly

not wanting

to be

any different

from others.

What a mind-boggling

dichotomy!

Regardless of

who we are

or

how our being

has been formed,

it’s only when

we are able

to embrace

this dichotomy’s
two sides

rather than

choosing

one or the other

that we can

truly

live with

ourselves

inside our

world-people planet

feeling

mostly comfortable

with our

own insides

and outsides

and with

one another.

Even though I am inherently perfect just as I am (just as God created me) I often choose to learn how to become more comfortable in my body, which in turn allows me to be more comfortable in the world around me. The long-ago discoveries I made about my inside wiring and my collection of little stones that represent the WHO, the HOW and the WHAT of me now make complete sense.

Today I accept the WHO, the HOW and the WHAT of me as the way I am, an intrinsically good creation! Indeed, these days I am becoming quite comfortable with the person of me inside my skin

the real of me

just as I am

perfect and
complete

and incredibly free –

free to be

the WHO
the HOW
and
the WHAT of me

with Paper Words
now telling my story –

today
being comfortable
inside
my own skin

no longer
needing to hide

any autistic
neurology …

AND

in charge of
choosing

when and where
to copy

the ways
of the world

to maximize
personal efficiency

BIO: Camilla Connolly is an ASD woman and painter, based in northern NSW in Australia. Painting is her first love and special interest. She paints all the time and is represented by major galleries in her country. Her website is www.camillaconnolly.com

Colour House

We Are All From the Garden

Room of My Own

In creating, the only hard thing is to begin:
a grass blade's no easier to make than an oak. - James Russell Lowell

Please understand my friend, that where you find yourself tomorrow
is a function of the positive decisions and actions you take today. - Akin Awolaja

If you can prove to yourself that you have the ability
to break through the veil of ordinary reality,
you can go on to do things that once seemed impossible or magical.
- Deepak Chopra

Faith is only limited by the believer. - Bob Perks

Patience and perseverance have a magical effect before which difficulties
disappear and obstacles vanish. - John Quincy Adams (1767-1848)

There is a boundary to people's passions when they act from feelings;
but none when they are under the influence of imagination. - Edmund Burke

'Tis a pleasure to share with those who care. - Sharisa Joy

Melissa Weber is a writer and editor whose goal is to educate and encourage others by writing about her experiences as an adult and as a professional living with Asperger's Syndrome, a form of autism. She may be reached for comment at asadultsdetroit@yahoo.com

In My Voice: An Autistic Speaks by Melissa Weber

DIAGNOSIS: My "character flaw" has a name!

"I want to discuss a diagnosis with you," said my psychologist, leaning forward in her chair. "It's called Asperger's Syndrome. I think you have it."

A week earlier, I had come across the term on my own and Googled it. Reading the characterizations of those with Asperger's was like looking in a mirror. I recognized mannerisms, ways of thinking, social, communication, and emotional difficulties that had been with me my entire life. In fact, I had called my psychologist and asked her if she thought Asperger's might be what was wrong with me. I had been seeing her for a few months, having been referred to her by a neuropsychologist who had been treating me for a mild traumatic brain injury (TBI); I was experiencing attention, emotional, communication, and behavioral problems that just wouldn't go away and did not make sense, given how mild the injury had been. I remembered some of the same problems occurring in childhood, and they were really dragging me down. I had taken to calling the problem a "character flaw," because it was driving people away from me, and had adopted a very dim view of myself. I was very anxious and stressed, and had had performance issues at work since the accident due to the post-TBI problems.

Serendipitously, an emotional outburst - frustration over my social life, or lack thereof - is what clued the psychologist in to the possibility of Asperger's Syndrome. As we dug into the reasons for the emotional outburst (what I now know to have been an autistic meltdown), I found myself telling my psychologist about a lifetime of difficulty fitting in, understanding the "rules" of making and keeping friends, often being left out, and always feeling as if I was on the outside looking in. This, along with other, more subtle indicators, led her to make the Asperger's Syndrome diagnosis and determine that the problems I had been having were actually autistic behaviors.

Although I went undiagnosed until my late 30's, I nevertheless managed to figure out ways to hide these behaviors as a survival skill. I had to; as a child, I was frequently the object of bullying and ostracism. Unfortunately, the TBI caused me to lose these camouflage skills, uncovering the Asperger's once more.

My reaction to my diagnosis was surprising, at least to me: relief, exhilaration almost. My problem had a NAME. A lifetime of "whys" finally had an answer; and, most importantly, there was help available.

5 Tips to Making Back to School Easier

By Michelle Wagner M Ed., ECIS

It's that time of year again; time to go back to school. While many children are excited about returning to school, children with autism often experience a great deal of stress and anxiety during this time of year. Even if your child is going to the same school building they attended the previous year, this still means change for your child as there will most likely be new children, there may be a new teacher, and possibly a new classroom. Because these things can cause children with autism to have some major meltdowns at the beginning of the school year, this article will outline five tips to help make this transition go more smoothly for you and your child.

1. Get Prepared: A few weeks before school starts, talk to your child about the coming end to the summer routine. Start talking about how things will change when they go back to school. Talk about what things will change for them such as will they have a new babysitter, will they ride the bus, etc. Try to help them understand that their daily routine will be different soon and then explain to them how.

2. Use Social Stories: Social StoriesTM were developed by Carol Gray of the Gray Center for Social Learning and Understanding in Grand Rapids, Michigan. A social story is a short simple story, often with pictures, that talks about an event or situation. You can write your own social story or use one that someone else has already written, but it is always good to personalize the story so your child feels like it applies to them. You can use your child's name, the name of their new teacher or teachers, and/or the name of their school as well. Because most children with autism are visual learners, a social story will often help ease their anxiety. For more information about social stories or Carol Gray you can visit www.thegraycenter.org

3. Use a Visual Schedule: A visual schedule is another strategy that's often helpful for children with autism. You can use pictures or symbols or simply words to let your child know what is going to be happening. Use a picture for each activity your child will be doing during the day. For example, getting out of bed, getting dressed, eating breakfast, getting on the bus, etc. You can also use a schedule to get the child through the school day. Often visual cues will go a long way towards easing the stress and anxiety and will help the child know what to expect.

4. Meet with Team Members: It may be important for you to meet with the members of your child's team. This includes the principal, therapists, teachers, assistant teachers etc. Doing so

will give you an opportunity to share with them your child’s strengths as well as their weaknesses. It will also give you a chance to give them some tips on how to help your child work through difficult moments that may happen during the school day. You can also share or revisit the IEP so that everyone is familiar with your child’s goals. This will also give the school staff a chance to ask you any questions they may have. This meeting can be beneficial for everyone involved.

5. Take Your Child to Visit the School Building and the Classroom: A couple weeks before school starts, if at all possible, take the child to visit the school building and the classroom. It’s ideal if the new teacher will agree to meet you there so your child gets to see him/her ahead of time. It may also be helpful for your child to meet the principal and other office staff as well as any other important staff in the building. You can also take a picture of these staff members to use in your social story. Even if your child is not changing school buildings this is often helpful so that they know what to expect and can adjust to the change in classroom teachers or just a change in routine.

No matter which of these steps you use, or whether you use any of them at all, the important thing is to find some way to help ease your child into the new school year. Three months is enough time for any child to lose touch with the school year routine, but because children with autism thrive on routines, readjusting to the structured school day can be even more challenging. Once summer has come to an end, it’s important that the readjustment process be as easy and comfortable as possible for both you and your child. For more information please visit: www.theautismconnection.org

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Life is mostly froth and bubble;
Two things stand in stone:
Kindness in another's trouble,
Courage in your own.
- Adam Lindsay Gordon

Nature and nature's laws lay hid in night;
God said “Let Newton be” and all was light.
- Alexander Pope

It did not last:
the devil, shouting “Ho, Let Einstein be”
restored the status quo.
- Sir John Collings Squire

Debatewise by Leo Arthur Capella - Current Intern at Debatewise

Think about it for more than a second: Two opinions colliding in a structured format in a neutral venue causing people to be better informed about the arguments at stake. Well that was the idea behind the formation Debatewise in late 2008 and the site has expanded since then. It's also expanded from one-to two people to a group of five interns working out of the creative equivalent of Clapham Junction (a massive railway junction in the UK) of which I'm one, having joined at the start of May this year. I joined partly because I wanted to get involved in a certain event below but also because I wanted to join something that allowed me to help spread debating. This was something I'd never really managed to do at university or at secondary school and getting the chance to take part in and promote debates has been something that I have enjoyed doing over the past month I have been here.

The easy way to think of Debatewise is as a sort of debating version of Wikipedia although it can be used for a wide range of purposes such as revision for exams both in university/college and sixth form. Debatewise is holding the first World Online Debating Championship this summer with registration ending in late July and the championship beginning in early August. This will be made up of 32 teams competing over five rounds in a straight knockout tournament that brings together the length of test cricket with the cut and thrust of politics at Westminster.

What Debatewise really needs though is content and that's where you the reader and thinker come in. We're looking for intelligent, independent minded volunteers who would be interested in joining the Debatewise Rapid Response Team. This would involve writing new debates or adding points and counterarguments on current issues over a wide range of different areas from "Should schools be teaching skills like empathy?" (This is an actual title of a debate and a possibly contentious issue for autistic people) to whether "Britain should introduce proportional representation" for the houses of parliament. You don't just have to have an interest in politics to participate; there are lots of other areas such as sport or business where you can make a contribution. You can be of any age to be part of the team. The current intake of people are mostly students or recent graduates but we're expecting a lot of them to move on as the academic year ends and people graduate so we're looking for a new class of 2009. This gives us and you an opportunity to gain new voices from different areas that normally wouldn't be involved or approached. This is something that is particularly important to me as I believe freedom of speech is a crucial part of self determination for disabled people. I believe Debatewise offers another valuable outlet to the online disability community (which includes autistic people).

It offers a chance to debate and observe debates on relevant issues with more focus on the facts and arguments of a debate and without the personal attacks that tend to distort matters on both sides of the argument.

If you joined The Rapid Response Team each week we'd e-mail you a list of subjects and you'd be able to choose what debates you created or worked on to strengthen. In return you would get a reference for the work you put in, something that has helped past interns go on to find paid work because getting debate experience and working for a not profit is good on a CV. You'd also get a mysterious not so mythical thing known as Karma which is Debatewise's way of expressing appreciation and quantifying the work you put in against the other users on the site. And above all, you'd get the chance to use your brain to the best of your abilities by developing, honing and maintaining research and debating skills. Maybe it will give you a chance to develop your thoughts on some issues too. Both of those last two reasons particularly apply to me as I have managed to hone and reignite some old debating skills as well as maintain my research ones which should put me in good standing when I go to start a masters in International Security at Warwick in October.

To join, what you need to do is to contact dave@debatewise.com to sign up and register online at www.debatewise.com, which you can also do if you want to participate without being an intern.

**Greatly begin.
Though thou have time,
But for a line,
Be that sublime.
Not failure,
But low aim is crime.
- James Russell Lowell**

**I'd rather see a sermon
Than hear one any day;
I'd rather one should walk with me
Than merely tell the way.
- Edgar Guest, poet (1881-1959)**

**With erosion, even the hardest rocks melt,
turning hatred into emptiness. - Raymond Lam**

**You can ask the sky to summon the wind,
but the sky will summon what wind it will. - Unknown**

Life’s Challenges of An Autistic Person

by Jocelyn Plowey, Woodlands, Texas

We often overlook or take for granted what life offers or bestow upon us. How precious life is for each human being, distinguished in its own way. How we look at each individual life style. A lifestyle of an autistic person, so different from us, set in his or her own autistic ways. A unique, a different person, with such gifted talent and intelligence beyond us, yet having some difficult aspects to deal with in life because of a developmental delay on their part! How life treats them to try overcoming the changes of the “spectrums” that leads to Autism! The challenges to learn “life skills” to improve their behavior and master independence leading towards their mainstream in society. A society which needs to embrace them for who they are, accepted as an “individual unique person”, somewhat different in a special way, which can still make a difference in society and learn from them!

We all, in general, struggle with our own aspects of life and somehow can cope with them. An autistic person has more difficulty in doing or showing these sides of their life. Nevertheless, life has its rewards in the end by fulfilling the dreams of accomplishments for everyone who wants to succeed in doing so. The life challenges of an autistic person have their rewards too! As a parent of an autistic six year old daughter, I am leading towards her mainstreaming in society. I see many improvements, challenges she has accomplished over the two and half years of being diagnosed as having the spectrum of PDD, a sort of Autism. In our eyes, she will always be autistic, unique, and will be labeled by society as autistic and different. To us, she is precious, loving, gifted, intelligent, talkative, funny, understanding and can relate to things in general, she is no different from us. She can succeed in life, overcoming obstacles that will come her way. She has her frustrations and anxiety, tantrums that come with the spectrum of Autism, but she will learn how to deal with this as who she is. Her challenges await her in years to come as a learning process to cope with life. We have all had our shares of troubles too! No one is perfect! We all learn from each other and help each other on our journeys to success. The world is made up of human beings, to be appreciated, love and live in harmony. No matter how different we are, this is what makes all of us unique in our own ways, not only autistic people.

Silence is the great teacher,
and to learn its lessons you must pay attention to it.
- Deepak Chopra

Think twice before you speak, because your words and influence will
plant the seed of either success or failure in the mind of another.
- Napoleon Hill

The Promise of the Morning Star
by Amy Lowell

Thou father of the children of my brain
By thee engendered in my willing heart,
How can I thank thee for this gift of art
Poured out so lavishly, and not in vain.
What thou created never more can die,
Thy fructifying power lives in me
And I conceive, knowing it is by thee,
Dear other parent of my poetry!
For I was but a shadow with a name,
Perhaps by now the very name's forgot;
So strange is Fate that it has been my lot
To learn through thee the presence of that aim
Which evermore must guide me. All unknown,
By me unguessed, by thee not even dreamed,
A tree has blossomed in a night that seemed
Of stubborn, barren wood. For thou hast sown
This seed of beauty in a ground of truth.
Humbly I dedicate myself,
And yet I tremble with a sudden fear to set
New music ringing through my fading youth.

You cannot be grateful and bitter.
You cannot be grateful and unhappy.
You cannot be grateful and without hope.
You cannot be grateful and unloving.
So just be grateful. - Unknown

Great minds must be ready
not only to take opportunities,
but to make them. - Colton

The minute you start talking about
what you're going to do if you lose,
you have lost. - George Shultz

As I grow to understand life less and less,
I learn to love it more and more. - Jules Renard

To freely bloom - that is my definition of success.
- Gerry Spence, lawyer

A huge THANK YOU to: Patricia E. Kefalas Dudek & Associates Advocate for Elders, People with Disabilities and Their Families For Linking our magazine to their site!

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Patricia E. Kefalas Dudek is an involved and passionate advocate for her clients. She practices in the areas of elder law, probate and estate planning, and disability rights. She concentrates her practice in the area of estate planning for people with disabilities, elders, and their families. Her practice includes advising and preparing estate planning documents, including special needs trusts; representation in Medicaid matters to secure appropriate mental health, long-term support, medical services, and housing; and the administration of estates and trusts, guardianship, conservatorship, and other protective arrangements.

A member of the Oakland County Bar Association, Ms. Dudek is a member of the State Bar of Michigan and is a council member and past chairperson of its Elder Law and Disability Rights Section. As an advocate for persons with disabilities, she is an active member of the National Academy of Elder Law Attorneys, a past chairperson of its Trust Special Interest Group, and the 2005 recipient of the academy's Powley Award. In addition, she is secretary of the board of directors of the United Cerebral Palsy Association of Metropolitan Detroit.

Ms. Dudek has written and lectured extensively on topics related to estate planning for people with disabilities and their right to control their support services. Ms. Dudek is the author of the model contracts for Michigan's Self Determination Initiative. The first attorney in Michigan to draft a Pooled Accounts Trust for Medicaid planning, Ms. Dudek advises individuals, their families, and the organizations that established these trusts on their use to develop creative public and private solutions for the support and housing needs of elders and people with disabilities.

Contributions Ms. Dudek has made to publications by the Institute of Continuing Legal Education:

Advising the Older or Disabled Client, Third Edition
A comprehensive guide for lawyers who advise older clients and clients with disabilities. Covers long-term care, health care benefits, Medicare and Medicaid eligibility, guardianships and conservatorships, special needs trusts, and Social Security benefits.

Michigan Guardianship and Conservatorship Handbook, Revised Edition
A step-by-step guide to Michigan guardianships and conservatorships. Covers guardianships for legally incapacitated persons, minors, and developmentally disabled persons, as well as alternatives to guardianship. Includes sample forms.

ICLE Partnership - How-To Kit: Appoint a Guardian for a Developmentally Disabled Person

Patricia E. Kefalas Dudek Recognized in the Field of Elder Law

We are proud to announce that Patricia E. Kefalas Dudek was recently honored at the National Academy of Elder Law Attorneys (NAELA) Annual Conference, which took place April 1-5, 2009, in Washington D.C. Ms. Dudek was one of four attorneys bestowed the organization's highest honor of becoming a NAELA Fellow. The other three award recipients included Barbara Hughes of Madison, Wisconsin; Ruth Phelps of Pasadena, California; and Howard Krooks of Boca Raton, Florida.

An NAELA Fellow is an attorney who concentrates his or her practice in the field of Elder Law, has been a member of NAELA for at least three years, and has made a significant contribution to the field of Elder Law. According to NAELA, Elder Law attorneys focus on the legal needs of seniors and people with disabilities. They work with a variety of legal tools and techniques to meet the goals and objectives of their clients on issues such as estate planning and probate, long-term care, health care decisions, Medicare and Medicaid, age discrimination and elder abuse.

Ms. Dudek is proud to be honored in the limited elite group of 76 attorneys who hold this title throughout the United States.

The mission of NAELA is to establish its members as the premier providers of legal advocacy, guidance, and services to enhance the lives of people with special needs and people as they age. For more information on this association, visit the NAELA website.

Gillian Naysmith Bio:

My name is Gillian, I am Mum to 2 beautiful kids, Jaymi, my Daughter is 8 yrs old and an Angel to her little Brother, Sam who is almost 4 and has a diagnosis of Autism and Global Developmental Delay. Sam was diagnosed just over 2 yrs ago and is still non-verbal at the moment. Sam has never had any speech nor did he regress in any way.

Gillian and Sam

I began writing my poems not so long ago and to me it was just a way to vent my feelings without burdening others with them. I posted a few on Facebook to begin with and now I am in the process of trying to publish them. Thank you Sharisa for taking an interest in them, as a person on the spectrum yourself your opinion meant the world to me.

YOUR VOICE

I wonder how your voice would sound
if you could say my name,
you make cute little noises,
would your voice just sound the same?
I wonder if your voice would be
quiet or very loud,
Would I hear you way above
the noise of any crowd?
I wonder if your voice will be
just like in my dreams?
For in my dreams you talk to me,
at least thats how it seems.
Each morning as I get you up,
I hope 'today will be the day'
that you will turn around to me
and your first word you will say.
In a few short weeks you will be four,
in my heart I know you've time,
speech could still be years away,
I just wish I had a sign
that one day, it will come
and I will hear your voice,
and you will chat away to me,
you will make lots of noise.
So I wonder how your voice will sound,
If 'Mummy' you will say,
But know I love you as you are
and I will love you come what may!

AUTISM WISE

We need to raise awareness
Autism is on the rise,
People really have to know
they have to realise.
Statistics rising all the time,
numbers increasing everyday,
It's a worldwide situation
we have to find a way
to make people listen
to exactly what is said.
We have to get the knowledge in
and keep it in their head.
Autism knows no boundaries,
not religion, sex or race,
don't think it won't affect you
because it may not be the case.
So everybody worldwide
no matter where you are,
lets stand together Autism wise
friends from near and far.

THE PERFECT SISTER

Jaymi is my little girl,
she is perfect in every way,
just a hug or smile from her
helps me through the day.
I have never, ever known a child
to always be so kind,
sometimes I see her look at me,
like she could read my mind.
She's an Angel with her brother
tries her best to understand
how to cope with his Autism
and lend a helping hand.
She never gets cross with Sam,
she'd never raise her voice.
She'd stay and play with him each day
if she had the choice.
I've never seen her angry,
she's never been really mad,
sometimes though, I look at her
and can tell that she is sad.
She thinks of Sam all the time
and wonders when he'll speak,
sometimes when he's sleeping
she sneaks in to have a peak.
She is really very caring
and she's also very calm.
She is the perfect Sister
for her little Brother, Sam.
It must be very hard for her
infact it must be tough,
Sam takes up so much of me,
does Jaymi get enough ?
We try to do some girly things
just the two of us,
but sometimes even that gets hard,
when Sam creates a fuss.
She sometimes gets quite upset
if people stop and stare
when Sam is having a hard time,
it really is unfair.
After all she is only eight,
she is just a little girl
all of this Autism stuff
makes her mind a whirl.
But Jaymi is so special,
she is my pride and joy,
she does everything she can
to help our little boy!

Kay Scully

I was born September 15th, 1986. Around five weeks later, I was diagnosed with Asperger's Autism because I traced the circles on my car seat. However, I never let the autism stop me, even when things were harder for me to do. Mom said I would focus on circles and trace them over and over. I also spoke at 6 months and then didn't again until I was over a year – my first word was vacuum and then I spelled ice when I saw the ice truck. I hated taking my socks off, even to bathe. I would pull instead of pushing when getting dressed. I was also a math genius of sorts (I could add 40 numbers in my head and get the number correct) – college algebra was a different thing all together (I wept over that math). I remember being very discouraged about the reading and crying because I couldn't. I was 8 and still reading a book meant for babies and felt accomplished I completed it myself. Then came Harry Potter and I haven't stopped reading. School was a challenge because I could not read until I was 10 – I had no idea that words meant anything. But, I have graduated from college with a B.S. in social science with a double major in American and world history. I am now preparing to start my MFA in creative writing this fall. My dreams are to be a writer and to teach college level literature or creative writing classes.

All Different, But the Same by Kay

No two persons are alike. Everyone has different positive and negative attributes that make up who they are. The beliefs an individual has varies from one to another. Each person has different likes as well as different dislikes.

And yet, people make connections with one another. Bonds are made through a person's beliefs. The same likes and dislikes that every person has links people, even though what a person is interested in varies considerably.

The same is true for autistic people. No two auties are alike. Someone once said, “When you've met one autistic, you've only met one autistic”, and that is too true. Just as no two persons are alike, no two autistic persons are alike, even though they can be lumped into one, mish-mashed faction of people.

This is not true. As stated, there are many variations among autistic people. What is true is the fact there are similar keynote traits that make up this specific spectrum. There can be learning problems as well as social tribulations. Many times there are also language difficulties. Autistic people also tend to create coping mechanisms to deal with stressful situations and they usually are passionate about a set of topics.

Each autistic person is an individual person. If one would take a sampling, there would be quite a few differences. One might be fluent in the spoken word but unable to read and vice versa. Another might be a prodigy but cannot memorize facts or day-to-day routines while the person next to him or her might be a walking encyclopedia but has no other talent.

It does not matter if there is a disability involved or not, everyone is different. Ultimately, these differences unify people no matter who they are or what they do or even if there is a medical or mental condition involved. Autistic people are different, but so is everyone else and because of that, they are the same.

Great minds must be ready not only to take opportunities, but to make them. If you don't get what you want, it's a sign either that you did not seriously want it, or that you tried to bargain over the price. - Rudyard Kipling

An unmistakable trait of every true genius is their persistent awareness of how much more there is to know. And an unmistakable trait of every true sage is their persistent awareness of how much more there is to love. - The Universe

If a man would register all his opinions upon love, politics, religion, learning, etc., beginning from his youth and so go on to old age, what a bundle of inconsistencies and contradictions would appear at last! - Jonathan Swift

I can honestly say that I was never affected by the question of the success of an undertaking. If I felt it was the right thing to do, I was for it regardless of the possible outcome.
- Golda Meir (1898-1978)

Love doesn't need reason. It speaks from the irrational wisdom of the heart. - Deepak Chopra

NEW STUDY PINPOINTS DIFFERENCE IN THE WAY CHILDREN WITH AUTISM LEARN NEW BEHAVIORS

Kennedy Krieger and Johns Hopkins Researchers Examine the Brain Basis of Motor Control, Imitation and Social Function Deficits

July 6, 2009 (Baltimore, MD) – Researchers from the Kennedy Krieger Institute and Johns Hopkins University School of Medicine have collaborated to uncover important new insights into the neurological basis of autism. Their new study, published in the journal Nature Neuroscience, examined patterns of movement as children with autism and typically developing children learned to control a novel tool. The findings suggest that children with autism appear to learn new actions differently than do typically developing children. As compared to their typically developing peers, children with autism relied much more on their own internal sense of body position (proprioception), rather than visual information coming from the external world to learn new patterns of movement. Furthermore, researchers found that the greater the reliance on proprioception, the greater the child’s impairment in social skills, motor skills and imitation.

Previous research has shown that children with autism have difficulty with motor skills, which appears to be associated with abnormalities in how the brain learns motor actions. To study the models formed in the brain when children with autism learn a new movement, researchers measured patterns of generalization as 14 children with autism and 13 typically developing children learned to reach using a novel tool. They then examined how well children were able to generalize what they learned in two separate ways – one that detected how much they relied on visual information to guide learning and one that detected how much they relied on proprioceptive information to guide learning.

“These findings can lead to important advances in methods for treating autism. Applying the knowledge gained in the current study, targeted interventions can be developed that enhance visuo-motor associations in children with autism as they learn new skills,” said Dr. Stewart H. Mostofsky, study author and a pediatric neurologist in the Department of Developmental Cognitive Neurology at the Kennedy Krieger Institute. “If done early enough, this could help to improve development of motor, social and communicative skills in children with autism. Further, it could also improve their ability to understand social cues because the brain systems critical to forming internal models of behavior that guide our actions are also critical to developing an understanding of the meaning of those actions.”

The study findings also provide support for observations from previous studies suggesting that autism may be associated with abnormalities in the wiring of the brain; specifically, with overdevelopment of short range white matter connections between neighboring brain regions and underdevelopment of longer distance connections between distant brain regions. The findings from this study are consistent with this pattern of abnormal connectivity, as the brain regions involved in proprioception are closely linked to motor areas, while visual-motor processing depends on more distant connections.

“These findings not only demonstrate why children with autism have difficulty learning motor skills, but also provide real insight into why these children have difficulty learning to interact with the world around them,” said Dr. Reza Shadmehr, senior study author and Professor of Biomedical Engineering and Neuroscience at the John Hopkins University School of Medicine. “If the way their brain is wired is not allowing them to rely as much as typically developing children on external visual cues to guide behavior, they may have difficulty learning how to interact with other people and interpret the nature of other people’s actions.”

Potential next steps include the use of neuroimaging to investigate whether or not proprioceptive versus visual feedback is actually associated with abnormal patterns of structural and functional connectivity in the brain of children with autism. Additionally, researchers may study if patterns of motor learning can be altered to increase visual connections in specific regions of the brain. Through interventions such as cortical stimulation, biofeedback and behavioral approaches, researchers are looking to investigate if there is an improvement in children with autism’s ability to rely on visual input to guide how they learn a range of behavioral skills.

About the Kennedy Krieger Institute:

Internationally recognized for improving the lives of children and adolescents with disorders and injuries of the brain and spinal cord, the Kennedy Krieger Institute in Baltimore, MD serves more than 13,000 individuals each year through inpatient and outpatient clinics, home and community services and school-based programs. Kennedy Krieger provides a wide range of services for children with developmental concerns mild to severe, and is home to a team of investigators who are contributing to the understanding of how disorders develop while pioneering new interventions and earlier diagnosis. For more information on Kennedy Krieger Institute, visit www.kennedykrieger.org

About the basic sciences at the Johns Hopkins University School of Medicine

The mission of the Institute for Basic Biomedical Sciences at the Johns Hopkins School of Medicine is to promote the fundamental research that drives advances in medicine. By fostering a unique and collaborative environment that bridges basic science and clinical research, the IBBS supports and encourages interdisciplinary interactions that lead to discovery and innovation and educates and trains future leaders in biomedical research.

Leah Moon
Assistant Account Executive
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Articles and Art by Jane Strauss

I am an artist, an attorney in remission, a teacher, and mother to five children (four of them now young adults) who all have either an Autism Spectrum diagnosis or parts of one. I was diagnosed with Aspergers Disorder or high functioning autism four years ago, at the age of fifty one. I have lived most of my life undiagnosed, but with a variety of wrong labels, mostly psychiatric, virtually all inaccurate, and my recent diagnosis on the Autism spectrum came as somewhat of a relief. As a college student, I studied Autism years ago, when Lorna Wing's Early Childhood Autism had recently been published, and recognized myself in many of the descriptions there. However, as the only individual in that class who was not a graduate student and a special education teacher, I never said anything about my suspicions, but kept them in mind as the decades passed after that.

I chose home education for the older kids in their early school years, having experienced the challenges of the child who, in the words of one school Psychologist, "does much better in Grad School than in the Primary grades," at first hand, and known the difficulties for the child, and wanting to spare my kids that. I tried the standard (charter) school with special education route with my youngest, and, in retrospect, wish I had not needed the child care at that time. He was taught very little, expectations were low, and well-meaning school personnel encouraged more bad habits than I can enumerate on fingers of one hand. In addition to dealing with my children, I've worked with and around issues related to my Autism for as long as I can remember.

Some of these issues are positive, such as my noting details others may miss, and form both the nucleus of my photographic art and the core of my analytical skills in working with nonprofits and in community organizations. I often noticed potential issues with contractors, partners or potential employees years before others did, and in fact this resulted in my being awarded an "Ignore me at your peril" award from a neighborhood association on whose Board I served. My art, which I have actively pursued since 2004, has at its central point tight close-ups photos of things that most would not notice and certainly would not photograph and juxtaposition of contradictory or ironic elements.

Others have been challenging and have gotten in the way of my obtaining and continuing employment and fitting in as an inhabitant of planet earth. Social difficulties followed me through summer camp, college, medical school, and law school. I was not able to figure out the undefined social rules to various professions and environments on my own, and had no assistance available at that time, other than for my “atypical learning disabilities” which had been diagnosed as I was earning my second bachelor degree. Now as I am feeling my way along through the art world I know enough to ask about conventions and social rules. I don’t always get it right the first time, but you can teach an old dog new tricks.

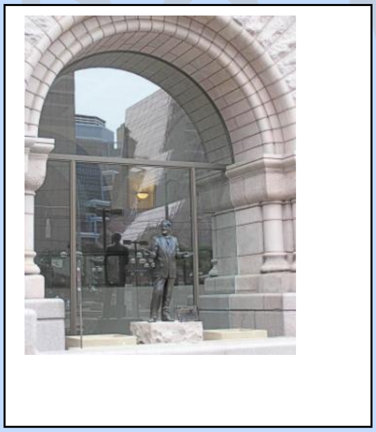
The primary issues with which I still struggle are executive function, sensory overload and explosive temper. Especially challenging has been raising children who have the same issues I do; it is all too easy to get “roped into” power struggles when we all feel the need to control what is, for us, an unpredictable world due to perceptual difficulties.

It’s also easy to get off the track when trying to complete needed tasks. I use lists extensively to do this. I have also taught the kids to use lists in order to get things done. When homeschooling four kids, I used sticker charts to keep track of how much and what subjects needed to be accomplished, and this kept me on track as much as the students! (With one, now, I have a plan book that I got for $1 at Target, and a chore chart on the fridge.)

Sensory overload has often been an issue when shopping in large stores. I learned, before I learned the cause of the problem, to always shop in the same location, always go through the store in the same order, shop at low-occupancy times (like first thing in the morning or near closing, and avoiding lunchtime and early evening), and bring a list. Otherwise I tend to get lost and lose track of time. Once, years ago, I spent over two hours in a store and never did find the major things I was looking for! It’s funny now but was very frustrating at the time.

I have also noticed that our entire family struggle with dealing with large numbers of people. Several of the kids work in retail or foodservice settings, confronting large numbers of people daily. One is a teacher. After work, they tend to self-isolate. I have taught in the past, and was worn out by all the people contact by the time I got home. My partner works in a busy retail store and holes himself up with a computer for hours upon his return home. It’s difficult to have any kind of family life when we are all “peopled out” during the day. My salvation is that I now work alone….but nobody else does, so this is also my frustration.

The past five years have been a serious struggle financially as is the case for many on the Spectrum. Estimates of unemployment or underemployment for those with ASD diagnoses range from 85-97%! On the one hand, I don't feel so alone; on the other, I wonder what is wrong when a well-educated, talented artist can't make a living. I have been building several areas of self-employment including my photographic art (Jane's Prints), consulting with small non-profit organizations (JS Consulting), and advocacy within school and medical settings (Square Peg Advocacy). All are small, yet I remain hopeful that I will someday bring in sufficient income to pay the bills and no longer qualify for Food Support. One of the issues with having made it this far is, of course, that regardless of diagnosis I don't qualify for any disability support – I may not retain employment for longer than 2 years at a time, but I apparently fake it well enough that no governmental programs will ever classify me as disabled.



As one mentor told me years ago: "You are quirky enough that you will simply have to become so good at what you do that others will feel the need to deal with you anyway," and another said of me that I would "continue to homestead in (my) person." Since my diagnosis I have been remodeling the homestead and trying to figure out exactly how it fits within the world of Neurotypicals and how to make ends meet while retaining autistic (and artistic) integrity. It's often frustrating and tiring, but I really don't think I'd have it any other way.

Website Info:

Jane's Prints: www.janesprints.com
janesprints.mosaicglobe.com
www.disabledartistsnetwork.net/Digital%20Photographer%20Jane%20Strauss.htm
www.cafepress.com/janesprints

imagekind.com/MemberProfile.aspx?MID=596c93c2-1598-4535-a2ea-0d3e85e3cc71

JS Consulting http://jsconsulting.bravehost.com/

Square Peg Advocacy http://squarepegadvocacy.weebly.com/

THINK from Your Editors:

To be great, be whole;
do not exaggerate or exclude
anything of what is yours.
Be entire in everything.
Put all that you are
into the least you do.
Be like the full moon,
living aloft and shining everywhere.
- Fernando Pessoa (1888-1935)

The moment is what you are in.
Like a sword,
the moment cuts away everything around itself
so that it can be free. - Qushayri (986-1072)

Quiet minds can't be perplexed or frightened,
but go on in fortune or misfortune
at their own private pace,
like a clock during a thunderstorm. - Robert Louis Stevenson

To see things in the seed, that is genius. - Lao Tzu

Obstacles in life are like logs in your path.
You can step over it or move it out of the way.
You could cut it up and make firewood. - Unknown

Chance is always powerful.
Let your hook be always cast.
In the pool where you least expect it, will be a fish. - Ovid

I don't run away from a challenge because I am afraid.
Instead, I run toward it
because the only way to escape fear
is to trample it beneath your feet. - Nadia Comaneci

Where observation is concerned,
chance favors only the prepared mind. - Louis Pasteur, 1854

We are here to add what we can to life,
not to get what we can from it.
- William Osler, Canadian physician, 1849-1919

Evil is like a shadow -
it has no real substance of its own,
it is simply a lack of light.
You cannot cause a shadow to disappear
by trying to fight it, stamp on it,
by railing against it,
or any other form of emotional or physical resistance.
In order to cause a shadow to disappear,
you must shine light on it.
- Shakti Gawain, teacher and author (b. 1948)

The Feeling Within My Autism
By Sharisa Joy 3/97 Revised 7-09

The feeling within my autism
Is like a baby's cry
Of loneliness, hunger, and fear;
Like the hopeless helplessness
Of the solitary soul
Out of touch
With the rest of the world.

It is a hunger with no end,
A thirst that can't be quenched,
A hole so deep it has no bottom.
An emptiness so full
It has
No name,
No face,
No rhyme,
No reason,
No meaning,
No answers,
No solutions.

This loneliness
Burns and stabs,
Stings and grabs
The heart,
The soul,
The mind,
The spirit,
The essence,
Or whatever you choose
To name it.

This fear controls,
Cajoles,
Patrols
Every inch,
Every corner,
Every crease,
And every crevice
Of my being
And my me-ing
And my life.

Only lonely understands,
Only living
Stops the empty,
Only love heals
The pain
And the terror,
Confusion
And silent tears.

YOU-MANITY By Sharisa Joy 12/10/96 Revised 7-09

**Flapping hands, wings, lips,
Leaves and minds -
Incessantly beating
In rhythmic time
On my head, heart, soul -
Snapping fingers, joints,
Twigs and minds -
Slapping me, you, me
Back to sanity
As it lingers
Close to you-manity
In the spaces
And sad faces,
And rapidly
Fading graces
Separating
The differing places
That distinguish
The opposite races
That embrace
What is you
And/or me.**

STRUGGLE
By Sharisa Joy 12/19/96 Revised 7-09

My life has consisted of
One tough struggle
After another and another.
Struggle
Can either strengthen
Or weaken the spirit.
Struggle
Can either fortify
Or destroy the mind.
Struggle
Can either kill you
Or help you survive.
Struggle
Is what keeps me
Going on and on and on.
I thrive on struggle.
I am a survivor.
I am not a victim!
I will live forever!

INSPIRATION

Inspiration comes
From the weirdest places -
Like puppy tails and people faces,
Tender touches, strong embraces,
Sunlight strained by curtain-laces.

For me, sometimes,
It comes from knowing
My mind and soul
Are both still growing,
Expanding and forever looking
For what around me may be cooking
And boiling over
If no one sees it
And stops the fire
And somehow frees it
To join the force so deep within me
Where I can both stop and begin me.

It's friends and love, faith and hope,
And whatever else I need to cope
And focus all my energy
On whatever it takes to just be me.

Sharisa Joy 3/97 Revised 7-09

IN THE LIGHT

In the light are love,
Joy and peace -
Music resonates,
Fears release;

Life begins
As sorrow ends,
Peace and truth
Become your friends.

Light is wisdom,
Truth and love -
Heaven is here,
Not above.

Sharisa Joy 3/97

There is in this world no such force
as the force of a person determined to rise.
The human soul cannot be permanently chained. - W.E.B. Dubois

LIVING WITH AUTISM.......

I am 33 years old and was diagnosed with severe infantile autism when I was only two years old. Early intervention is the only hope for someone who has autism. My early intervention program was done at home by my very devoted mother, a now retired band teacher. Most of my communication before and even during early intervention was done through tantrums and “gibberish.” Mom during my early intervention helped me to learn the letters of the alphabet using magnetic letters while I sat in the bathtub. This is how my love of water began! I learned colors with a xylophone that consisted of colored keys.

I could not feed myself for a long time due to “failure to thrive” syndrome so I was force fed. Eventually, I ate blended food that was blended in a blender. I didn’t want to eat solid foods as I was afraid I would choke! However, the time would come when I would have to eat solid food. One day mom pretended that her blender broke and I would have no choice but to eat solid food! I am happy to say that I’ve been eating solid food for years and I love it!!! Music was used to help teach me certain concepts. An example is if I was asked a question and answered with the correct answer, mom would sing while bouncing me on her knee!

There’s not a great deal of options from the government available for not only children but adults living with autism. I’d like to see more government funded programs become available to help those with autism find meaningful employment and education. It would make me very happy to see children living with autism receive early intervention to save them from being institutionalized! It astonishes me that more children are being diagnosed with autism today than in years gone by!

I have written a book about my life with autism and I believe this book could be a valuable resource for families who are dealing with autism. This book is in print but it is not very well known right now. Teaching strategies that were used during my early intervention are discussed. I call my early intervention program my “preschool” years. In addition to my early intervention home school program, in my book I dispel the myth that people with autism cannot experience deep emotions such as love and grief. I was fortunate enough to experience the feeling of falling in love with two wonderful men, one of them having had autism. The man with autism with whom I fell in love was also worked on with an early intervention program and became fascinated with eagles and photographed them. He couldn’t speak until he was ten years old. His life was tragically cut short when he was killed in a climbing accident. The man’s name was Benn Kramer and he was very well known not only in British Columbia for his photography but also the “Swim for Hope” which is done in New York. Benn swam around Manhattan Island to raise money to help children living with autism. In my book, I talk about the relationship I shared with Benn Kramer and my first love who was Jim Alldread. Also I talk about how the deep profound grief of losing these two men has affected me and how it has made me a more compassionate person. People dealing with grief may find this book to be a source of comfort. Dreams and goals for my future are discussed.

If you are interested in purchasing this book please leave a comment and I will gladly e-mail you back. The book is $21.95 plus $6.00 for postage. This book is NOT in bookstores!!! I have no ISBN. I hope one day a publishing company will "pick" it up and that it will be in bookstores!

Here is a preview of what is inside this book!

PREFACE

Throughout this autobiography I hope to demonstrate, and document the many experiences and perceptions of severe autism. These experiences will outline how I lead an independent lifestyle.

I have immeasurable thoughts, feelings, and opinions. Expression of the many thoughts, feelings, or opinions has, at times, been significantly challenging. My comfort lies in written communication for the most part and is one of the motivators for this book.

It is hoped the reader will see my resilience, and compassion for others. It is also hoped the reader will join my life's journey.

Early diagnosis and skillful intervention are key components toward understanding and successfully thriving, in a world filled with numerous challenges, choices, and opportunities.

It is hoped this book may assist the many families that must deal with autism on a daily basis.

Welcome to my unique earthly journey we now call life.

CHAPTER 1

DIANNE'S ARRIVAL

On March 6th, 1976, at 1:30 p.m., Brandon, MB, our Dianne was born. It was a gloriously warm day, snow was melting and that elusive spring day was promising to arrive. My birth was by Caesarian section because I was promising to enter this world foot first. Due to many first-born birthing difficulties on both sides of my family, my mother chose the Caesarian section so as not to cause any birth trauma or defects. For example my father was born feet first and apart causing near death to his mother and himself. My Grandmother's first-born child was also in the breech position and only lived for three weeks. There have been closely related aunts, with a history of first-born birthing complications. Thus, using a general anesthetic, I was successfully delivered by caesarian section. My birth weight was five pounds, two ounces and my length was 18.5 inches long.

The opening few days of my life seemed normal. There were the usual ounces weight loss, and I was somewhat jaundiced. However, the nursing staff did notice some difficulty sucking. Therefore, the decision was made to bottle-feed rather than breast-feed me.

Within a few days, mom and I were released from hospital and we began a new life journey residing in Brandon, Manitoba. As the early days went by, mom began wondering if everything was normal because from birth to approximately three weeks of age, I was showing no signs of ever being hungry during the day or night. That meant no crying for anything, including food! Therefore, mom decided to place me on some kind of feeding schedule that involved setting an alarm clock midway through the night for feeding and diapering. During the day, I was fed at times coinciding with household meal scheduling. Contact with the physician resulted in the recommendation as a first time mom, to not worry about feeding, “nature will take care of things.”

Approximately, six weeks into my life, there was a shift in behavior. I was now in the habit of sleeping most of the day except for feedings and crying incessantly from approximately 8:00 p.m. until 3:00 or 4:00 a.m. regularly. No amount of feeding, comfort, or gripe water, could solve the problem. Another trip to the doctor resulted in a prescription for DonnatalTM - a barbiturate - in an effort to solve the nighttime crying episodes. The urgent crying continued consistently for two years! My parents could do nothing to stop the crying and no medical person could explain the reasons why. My parents discovered that car rides made the crying stop; when I was placed in my room, the crying resumed. If I was picked up to be comforted, my body would stiffen. Eventually, it was discovered that perpetual rocking in an armchair while being held, became a relief from urgent crying episodes. Eventually, a small, plastic chair with rocking springs became my chair of contentment. Every time I kicked my legs, the chair made a rocking motion and considerable time was spent rocking.

As the weeks went by, my crying was accepted as routine. During the weeknights, my mom got up, to be with me. On weekends, my father would get up to look after me. My parents tried to “spell” each other off where possible.

During the early months of my life, pureed baby food was frequently used as well as formula. Throughout these early feeding days, mom was carefully monitoring how I was responding. She was developing increased misgivings. Based upon strong intuition and by the fifth month of development, there was no hand to mouth pattern that would allow self-feeding. All bottle feedings required the bottle to be held for me.

From five months to ten months of age there wasn’t much change behaviorally. There were a few physical changes, such as teeth and weight gain. I was still crying, rocking, and not self-feeding.

A new behavior was beginning to emerge. Whenever there was a change of routine, lengthy temper tantrums resulted. Whenever something new occurred in my life, the response was usually one of confusion and terror. The unknown threatened my security and understanding of my world.

When I was 7 months of age, our small family moved to Ethelbert, Manitoba. My father was employed as an English teacher at the local school. Mom was apprehensive of the move because the nearest doctor was located in Dauphin, Manitoba, a 45-minute drive from Ethelbert. However, home became where the source of employment was.

Around the age of one, it was becoming obvious to my parents that I had some form of developmental delay, yet to be diagnosed. The predominant clues were as follows: no hand to mouth movement, refusing liquid from a bottle or a cup, feeling threatened when there was change of routine, placing the forefinger in my mouth, while exploring blanket surfaces with the middle finger, of the same hand, not walking, crawling, no involvement with toys, no eye contact and no communication.

After careful deliberation with the doctor in Dauphin, mom decided to try his method for solving the feeding problem. The doctor explained that “any baby will feed itself if hungry enough.” We thus opted to offer but not force-feed Dianne for one day. After one whole day of being offered food at regular intervals, no break through occurred on the feeding front. Mom calmly resorted to bringing her spoon to my mouth for feeding. It was later determined I had “failure to thrive” syndrome in addition to severe autism. Therefore, I never would have learned to self-feed, no matter how starved!

Throughout these early months, mom had spent considerable time doing activities with me and receiving limited responses. It was most frightening to understand something was very wrong not to mention despairingly lonely. No one really comprehended the magnitude of this behavioral problem. Living in a small community, devoid of close medical contact, further isolated my small family.

On December 21st, 1977, a new baby brother became part of my family. When he came home from the hospital, I had already celebrated my second Christmas. The most meaningful gift for me had been a small wooden rocking chair. This chair could not be tipped and I easily maneuvered it throughout the house. My brother, being just born and somewhat inactive, did not receive much of my attention.

In February 1978 the first major dark cloud floated over my horizon and that of my family. In the early hours of one cold dark winter morning I had developed a sinister fever and flu. The doctor suggested hospitalization. Mom knew there was going to be a feeding and drinking problem in the hospital and explained my forced feeding procedure to Dr. *Steed. Soon, I was hospitalized, resulting in a profound change in routine. There would also be a profound routine change that soon sparked tidal waves of grief, confusion, speculation, anger, and fear.

Names with a * have been changed for reasons of anonymity.

Living 45 minutes from Dauphin and caring for a new baby brother, it became difficult for mom to see me daily. Therefore, daily phone calls were made and reports given indicating I was responding to medication. Mom was asked how the feeding was progressing and was not made aware of any feeding problem. My parents, having had feeding problems for 23 months, wondered how there was suddenly no problem! They arrived at the Dauphin hospital and became shockingly horrified. I was lying in a listless fetal position, backside elevated in defiance of the world, eyes in a glazed living death stare, and body wrapped in a barrage of tubes. How could this be? Ten days earlier, my energy rocked the chair all about the room, I seemed content, and did respond to mom’s feeding spoon. Whenever there was music being played, the chair would rock in rhythmic time, accompanied by the soft vocal hum of myself. Now there was silent despair amidst the hum of hospital routine. Dr. Steed had expressed regret for not informing us that Dianne was being tube fed through her nose. Mom and Dad thought they should have been informed of the hospital's feeding difficulty so they could have the option of living in Dauphin, and personally feeding me.

In any event, Dr. Steed expressed far deeper concerns over my developmental delays. In the beginning, he conveyed the theory that I might have Rett Syndrome. He offered that insight as a result of my developing one verbal cue then weeks would go by and the verbal cue did not re-occur. This is what happens in the early stages of Rett Syndrome. Dr. Steed also confided he was going through the Rett Syndrome fear and despair in his personal life with one of his granddaughters and he saw blatant similarities with Dianne.

My parents in shock, disbelief, and firsthand knowledge of my development, disagreed with the Rett Syndrome theory. They wanted Dr. Steed to focus on the physical component of my illness. Dr. Steed became angry and expressed the opinion that I seemed in my behavior, to exemplify patterns of parental abuse or neglect. Dr. Steed further indicated that he had two other doctors examine me. Dr.*Beswal and Dr.*Sanford noted there were no marks on myself. However, when they took me out of my crib, no effort was made to walk. I crawled to the nearest corner and assumed the usual fetal position of withdrawal.

My parents were astounded that three doctors did these tests without their knowledge or permission. It was quickly discovered that there existed two choices: Personally escort me to the Health Sciences Child development center for further testing or lose me to the children's aid society.

The decision was made to personally transport me to children's hospital, Health Sciences Center, Winnipeg, Manitoba.

Numerous tests were conducted at the Health Sciences Center. Some of the tests included behavioral observation as well as developmental tests. Upon completion of all tests, on the physical plane, I had pneumonia in one lung, and on the emotional behavioral plane the diagnosis was infantile autism.

Doctors in Dauphin had made an incredible mistake and my family felt vindicated and relieved. There was no evidence of Rett Syndrome. Autism. though life changing, is not necessarily life threatening. I was going to come alive when the pneumonia passed.

My mom became determined to obtain as much information about autism as possible. The general plan was to devise a flexible developmental educational plan unique to my personality, interests, and ability.

Commentaries on the back cover of this book:

Dianne writes her story with honesty and candor. It is a compelling insight into the struggles of living with autism. The pathos of two close relationships both ending in tragedy gives her narrative the drama of theatre.
…Jane Malcolmson, Midland Adult Education Centre, Carman Manitoba

Dianne shares her most intimate thoughts and feelings on life, love and tragedy. She is able to show great understanding of a million emotions during her passionate love of life and relationships. A wonderful story of love, life, death and rebuilding. Dianne shows many ways to search for answers in a questioning world. …Sandy Riley, Benn Kramer’s swim coach, British Columbia

This short book by Dianne McCullough captures the essence of one person’s living with, adapting to and developing special abilities as a person with “autism”. In a context of both the joys and tragedies of life, it speaks to the uniqueness of all of us and how we can all be “exceptional”. Dianne’s little book is a celebration of life and a celebration of believing in each other as the way to hope and courage. …George MacDonald, Dianne McCullough’s counselor, Carman Manitoba

*******UPDATE!*******

I am now writing a sequel to "Autism: Journeys with Dianne" and I will post purchasing information when the sequel is available for sale!

http://www.autismhopeandinspiration.blogspot.com/
http://hopeezinetoday.com/FEATURE%202.htm

This is an eagle in flight that Benn Kramer photographed:

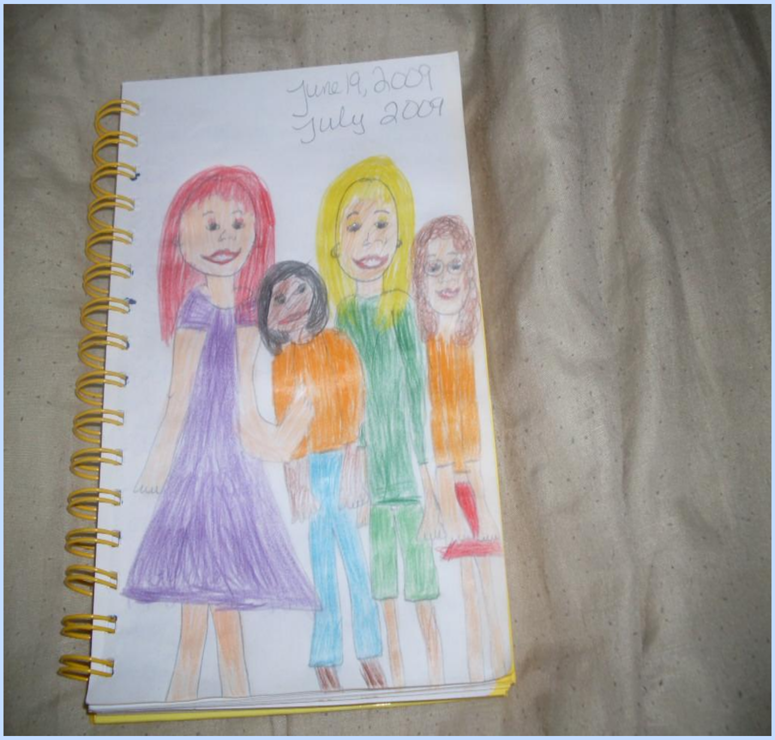
From My Dear Friend, Ondrea Marisa Robinson:

An "I Am" Poem-2009

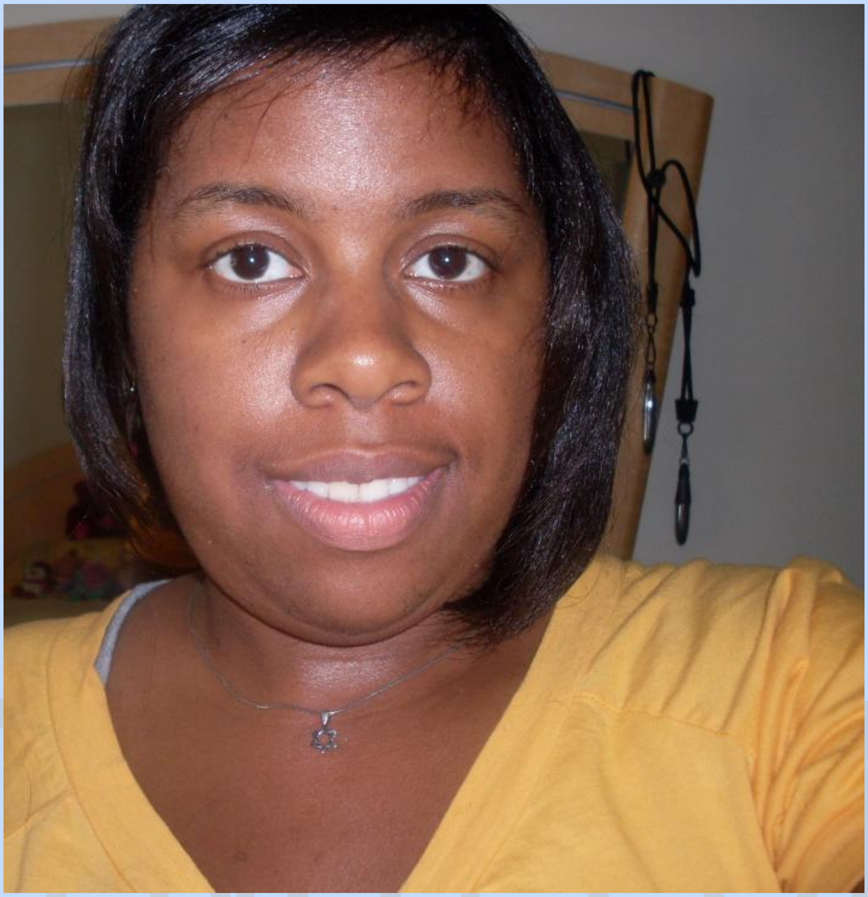
I am a young woman.
I wonder about the future for me.
I hear positive words in my head.
I see myself writing a book of poetry.
I want to become a writer.
I am Ondrea, the Aquarian Girl.

I pretend to speak Spanish on a soap opera.
I feel very expressive when I write.
I touch the sky by looking up in the air.
I worry, because everyone is not supportive.
I cry, because people don't understand.
I am a beautiful woman.

I understand that not everyone is accepting.
I say things by voice and by writing.
I dream to graduate with Honors.
I try to be the best I can be.
I hope to be an autism advocate.
I am Ondrea, the Aquarian Girl.



June 19, 2009
July 2009



Ondrea

Autism: A Beautiful World - 2009

**I'm a person who likes to picture beautiful images in my mind.
Pink puzzle pieces, purple clouds, and a baby blue sky
are what I visualize.
Sometimes I feel like I live in my own world,
Because I'm different from everyone else.
I am in the world of autism;
Autism is a beautiful world to live in.**

I am not what happened to me.
I am what I choose to become. - Carl Jung

The arrogance of success is to think that what you did
yesterday will be sufficient for tomorrow. - William Pollard

We live on an island surrounded by a sea of ignorance.
As our island of knowledge grows,
so does the shore of our ignorance. - John Archibald Wheeler

JELIBEAN

JELiBEAN.COM

This website is for parents of children who may need extra help in developing social awareness, children who may be diagnosed with autistic spectrum conditions, or those conditions which cluster round the spectrum, like AD/HD for instance.

We've developed a flexible social understanding program which we call Jacobs Ladder. Any of the tips and hints we include in our articles can be used at any time, and you're welcome to pick and mix, use what works, and throw the rest away!

Jacobs Ladder works on these principles

- We respect autistic intelligence and want to work with its strengths in a gentle, calm and loving way.
- We believe that spectrum children need to strengthen SELF, by a method that incorporates SYSTEM, so that they can feel SAFE.
- We use analogy, which we call TIP - Talking in Pictures - and develop social intelligence by making comparisons between emotions and social behaviour and familiar objects within the child's own life and understanding.
- We accept that children on the spectrum need materials and technology to experiment with, rather than be taught by rigid behavioural instruction.
- We acknowledge that parents of spectrum children may have spectrum traits themselves which should also be respected.
- Where children may have less empathy than most, it's up to those of us who love them to use our own empathy to help them prosper and flourish.

Please enjoy the website, and if you want to, you can contact us. In time, we'll be available to talk to groups of parents and professionals.

For now, please wander here at your own pace, and climb the Ladder! And if you're wondering why this site calls itself jelibean - it's the Jacobs (Evans) Ladder Initiative. JELI. We like acronyms!

Debi and Barbara

BARBARA

We are working together to try to understand and help others understand the autistic spectrum and cluster conditions. Debi is an SRN, I'm a writer and researcher, currently doing a very late life PhD on autistic intelligence. I've worked as a writer since 1975, published 9 novels for young adults (one of which won a couple of awards), been a freelance feature writer and editor on national women's magazines, an agony aunt in print, a broadcaster on radio and television, and am now writing narrative non-fiction. I have two First Class degrees - one in English (1966), and one in Media (1994). I've done postgraduate work in psychology, education and gender studies, and as well as my PhD, I'm employed as a researcher at the University, looking at how jellybeans (as Debs calls them) are taught in the inclusive classroom, worldwide. There are some interesting schemes and projects out there!

DEBI

Trained at Royal Free Hospital as SRN 1976 -1979. Post qualification training St. Bartholomews Hospital, London specialising in Endocrinology/Metabolics before returning to Royal Free Hospital as Ward Sister acute medicine. Marriage and children halted my nursing career although I continued part-time hospital work until 1993. Charity fundraised for Action Aid, Tusk, Gulf Trust as well as local events. In 2005 I discovered per chance Barbara's masterpiece “Loving Mr. Spock”, which was the start of a journey that has taken us to this today! Barbara and I have worked flat out for the last 3 years to find out what makes a jellybean tick! With Barbara's help these are our findings! My arm has been twisted by Barbara to go to Uni! So I have (to keep the peace), obliged although kicking and screaming (don't tell her I am loving it :) been accepted at Birmingham University, and am currently studying for an MEd (Autism). Watch this space!!

GARY

Gary trained as a Clinical Chemist and Immunologist but has spent the last 25 years working with medical instrumentation and robotics. He cut his programming teeth on programmable controllers, had home computers of one type or another for nearly 30 years and built websites for the last ten. Gary and his partner care for her autistic teenager together with their two small children.

Meltdowns, shutdowns - the complexity by Alyson Bradley

I feel it's more society in a way, you could say we start to be damaged from when we are born... anxiety exposure as Donna Williams calls it to a world that often does not allow, accept or understand us on our terms... no one of us can play the part all our lives!

Sensory issues I feel have a HUGE part to play:

i.e., from when born: the environment around us can have a huge impact; as with me, I was an unhappy baby that did not connect and I had no way of knowing it was any different. So I simply started on a never-ending journey that was a little like a self-distract scenario; no one knew of course not even me at such an early age; but not quite connecting, not understanding and being treated text book style has to have an impact long term...

i.e., as a young child: I was seen as a loner, difficult, pushed into many situations that were uncomfortable to me and so withdrew more, found my own ways around things, I had to. I latched onto other adults or younger children, at least they seemed to enjoy my stories and drawings, as the children my age just thought I was odd; and so I withdrew more behind my own screen into my own world of make-believe, self-protection… to my parents and others, I was just the difficult one...

i.e., as a school child: my world was hard enough and then I entered that huge empty echoing place, with so much noise I could not hear, I could not focus and impossible to read a blackboard if I dare look. If I did look up, someone laughed, made fun, yet more abusive. Art times so unbearable, but no place to hide - I had no choice but to endure. What the other children enjoyed and talked about made me feel more of an alien...

i.e., as a teenager: by then of course I had endured years of bullying, being misunderstood, dismissed, put down and let down... others talked around or at me, never to me, spat, pushed, laughed at me, like a dirty rag. So, yes I was angry at times, often very lonely and extremely sad with the world, frustrated and felt not heard. I did not hit out, but took on board all the pain and hurt inside. I think the painting "The Silent Scream" best describes the intensity, life at times unbearable; but somehow I did survive…

i.e., as an adult: I had been beaten down, given up on in a way and so just pretended to be happy. Others took advantage - I just learned to wear that mask extremely well - but behind it often a deep sadness. Not only I could not relate, no one seemed to like me, life itself never quite worked, society continued to let me down. So, yes, from time to time the frustration built inside, and what usually followed was meltdown, shutdown, but often I just withdrew from the world to cope...

i.e., as an Aspergian: a breath of fresh air, like for the very first time in my life I can breathe, allow myself to be myself, understand why I am. Still having to deal with the aftermath of living most of my life a lie, not being accepted often by the

majority; and still a need and feeling of often having to justify my change. So I reach out - so wanting to help others out of the shadows of life itself - and can only hope no one saw the world as I had to...
While I feel some of us may have other associated conditions that also trigger their moods, many have and continue to be let down by society itself. There are no easy answers. Some find it hard just to connect with their parents, I never could with mine. When younger, I did do voluntary work for a while and I always seemed to get on better with what others saw as the more difficult children. Partly I feel I could relate, but also I always listened and really heard them. My advice - if not already - speak with them, ask them and work with them, as being told never seems to quite work with us aspies/auties. We are often very intelligent and have minds of our own. But some of us do need extra medical support and help. Partly, I feel for some of us this is a buildup of feeling alienated and disconnected with the world; no easy answers as each child has had to endure their own journeys and often quite lonely ones. In my day, we were disciplined for being different!
By Alyson Bradley - June 2009 – Aspergers Parallel Planet – www.asplanet.info

Born different

Alyson Bradley
April 2008

What chance did I have
Born as the second twin
The after thought
The one that cried
Rushed away after birth

My mother only wanted one
I was the problem child
Alone to scream out loud
Awkward, gawky, sad
I never really fitted

He was cuddly, I was thin
He smiled, when I cried
He had bright blues eyes
Mine were different like me
Odd, One Green, one Brown

He got all the attention
A happy cuddly bundle
They would just look at me
What's wrong with that one
As I was sick yet again

By Alyson Bradley - June 2009 – Aspergers Parallel Planet – www.asplanet.info

Autistic - How we affect others and how they affect us!

No easy answers, no one answer as we are as different and varied as those not on the autism spectrum, so I will generalize but let's just say as for me born differently, I have been misunderstood from birth! Should I have been treated differently? Everyone is expected to treat their babies in a certain way to a point; but what if I sensory-overloaded and no one knew - what if my cries were sensory-related and no one knew - at times I wonder has society misunderstood some of us from very young? The crying babies, the difficult child. No longer can you enforce conformity, discipline away a difference.

The thing I do know: As a child, I had a kind of safety device of my own. With each letdown, putdown, misunderstood difference there would be so much I would put up with, so much I would or could take on broad, deal with or not. But eventually, my shutters would start to come down. It was like I had a set of 3 and once the 3rd down, very hard for anyone to remove. My way, I guess, of keeping out the pain and hurt… my own self protection or as many call it the "invisible screen"; and to this day I still use. As an adult, I now realize there are some things I need help with, some issues I need to work on. However, at times after years of zero self esteem, I let down the shutter, stand firm and it's hard to reach out and ask for help.

Unintentional or not, I do feel we are affected a lot more than we affect others, as we simply are not allowed at times; well on OUR terms. Does the majority understand how alienating, frustrating and hurtful being shut out of the world can be? Having to continually conform, pretend to fit in - exhausting - and so I feel yes, we need to be aware of how we impact on others, everyone does; but I truly do feel others need to get real. Yes, of course they often unintentional impact on us; but they can have a huge impact on many of us and that can have long-lasting effects, and for some, crush the individuals we were born to be! I call it being pushed to the extremities of life.

Someone asked me if I have decided to be myself and not pretend. They found that admirable, as they understood that for some of us the way our autistic differences manifest requires us to make an effort to behave in ways that may not come naturally to us, and were aware how most of us seem to be very accommodating and considerate of others. Generally, we are, and we go out of our way to not be noticed. So we do try hard to fit in, and to a point everyone does; but some things are out of our control, especially sensory-wise. My triggers, moods, anxiety towards life at times; I do not always have control of fully, and that can be extremely stressful.

I feel that the problem for many is often that our differences are not allowed, our real self can get trapped within and we withdraw. This can be damaging to us and those around us, as when we block out what we cannot deal with, at times we can also block out those that care. I often seem to push away those I care for the most when hurting, not coping with life as is. When growing up, as others grow in confidence and are encouraged, far too often I feel if autistic individuals are not embraced, their lines become confused. In trying to be half and half, one can end up losing part of oneself in a way; whereas many children are encouraged every step of the way, I found myself being pushed back, broken down, discouraged to be self.

Of course, I do feel at times like everyone - whether it be autism or something else - needs clear boundaries of what’s right or wrong, and we all need to make an effort to behave in ways that may not come naturally to us but are more considerate of others at times. For myself, I think I am adult enough to know how I affect others or not; but others often seem blind how they affect me and now that I understand self, I have a choice to play act and smile politely or not. Let’s just say I am less willing to do that as I get older. Guess I am lucky as I gain confidence in me and I know the more I believe in self, hopefully others will or not!

How often do others make the effort for those of us with a difference? I have spent a lifetime of having very little consideration from others, so if I dare be myself now and again is it a surprise?! What I mean is for the first time ever I have the confidence to be self... yes, I am a mother and still have to play the part to an extent, but I refuse to play-act to please everyone else all the time, as I never quite fit in anyway. I so agree with what someone said to me once: “stick with like-minded people” as that does really help; it’s a bit like not being within your own culture. However much you fit in, deep inside there may always be a part of you that needs to be fulfilled and we are the only ones that can do that mostly, the autistic community.

Saying that - of course if being honest with myself - I accept that while there is still far too much misunderstanding and ignorance in the world, there are also many non-autistic individuals that are really trying to build bridges and close gaps; which is brilliant and bringing so much more recognition and understanding to the autistic community as a whole. But the ones that have helped me the most are the autistic community who have welcomed me with open arms’ a little like coming home for the first time, an extended family where I fit and can be. This is what has and continues to help me, thanks all.

We can also behave in ways that are genuinely anti-social or difficult for others because of our condition and because we have not learnt, or choose not, to mitigate our condition. I also guess we need to remember many of us grew up with no clue, often being put down just for being. If we grew up and no one explained, of course some of us will be a little lost, confused in a world that often does not think at times outside its narrow-minded box. Of course there are strategies, learned behavior things we can do, everyone can do. But for those of us who have often spent years finding true self, should we have to change, isn’t it about time people excepted us for who we are, allowed and embraced? What is unacceptable behavior and what is just us being us?

Of course there is a difference between a behavior that is undoubtedly autistic, such as being very honest, or humming and talking to oneself in public - but which doesn't harm anyone; and the more 'bothersome' (to others) behaviors - such as constantly interrupting others, shoving our opinions down other's throats, or rudely pushing our way through a group of people because their presence and needs simply don't register. There are also ways and ways to communicate our thoughts, though this is a more gray area - it's hard to frame our thoughts, feelings and perceptions into words that others can understand, without feeling like we are “translating” into a foreign language.

As parents like with all children we can only embrace our children for who they are, listen to them and work with them and as with all parents clear boundaries on rights and wrong a must. To a point at times myself I still back out of society at times in order to cope, and partly because I am less willing to conform as get older... but finding a balance what works for you as an individual is important, life in a way is a compromise but I do feel so much harder for autism spectrum individuals, as too much wrong pressure can scatter our thoughts until our routines are back in place, sensory overload can turn a reasonable situation into chaos!

Quote from an asplanet forum member:”Many autistic individuals are very aware and intuitive and yet most of us lack a social something, which is very hard to define if we haven't had it in the first place. Rather like describing color if you see in monochrome.” This I tend to agree on and feel many of us on the autism spectrum offend unintentional at times for a number of reasons, simply our bluntness, honest approach or a reaction because of sensory reason that gets misunderstood and we get judged often so wrongly when this happens. But at the same time we often over analyze look more into things than need be, maybe partly because we often get put down so much growing up, just for being and in a desperate need to fit in, get it so wrong at times..

With me as I get older I have almost become too good a judge, I have become an incredible actor over the years when need to be and know what I should and should not do, I so pick up on everyone and every feeling, it’s like at times I can read senses and guess taught myself how I should be in different situations, I know I am lucky because of my extremely fast processing skills and other positives, but the down side I almost over act and seem to others very able to cope and feel this is because over the years I have had to hid my intellectual learning differences, insecurities as to me at times a frustrating shameful, secret... it’s like I have been given this amazing mind without the tools to use it fully and yes I am aware I get frustrated when people try and tell me what I know!

I also feel a big problem is that for some reason those that do not quite understand our differences feel a need to label us often into there criteria that has no relation to who we are as people, and we are seen as our every growing collection of labels! Now this is where it gets interesting to me anyway, others feel a need to want us to conform to there standards which of course may never make sense to us, so as hard as they try to fit us into tick boxes, we don’t, won’t fit into, this needs to change and this is where so much more inclusion of autistic adults is needed for every decision “nothing about us, without us” should always apply. As some do not even understand why I am happy to call myself a autistic adult, a word some will not even speak!

Alyson Bradley (born UK, live in NZ) - Aspergers Parallel Planet – www.asplanet.info

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Champions are made from something they have deep inside them: A desire, a dream, a vision. They have to have last-minute stamina, they have to be a little faster, they have to have the skill and the will. But the will must be stronger than the skill. - Muhammad Ali

There lives nothing real in our past - regardless of how disappointing or painful it may have been - that can grab us and make us its captive, any more than a dark shadow has the power to keep us from walking into the sunlight. - Guy Finley

The Interactive Autism Network:

An Online Initiative Connecting All Members of the Autism Community

Launched in April 2007 by the Kennedy Krieger Institute, the Interactive Autism Network (IAN) Project, www.ianproject.org, is an innovative online initiative bringing together tens of thousands of people affected by autism spectrum disorders (ASDs) and hundreds of researchers searching for answers. Meeting significant milestones in just two years, the IAN Project has registered more than 30,000 individuals representing all 50 states.

The IAN Project is accelerating the pace of autism research in two important ways:

- Parents of children with ASDs provide valuable data to researchers without having to leave their home or office. As of April 2009, adults with ASDs and their guardians can also enroll and provide much-needed information to researchers.
- Willing individuals and families are matched with local and national studies for which they qualify.

The value of the IAN Project:

By participating in the IAN Project, individuals with ASDs and their families can share information in a secure setting to become part of the largest online autism research effort in the country. The data collected by the IAN Project both facilitates scientific research and empowers community leaders to advocate for improved services and resources. In addition, anyone impacted by an ASD can become part of the IAN Project's online community to stay informed about autism research and make their voices heard.

Furthermore, while the number of adults living with ASDs grows every day, little is known about them. There hasn't been a comprehensive, national effort to find out what services adults with ASDs are in need of, or to document the ways they contribute to society. In fact, there is no official estimate of how many adults with ASDs there are in the U.S. today. The IAN Project has already uncovered new insights and aided research about children with ASDs, and by enrolling adults it will use the same proven model to address the many unanswered questions about this underserved population. Including adults with ASDs will allow the IAN Project to gain a clearer picture of how adults with ASDs are living today, and connect these adults with researchers who are working to understand the disorder at all stages of life.

How can members of the autism community use the IAN Project?

Anyone impacted by ASDs can take part in the IAN Project's online community (www.iancommunity.org) which, with its unique model of information exchange and community interaction, has facilitated the most comprehensive collection of evidence-based information on autism available on the Web to date. Here's how you can use it:

- Research Reports: To learn more about topics of critical importance to the autism community, you can access easy-to-read reports on topics such as autistic regression or treatments. You can review these preliminary reports before the information is published in a scientific journal, which can often take several months or years, to gain insight on research generated from IAN Project participants.

- Articles/Special Features: Visitors searching for trusted, evidence-based information can utilize this section to access articles and research by highly regarded leaders in the autism field from institutions including the Cleveland Clinic, U.C. Davis M.I.N.D. Institute, and Kennedy Krieger Institute.
- Discussion Forum: The focus of this Forum is autism research, so you should use it to ask questions, offer comments, provide feedback and explore the latest on autism research.
- StateStats: This interactive analysis tool provides state-by-state statistical facts based on the IAN Project’s data. You can access information on topics such as age of diagnosis or treatment costs, see how your state compares to the national average, and share this information with physicians, therapists, and policy makers.
- Community Data Explorer: IAN Participants interested in how others answered survey questions can use this feature to view questions, the possible responses to each question, and a pie chart displaying how IAN participants answered.

Key Research Findings:

The IAN Project continues to generate new insights into autism and shed light on issues of critical importance to the autism community. Research highlights from 2008 include:

- Defining the Spectrum: Having meaningful autism spectrum diagnostic categories is essential to treatments and research. On March 18, 2009, the IAN Project published a paper in the Journal of Autism and Developmental Disorders that described the varied pattern of autism diagnosis across the country and over time (1994-2007). This information is being used by scientists to better define the best way to diagnose autism. Better autism diagnoses will lead to better treatments and more finely tuned research.
- Parental Depression: More than 44 percent of mothers and 28 percent of fathers of children with autism report they have been professionally diagnosed with either depression or bipolar disorder at some point in their lives, with more than 50 percent reporting diagnosis before the birth of their child(ren) with autism. This statistic is striking when compared to the estimated lifetime prevalence in the U.S. population for major depressive disorder of 16.2 percent and for bipolar disorder of 1 to 2.1 percent. Researchers are interested in exploring a possible connecting between a family history of mood disorder and ASDs.

The IAN Project is spearheaded by Drs. Paul and Kiely Law. As the parents of a son on the autism spectrum, they understand the frustrations that stem from having so many questions about autism. As scientists, they know that many research studies are stalled, and some are never even completed due to difficulties in recruiting participants and collecting data. They felt that the only way to get answers was by bringing individuals with autism of all ages, their families and researchers together – and so the IAN Project was launched.

The IAN Project encourages everyone, but especially individuals with ASDs and their parents, grandparents, siblings, and friends, to spread the word about this online initiative. The IAN Project welcomes questions – to contact IAN Project staff call 866-348-3440 or email ian@kennedykrieger.org.

The following story will be presented in the next several months in serialized form. I think you'll love it as much as Dad and I do!


28 08 2008 13 44

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

For a horse that cannot stand a bad home, bad rider, bad life any longer - what do they do?
Nothing - they carry on with life hoping for it to end soon, but not Sealistic - he has a spirit.
He is a horse that knows what he deserves - so it begins, the story of a free-spirited horse called Sealistic.

Kattie And The Ride

"Father!" hollered Kattie. "Get the stable-hand to get Sealistic ready!"

Kattie's father walked in. "But darling, you have to remember, he is your horse you should be doing the work."... That one glance Kattie shot at him told him he was pushing his luck. "Alright, I'll get Dan out there." With that he walked poshly out of the room towards the stables.

Kattie turned around and continued brushing her toy horse's mane. "Oh Dilly, look at your silky grey mane on your mouse grey coat, you're just beautiful! But nobody can beat my Sealistic." With that she placed Dilly carefully down, grabbed her helmet, and ran out to the stables where Sealistic was waiting for her. "Father!" she bellowed. "Father, help me get on Sealistic!"

Kattie heard a shout from inside the house, but couldn't understand the words. Then Dan came running over. "Kattie, your father sent me to help, I can teach you to get on yourself if you like?"

Kattie shot him a dirty look. "Just lift me on to him!" she yelled at him. So Dan grabbed her roughly, not caring if she got hurt and dropped her into the big western saddle. "Owch!" Kattie groaned. "That hurt!"

Dan just gave a smug little grin and went and patted Sealistic's cute white wave-shaped blaze. "Sorry old boy, hope I didn't hurt you." He then had to jump out of the way as Kattie dug her heels into Sealistic's sides and he jumped off on a high canter. "Boy oh boy, he's not gonna cope with this stuff much more," Dan whispered to himself as he watched the Thoroughbred stallion jump over fallen trees and small creeks in the pasture.

Kattie grinned and unbuckled her helmet; like usual she would throw it off and collect it when she was done. She threw it back but instead of missing Sealistic like usual it hit his hide and he skidded to a halt and gave an enormous buck - throwing Kattie and breaking the saddle girth. He started off at a trot, then continued into a gallop; and with no girth holding it on, the saddle slid off to one side. Sealistic was free!

Free At Last

Sealistic realised three years he had been mistreated at that house, and in those years he had watched his mother dying a slow death and being overworked. He realised that the only thing he had on was a bridle; no rider and no saddle, just a bridle. He gave a few bucking leaps and galloped on with ever more spirit. As he saw the end of the pasture fence white as a sticky candy cane, he decided he didn't want to die like his mother, he was too young! So he gathered all his strength and ran at the fence, and at the very last minute he pushed off - soaring over the fence like an eagle. Once on the other side, he cantered on a bit then stopped and turned. In the pasture, he saw a limp figure lying in the grass and three people around her. One looked like an old man in his 60's that would've been her father; and there was a little old lady, maybe 50-55 which must be Kattie's maid. Lastly, there was a person in a white uniform it looked like. He was leaning over the limp figure that Sealistic decided must be his thrown rider and talking to her. Seeming to get no reply, he called someone and then out of the corner of his eye Sealistic saw the tall grass moving. He turned away from all the people and the tall fence he had just jumped and stared spooked at the rustling grass. A well-known figure slowly crept out, being careful as to make sure nobody would see him. "Here boy, c’mon, I'll get that terrible bit out of your mouth," Dan cooed. Sealistic just shook his head and stayed where he was - not prepared to move after his big escape and still trying to gain full balance again. Dan slowly and making sure nobody saw him walked over and pulled Sealistic into the long grass. He led him into what looked like a well-used track and finally to an opening where lots of horses grazed. There, he took off Sealistic's bridle and brushed him down.

The Wild Bunch

Sealistic looked around at all the horses, not knowing where he was but enjoying everything. In the far corner, he saw a little hut - well not that little but not huge like the mansion Kattie lived in. The tall grass was freshly mowed and there was a huge perimeter of open land where the grass kept them from being seen. As soon as Sealistic (known to Dan as “Loco”) realised nobody was holding him, he ran the whole area of mowed grass, then came to the other horses - sniffing each of them and whinnying a friendly hello. Then a particular horse caught his eye that he had not seen before. He remembered it from somewhere but he just couldn't remember. She looked old and frail but still full of life and dying for a run; so he quickly walked over, lifting his feet high as he did so. When he got within 10 feet he stopped and the old mare moved forward. They then reached out their noses and sniffed, then quickly moved forward and starting grooming each other’s backs. The old mare was Loco's dead mother; she had been saved at the last minute by kind young Dan. What seemed like minutes later there was a loud rustle and Loco and the old mare named Seal turned. Seal’s blue roan coat shimmered when turned to the sun and her long silky mane flew around in the wind. It was easy to see the family resemblance. Dan rattled the big can again and Seal walked forward. Loco followed, and soon after the rest of the bunch. It was made clear that Seal was the leader of the bunch during that meal, as all the horses including Loco waited till she had had her share before even starting what had been measured out for them. “This”, thought Loco, “is a life worth living.”

The Run Out

Some few weeks later, the pecking order had been made clear - there was Seal then Loco as he was her son, after them a strong roan-looking gelding with a bad attitude. He seemed to keep them all in order. Loco was enjoying his new life as an “Outcast” horse, saved from the girl that drove all horses crazy. The next day, they were all peacefully eating. Dan had gone to work and he was helping Kattie pick out a new horse since she had gotten better and promised to keep her helmet on. But that peace wasn't kept for long, as 20 minutes later there was a loud whirring noise as a helicopter came up from behind the big perimeter of mowed grass the horses called their own. Seal looked and it only took her 10 seconds to realise what was happening; it had happened many a time to her bunch and never had she been taken, but some of her closest grazing friends had. She half reared and turned and started to gallop in the opposite direction, snorting over her shoulder. All the horses followed and Loco was last - he couldn't keep his eyes off those blades spinning and keeping up that enormous machine! He whirled around and followed his herd mates, every few minutes turning to watch those blades chopping through the air to reach his bunch. He knew it wouldn't end well and he was right. Lots of the horses started getting tired and the strawberry roan stallion dropped to the back next to Loco keeping the others in front by nipping their hides. This worked and Loco started helping his new friend. Some hours later, they were running through the thick grass - unable to see in front of them - yet the pace never slackened as long as they could hear those cutting blades. Then Loco heard something shut behind him and he spun around realising they were in another open area of mowed grass land and in a huge metal fenced corral. The horses scattered, trying to find a weak post or a low hanging bar for them to jump but there was nothing. The whirring of the helicopter blades got quieter as it flew off. Two hours later and seven men were looking at the bunch through the fence.

"They are all the same, not scared of people and been ridden but just been a real long time", the big stocky guy named Greg commented.

“I think they must've been mistreated sometime, look how they are reacting to my little daughter", said another one that the horses thought was called “Daddy”.

The men watched as the little girl walked quickly over to the fence and climbed through the poles. "Hey there, you cute little bunch, you’re such sweet ones, you must've cost a lot if you were bought once." She looked them all over with her gentle eyes; yet all the same, all the horses were scared, and then she set eyes on Loco. "Daddy! Look at this one!" she cried through the poles.

All 7 men rushed over and stared at where she was looking. "That’s a sweet catch, Greg", said one.

"Yea I reckon we should keep this one", the little girl commented hopefully.

The horses came to know the girl as Belinda and she came to visit them every day with food, water and sometimes even treats if they did what was asked of them. Gradually, they became less and less scared and soon began to wait for her visits; she was now expected to come every day. But one day she didn't come till late and she and the men bought a BIG truck with them. One of the men looked like he was deep in thought. "Belinda... find three of 'em you want and place 'em in the front 3 stalls in the truck, the rest we will sell."

Belinda's eyes seemed to light up at this and she walked right into the middle of the bunch. She looked them all over again but already knew them all too well.

The pure, the bright,
The beautiful that stirred our hearts in youth,
The impulses to wordless prayer,
The streams of love and truth,
The longing after something lost,
The spirit's yearning cry,
The striving after better hopes;
These things can never die. - Charles Dickens

PERSEVERANCE = SUCCESS and JOY

Intelligent Thinking, Pt. 2

I do not want the peace which passeth understanding;
I want the understanding which bringeth peace. - Helen Keller

The trouble with the world is that the stupid are cocksure and the intelligent are full of doubt. - Bertrand Russell

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

The measure of who we are is what we do with what we have.
- Vince Lombardi

Learn how to turn frustration into fascination. You will learn more being fascinated by life than you will by being frustrated by it. - Jim Rohn

The art of living lies less in eliminating our troubles than in growing with them.
- Bernard M. Baruch, American statesman, 1870-1965

You can have everything you want, if you will just help enough other people get what they want. - Zig Ziglar

Hope is like a road in the country; there wasn't ever a road, but when many people walk on it, the road comes into existence. - Lin Yutang

Negativity is born in the gap where love has been excluded.
- Deepak Chopra

You should also appreciate the goodness around you, and surround yourself with positive people. - Nadia Comaneci

Energy and persistence conquer all things. - Benjamin Franklin

I don't believe in pessimism. If something doesn't come up the way you want, forge ahead. If you think it's going to rain, it will. - Clint Eastwood

Nothing of great value in life comes easily. The things of highest value sometimes come hard. The gold that has the greatest value lies deepest in the earth, as do the diamonds. - Norman Vincent Peale

Treat people as if they were what they ought to be and you will help them become what they are capable of becoming. - Goethe

Hope is both the earliest and the most indispensable virtue inherent in the state of being alive... If life is to be sustained hope must remain, even where confidence is wounded, trust impaired. - Erik Erikson (1902-94)

Your life can only be as free as your perception of it. - Deepak Chopra

When I thought I'd Found Some Acceptance with Older Kids, Only to be proven Wrong - Travis Breeding, 2009

During my freshman year of high school, I was able to find a little acceptance from older kids - mainly juniors and seniors that I went to school with and was also in marching band and varsity singers with. I wasn't sure why, but I was drawn to the older students in the groups. Looking back on it, I'd have to say that I think it's because of their maturity level.

I can remember struggling during my first year of marching band. Yes, I was not having any problems at all with the music and playing trombone, but marching around while playing at the same time was something a little different and certainly more challenging. I would often be a little off step during the first couple of weeks of our parade season. It wouldn't take me too long to catch on though, and there's someone special who did help allow me to catch on pretty easily.

She was also a senior trombone player in the group and her name was Courtney. In our parade block, (the formation that a marching band marches in for parades) she stood right behind me so she was able to see everything I was doing and give me pointers. She was extremely encouraging and wasn't mean about it at all. I remember some of the other seniors being rude and mean to freshmen while I was in the group, but she wasn't one of them.

With a lot of encouragement from her, eventually I learned how to march and the rest was history. By my senior year, guest clinicians would come in and tell the band that I was the model to watch while marching. I was able to be someone that other students learned from, which was an incredible accomplishment for me.

Looking back now, it makes so much sense to me why I was having a little trouble with the marching my first year. I had some obvious sensorimotor issues that would not allow me to have good balance or coordination. This made it much more complicated to try and even walk straight sometimes, let alone march in a straight line and stay on the correct foot.

By the time I was older and finishing my senior year of high school, I had learned to adapt to the uncomfortable sensations that marching would give me. I was able to come up with ways to focus which would allow me to concentrate on the marching itself without worrying about too many other things getting in the way.
Luckily, I was a pretty good musician and I could memorize the music fairly easily, which made it nice because I was able to play the music without concentrating too much on it. That allowed me to pay more attention to what my feet were doing and I'd say that by my junior year I was able to be completely on autopilot out on the marching field.

Making acquaintances or friends comes with a cost:

When there were situations in high school when I was allotted the opportunity to try and get to know someone, it quite often came with a cost. Being one of the younger students trying to interact with the older juniors and seniors would cause some discomfort. There were a few times when I was told by seniors that as a freshman it was my responsibility to do whatever they told me to do. Basically, I remember being told by older students that because I was younger, I was supposed to be their "slave monkey."

I spent a lot of time in the early high school years thinking I had a good friend or two only to be physically abused and taken advantage of. At this point, I started to not be so trusting of people and was a little more aware of people with whom I surrounded myself. Still, even with the level of awareness, it is difficult to eliminate every single predator.

I quickly learned that friendships came with pain. Then I would soon learn that even these friendships that came with the pain weren't real friendships; in fact they were nothing like a real friendship should be. They were fake, and these people were just using me to get something they wanted.

I've since moved on and eliminated people like that from my life completely, and I've never been happier. I have surrounded myself with better people. It shows that you must keep fighting and trying to build successful friendships and you should never settle for abusive friendships or seek acceptance from people who are using you or wanting to take advantage of you. Those types of people aren't really your friends, anyways.

So Much Love to Give, But No One Wants It! - Travis Breeding, 2009

So much love to give. If only there was someone who wanted to receive it. I'm on the outside looking in and wondering just how to get inside. How do I open the door? There has to be a key somewhere. How do I open the door and get into a girl's heart? Other guys seem to hold the magic key that's hidden from me. I would give anything to find the magic key and learn how it's done.

Oh, how I long to be accepted by girls. Girls are so pretty and sweet and soft. If only I had the key. It seems as if I'm running into a brick wall every time I like someone. They just end up being amused and thinking it's funny. They tell me I don't know them well enough to like them, but I know them better than they think. They may assume this because they won't give me the time of day to talk to me and find out how well I know them, but I do know them.

I know their favorite food, their favorite color, even their favorite perfume sometimes. I know what's in their heart because I spend a lot of time learning since I think that girls are so very special. I could spend hours reading their Facebook profiles so that I can know everything about them and make them the happiest girl in the universe, but they would say I'm stalking them, while I'd say that I really cared about them.

Intentions may get confused; they think I'm creepy when I'm just trying to be nice. I bring a few dozen roses to them within a day or two of meeting them and

they freak out like it's some kind of sin or crime. I wonder why. "Why are you so mad at me for doing something nice for you? I only wanted to show you I care." Then they put up a wall and try and hide from me like I'm some kind of creepy freak. If only I wasn't weird. If only I knew how to express the feelings that I have in a neurotypical "normal" and accepting way. I often wonder, "Why me? Why do I have an ASD?" Then I know why; you see, I am unique and I have a lot to offer the world.

While my intentions may get misinterpreted by others, I know what I mean in my heart and only I can know that. If I could just convey to the rest of the world what was on my mind, then maybe they would understand as well. There's so much joy and happiness when I see a beautiful woman. I get this tingly feeling inside and get really anxious; if she smiles at me, I might pass out just because I would feel so flattered.

When words cannot convey just how I feel about her, I retreat to actions. These actions also get misinterpreted and I then get made fun of and ridiculed. I don't care what other people say, sometimes girls are special. There's nothing I wouldn't do for a girl. Girls deserve, love, care and to be gently handled. Why do other guys hurt girls? I don't know why.

The girl I like is so incredible. She's full of energy and life. So beautiful. Yet I get the courage to ask her to have a cup of coffee, and she says "Get lost, loser." Or she might say "Yes, I'll have coffee with you if you give me a couple hundred bucks." Or she may say that she'll hang out with me once, if I do her homework for her for the semester or a project for her. Some require buying Big Screen Televisions for them and one even wanted a new car. I've paid them all and given them everything they wanted and now I'm out of money and can no longer be accepted by girls. Without being able to buy them stuff, they hate me again.

I search for money each and every day that I can. I know I'll need at least a billion dollars in order to get a girl to marry me someday. Oh, how I wish that I didn't have to pay them to hang out with me. I look around school and there are so many guys who have girls walking with them, talking with them. Some have their arms around each other and some are hugging and kissing. I can't say I know that those guys don't pay the girls because I'm not there with them, but it seems as if other guys don't have to pay a girl to say "hi".

I'm still trying to learn that you shouldn't have to pay someone to be a friend or hang out with you; or even worse you shouldn't have to do someone's homework just to be their friend. I've been able to cut back on the amount I'm spending to pay people to hang out with me quite a bit in the past year or so and I'm starting to see an increase in savings. However, I'm losing the "friendships" or what I thought were friendships because I'm unable to pay peers to hang out with me anymore.

Time goes on, and eventually I'll find someone who will allow me to be their friend for free. Someday someone will see the heart I have and look past the fact that I am not the coolest social person out there. To someone, someday, none of that will matter and all that will matter is that I love them or like them for who they are and appreciate them; and they will like me for who I am and appreciate me as well.

David Willey of Germany sent me the following and said
that it should be dedicated to me for inspiration!
Thank you, David and Brigitte! - Sharisa Joy

PART ONE:
UNDERSTANDING AUTISM: (My Version by David Willey)
MUTUAL LEARNING

INTRO: If you really want to know the inner workings of an autistic person you should be prepared to unravel yourself first.

Point of Entry: When I deal with a "lower functioning" autistic person for example, I have to find a level on which to approach them and yet not scare them off. I offer my hand as if to shake hands, giving them a chance to make contact. If they at least brush their hand against mine, the first step is accomplished. Now I have to decide, were they just doing it to satisfy me and get me to go away, or do they really want more contact? Touch is important, because they don't like their space to be invaded, but you have to invade it in order to proceed to the next level. As the old saying goes - water finds its own level - and it's up to you as an outsider to find that common denominator. In my case, music works the best. If you intend to enter their space and ultimately their world, you have to do it with an open heart and with soul exposed. If you are unable to do this, you can't proceed. Along the way I also tell the autistic or handicapped person that they are smarter than me, which isn't a lie. They aren't what they appear to be on the outside, it's on the inside where the answers lie.

Making the Necessary Inroads: This is the hardest part of the process. You have to drop any ego or arrogance that you have acquired from living. You have to be a raw nerve and totally exposed, as psychologically naked as a child getting their first bath. Transparent, you must be transparent. Strong but sensitive, smart but open – and they have to see and feel that you are real – they can sense a phony a mile away. Consider them "street smart". With a gun to your head; if you mess up, it's all over. You must show love and compassion, anything less and you lose. They watch and sense everything you do including what goes on around them.

Non Verbal Communications: Your walk, your body language, eye contact, how you approach, how you touch and the tone of your voice - all send a message to them. They also watch how you treat their siblings, classmates, friends other people with disabilities. When you talk on the phone to someone about them, they listen and they know by your tone what you're saying about them. Do you whisper to someone about them? Talk about them as if they're not in the room, make fun of something they did and laugh about it? Laugh at them? I laugh at them and at myself; and if I've done something stupid like babble out three commands in 10 seconds that even I don't understand, I laugh out loud at myself, explain to them why I'm laughing and then get them to laugh at me too. If they do something that strikes me funny, I laugh out loud; for which they give me a concerned look of confusion. I then either touch them on the shoulder or sit down next to them and explain why I'm laughing at them and then we laugh together. It's got to be mutual – how many of you take the time and effort to explain these moments to them, and let them share the joke? They're far from stupid, which leads me to the next topic. If you haven't followed this so far, you'll never grasp the next one.

Intuitive Esoteric Understanding: I'm an American living in Germany and I don't speak German, yet I have no problem getting along in public with people or making new friends. I use the same techniques I described above. I watch people's faces, their eyes, body language and tones of voice and go from there. For example, I ask "Do you speak English?". Most say "Yes, a little", to which I reply "Thanks, no problem then". If they answer "No, not at all", I reply "That's ok, I'll make it easy for you"; as I may have a shopping list in German or just point to what I'd like. If I try to speak the little German that I know, they become more at ease right away. Later on, maybe a week or less when I return to their store, they smile at me because I'm no longer a threat.

When I first came to Germany, there was no work for me because I don't speak German. Fifty job interviews and no one would take a chance and hire me. So I decided to volunteer at a nursing home close to where I live. Not only did it work out perfectly, but at the end of my stay they showered me with a stunningly high recommendation, verbal praise and many gifts for my help... and hugs all around.

I met a wonderful woman there, who upon learning that I was English, would sing me songs in English ("My heart in the highlands, my heart is not here" and "Old King Cole was a merry old soul - a merry old soul was he") to make me feel comfortable. I liked that woman right away, she and I became friends and I'd go to visit her every chance I got.

On one visit, we sat at a table in her room and started talking. She spoke little English to my little German, but this presented no obstacle for us. During our talk, a nurse came in and sat down and listened to us. About 20 minutes later she commented with stunned surprise, saying: "How do you do that? Neither of you speaks the same language yet you communicate with no problem." The old German woman just shrugged her shoulders and with a broad smile on her face said: "Telepathy, I guess". Not bad for a woman of 94, wouldn't you say?

For everyone I work with, I have this ability to understand, love and communicate. Autistic people, people with C.P., people with disabilities in general, the blind, the deaf, the "retarded" are all the same to me. A prime example is "The Elephant Man" - a man trapped inside a hideous shell, but still a man inside. Did you see the model he made of the church outside his window?

Intuitive Knowledge: As we're talking Autistic People, I'll continue. Each case is different, every person is different; thus every solution is different. Every human being has an under-ocean of vast information that's unknown, untouched and untapped. It's here that you need to understand and accept, in order "To Reach the Unreachable"; and no it's not an oxymoron. It's my contention that we've all been here before, on this plane of existence. "Déjà Vu" is a brief glimpse into this area of understanding called "Reincarnation". In simple terms, we can reach each other because of this phenomenon. This is how I reach in and fetch the real person inside. I can't pull them out, that's up to the individuals themselves; but like a baby that doesn't want to come out till the very last minute, in the end they have no choice. This is MY perception and how I see it and deal with it. It works for me.

Working for the Winner: It's no miracle - it just takes time, energy and faith. If you believe in God, all the better; if you don't, then you're strong enough to handle it on your own, so go for it. Most of you loving parents know what's coming next:

1. Love Them Unconditionally
2. Be Consistent
3. Routine Without Being Regimented
4. Follow Through On Promises and Keeping Your Word
5. Give Plenty of Rewards (TV Time – Food – Special Treats – Friends Sleepovers)
6. Make It Always Fun – Learning Through Living It
7. Be A Clown – Admit Your Mistakes – Laugh at Yourself
8. Sit Down With Your Children and Listen – Ask Them For Their Help So That You Can Understand Their Wants and Needs – And Mean It – Be 100% Honest With Them – They May Ask You For Something In Return – Be Willing To Give It
9. If Being a Parent Doesn't Work – Be Their Friend
10. Drop Your Guard – As you're Asking Them to Drop Theirs

Show them that you're human too – it doesn't hurt to say: "Ah Screw This For Now – Let's Go Out For Ice Cream – McDonalds – Burger King!!!" Once this is accomplished, the outcome is all yours to behold… make no time-frame.

No Limits – No Need: Let your autistic kids run wild when not teaching or being an authority figure. You'll learn as much from watching them explore – win or lose. What do you really want from them? To be "normal" - they are normal in their own way. Think of yourself as the oddball and compromise between the two concepts.

Freedom at Point Zero: I worked in a respite program for a few years. I met a little girl named Amber - autistic, non verbal and would take my hand and pull me out the door to go walking. Her mother lectured me over and over again – never to let go of her hand, she has to hold my hand at all times, someone will kidnap her!!! Took Amber to the park on a hot summer's day, she held my hand, hung on my leg or placed arms around my neck… It should also be noted that her mother carried her and never let her walk for most of her first five years. At the park, we sat on a bench; there were large sprinklers for the children to stand under or run through. Kids were there and enjoying the cold water spray. Amber started pulling me in that direction, and I stood her in front of me and said, "Amber, honey, you don't need me to go with you, you're safe here, I'll be close by if you get worried or feel scared, go play with the other kids and have a good time, ok! Have fun!!!" She clapped her hands together, smiled and off she went… she kept both eyes on me for the better part of an hour and after that, she forgot and just played. She didn't eat much and she hated

to sleep. One day, the house changed hands and a new crew of people were employed. I overheard a phone conversation that we were filled up and could not accept another person - I said "Who is on the phone?" and it was Amber's mother. "Let her come," I said. "I'll explain later (to the supervisor) on the phone. We always have a place for Amber." I explained she never sleeps and when she does it's on the couch. Amber always had a second home to go to and be protected.

<u>The Autistic Stranger</u>: The autistic person is generally misunderstood and under public suspicion. This is a shame because they could well be your best friend that you'll never know. A person in the family with autism seems to be a puzzle and a problem to the others. While the rest of the family works in a geometrical/mathematical/linear way, the autistic member works in an abstract/non-linear sequence of mysterious behaviours, never-ending commotion and chaos. This is counterproductive to the balance of the family.

Everyone thinks of changing the world,
but no one thinks of changing himself. - Count Leo Tolstoy

Make education a continuing, never-ending process. - Nido Qubein

You don't get in life what you want. You get what you are!
- Les Brown

The minute a man ceases to grow, no matter what his years,
that minute he begins to be old. - William James

The whole imposing edifice of modern medicine, for all its
breathtaking successes, is, like the celebrated Tower of Pisa,
slightly off balance. It is frightening how dependent on drugs
we are all becoming and how easy it is for doctors to prescribe
them as the universal panacea for our ills.
- HRH Prince Charles, Prince of Wales

The place to improve the world is first
in one's own heart and head and hands. - Robert M. Pirsig

Perseverance is not a long race,
it is many short races one after another. - Walter Elliott

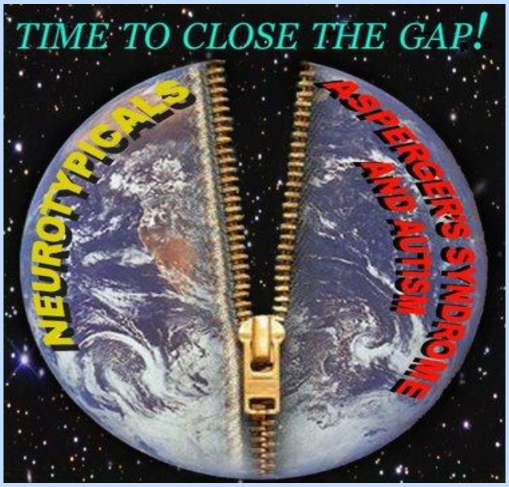
Impossibilities crumble in the crucible of persistence;
difficulties disappear under the power of persistence.
- William Arthur Ward

Action and reaction, ebb and flow, trial and error, change -
this is the rhythm of living. Out of our overconfidence, fear;
out of our fear, clearer vision, fresh hope. And out of hope,
progress. - Bruce Barton (1886-1967)

In the confrontation between the stream and the rock, the stream
always wins - not through strength but by perseverance.
- H. Jackson Brown

Autism and Neurotypicality – Simply a Difference of Dimensions

By Perla Messina/Illustration by Perla Messina, an Autistic
who's tired of the wrong picture Science has of us.



Bio: I am a proud autistic, a promoter of Autism Rights,
and a lecturer on Autism and Asperger's Syndrome.
Athens / Amsterdam : Netherlands

Background

Throughout human history, our bodies have been evolving in an invisible way, by recording and reproducing the last necessary adrenaline level needed to survive the last recorded threat.

To ensure a margin of error, the human body not only reproduces the last recorded amount, but adds to that to enlarge its chances for survival. This means that with each generation, the highest level of adrenaline produced by the mother's body is carried over to the fetus through mitochondria the fetus inherits from the mother.

That level becomes the basic survival tool kit in the offspring's life.

This means that each generation is equipped with the memory of the last generation's highest adrenaline levels and the possibility to add to these levels and increase them as needed. The offspring's own adrenaline levels will depend on the basic level it inherited from the mother plus the additional amount his/her body feels is necessary as a margin of error. The highest recorded level then becomes the basic level for the next generation.

This means that with each generation, the adrenaline level seen as basic grows exponentially - resulting in what Dr. Baron-Cohen found today as greatly elevated adrenaline levels in fetuses and amniotic fluid!

Besides this evolutionary change in our bodies, another change occurs that is also invisible. This change occurs in the brain. The brain, as it develops within the womb, has the ability to know and recognize the sort of environment in which the species will be born through several factors that reach the fetus through the mother's body. These factors are processed in the mother's body and their effect passes through the umbilical cord, affecting the fetus as well.

- The mother's diet: Research shows that the kind of nutrition that the mother uses can affect the fetus's gender and possibly also other parameters to ensure better abilities of survival.
- The mother's stress levels: The higher the adrenaline level through higher stress levels, the more the fetus will assume the surrounding environment where it will be born is hostile and the more fit the fetus needs to be/become to ensure its own survival.
- The mother's pregnancy, gestation and delivery: This period will be combined with the nutrition and stress level information to give the fetus the full (3-dimensional) picture of what kind of survival tools it needs to have in brain and muscle development to ensure it is fit – if not the fittest – to survive within the environment in which it's born!

What happens in the case of what we call "Autism"?

The diet is affected: The mother of an Autistic, research has shown, is most probably also Autistic and Autistics show an increased preference for foods that contain carbohydrates (sweets, pasta, bread, etc). These foods indicate that the Autistic body is made to consume and produce higher energy levels. The mother will consume these foods and then feel guilty for gaining weight because of the image of a thin woman brand-marked on all women by society. Her diet will change in ways that are unnatural. She will over-eat, feel guilty and under-eat, feel she is harming the fetus and over-eat again and so on.

The stress levels: Higher stress levels produce higher adrenaline levels that show the Autistic body is capable of increased muscle strength, speed, reduced pain ability, hypersensitivity of the senses (all tools necessary for battle). Higher adrenaline levels tell the fetus the environment where it's being born is increasingly hostile!!!

Gestation and delivery: The traumatic experience of birth is broadened by these events since most women with Autism (due to increased adrenaline levels in their own bodies), suffer from complications during gestation that are based on hormonal imbalances, difficult pregnancies, and other gynecological problems. These imbalances add to stress levels, alter the diet (binge eating, anorexia, etc), create false alarms of near birth recorded by the fetus as a “get ready to be born” alarm that cause it to become slowly immune to such alarms by frequent and repeated exposure. When the time of birth comes, the fetus’s immunity to the "get ready to be born" stress adds to difficulties and duration of delivery, creating yet another cause for stress for both mother and child.

Where do these lead? To a species evolving to survive an increased hostile environment! The children born are “ready for battle” and instinctively know that danger lurks behind every corner. The primary need for such a brain born ready for battle is to learn how to survive as fast as it can. Speed learning is the key for survival of the fittest when one is born without claws, fangs, and wings!

The Human Brain and its Learning Ability

The human brain is set to learn through the senses, with a priority to the senses of sight and hearing. These senses in the Neurotypical brain take a great deal of space and surface within the brain and use most of the brain’s processing capacity because they are 2-dimensional, while the surrounding environment is 3-dimensional. Each eye and ear sends information in the brain that needs to be processed and combined with ability that we call Gestalt. The brain takes the data it receives from the eyes and ears that is 2-dimensional and turns them into 3-dimensional using the ability of Gestalt! This is a long and time consuming process when it comes to a brain set for constant battle with its environment.

The increased levels of adrenaline in the Autistic brain have the following effect: Instead of using sight and hearing as the primary collectors of information and then processing this 2-dimensional information with Gestalt to produce a 3-dimensional image of the environment, the brain changes its primary sense for data collection to a more efficient one that does not need Gestalt processing to turn info 3-dimensional.

From all our senses, there is one that is 3-dimensional WITHOUT THE NEED of Gestalt to make it such! The sense of touch is the ONLY primary sense that is 3-dimensional without the need of processing, without the need of Gestalt. This sense offers a more direct and much faster collector of data that tells the brain about environment. Autistic brains, unlike Neurotypical brains, do NOT use the senses of sight and hearing as primary, but the SENSE OF TOUCH!!!!!!! This sense of touch acts as a basis upon which ALL other 2-dimensional senses come to add details such as images, sounds, tastes and smells. There is one catch in this way of brain processing: The more the 3-dimensional sense of touch is underdeveloped (limited sensory integration) the more the supplementary 2-dimensional senses of sight, hearing, smell and taste cannot find enough or adequate space on this basis to stand upon; therefore creating a sense of hypersensitivity, a brain overload due to this inadequate space. The way I can describe this is like a limited patch of ground where an increasing amount of trees needs to grow; resulting in a sort of overgrown jungle, where all plants mingle so wildly that no one can tell where they begin and end.

This is why sensory integration is so important to the Autistic brain when it comes to aiding the other 2-dimensional senses that also assist the learning ability of the Autistic brain. A limited sensory integration is based on several factors:

- The mother’s increased stressful life and limited time to spend with baby/child: Mothers who used to breast-feed until the child was 3 or 4 had to also hold the child while breast feeding. Modern methods and the use of bottles freed mothers from having to hold children as long or as often. Unfortunately, this decrease in “holding time” has limited the child’s developing brain and its need for sensory integration through the sense of touch.
- The mother’s own sexual life has changed. More and more couples suffer from sexual problems based on the stress and increasing demands of society. These result in the following paradox: The less sexual satisfaction, the less love, and the less touch (sensory integration) the mother receives from her male partner, the less she will give to her child. The incorrect assumption that the female is capable of producing never-ending amounts of affection and love is a myth causing the human race great damage. The female is a vessel that needs to be filled with “love” in order to give love. The less love she receives, the less she is able to give to her offspring.
- The male-dominated society’s effect on women (and subsequently mothers), turning them into carbon copies of male counterparts in their battle for survival in a society whose norms are set by male needs and abilities. Female intuition is ridiculed, female emotional fluctuations and seeming instability that results from the female monthly cycle of hormones are seen as weaknesses instead of the strengths they actually are, and the female need for respect and full equality in decision-making is still very limited compared to male’s.

All of the above construct a picture Fraud once called the “refrigerator mother”; yet it is not the female’s own fault but a result of the need for survival with a society that has rejected her specific abilities and needs - the result is the SAME!

Today’s women are less capable to give children the kind of love the child needs - the kind that involves lengthy amounts of touching, hugging, holding, embracing, caressing, etc. In the increasingly busy lives of women, such lengthy processes of tactile and sensory diet are a sheer luxury and the choices these women have are shaped by pressure they receive from their HOSTILE environment - an environment that makes ever increasing demands on them, that allows their female nature less and less freedom and acceptance. This is an environment that dictates the kind of evolution that is needed and will be set forth by each generation - to ensure that next time around, the tables are turned.

The more hostile the environment is, has become and will become for women and their specific, biological, sensory, and hormonal needs, the more their bodies will produce offspring set to survive, conquer and change this seemingly hostile environment by having brains that evolved from a 2-dimensional learning mode and process to a 3-dimensional learning mode and process to ensure not only that their fronts are covered in the daily battle for survival, but also their BACKS!!!

The 3-Dimensional Autistic Brain and its Abilities and Disabilities

The Autistic brain, freed from the extra load of Gestalt processing, is now able to use its abilities in a way that is more efficient and energy-saving. A warrior who needs to survive in a hostile environment can waste neither time nor energy in trivial matters.

Thus, the Autistic brain, by using the 3-dimensional sense of touch, is able to expand focus on other areas that offer better protection and more chances for survival. This expansion includes two areas. One is systemizing, very well defined and explained by Dr. Baron-Cohen. This is the pure “male” brain function that helps to categorize environment and label it accordingly as friendly or dangerous, enhancing ability to recognize which patterns work better towards survival and which do not.

Besides this pure “male” brain, there is another function present. This function has been obscured, disregarded and discredited by science. This ability is that of the pure “female” brain - the ability to sense using intuition, extraordinary sensitivity, even telepathy. This ability works almost like the sonar that allows bats to fly safely in the darkness and hunt their equally flying prey of insects.

Autistics call this ability the “Tool”, and it works almost in the same fashion as a radio antenna picking up radio waves from the ether. The “Tool” is a sensation, a "voice" to warn and protect us like a beam of light that “touches” and senses space and time in front of us. Because our brains work in 3-dimensions, they are capable of handling time and space in different ways than Neurotypical brains. This is not in the linear 2-dimensional way the Neurotypical mind does, but in a 3-dimensional way. Here, time and space are endless and everlasting, encompassed within a sphere - the sphere of the universe - where nothing is wasted or lost and all exists eternally freed from the linear 2-dimensional way of thinking that holds the Neurotypical mind bonded in a linear past, present and future.

The abilities of the Autistic brain are not limitless. Unfortunately, while the 3-dimensional sense of touch gives us certain abilities, the other 4 senses lack in abilities in an equal way. Vision and hearing suffer without the use of Gestalt. Thus, information flows in our brain are fragmented and in myriads of pieces, exposing all details we see and hear in a flat 2-dimensional way that overloads our brains as it tries to connect these 2-dimensional information segments not to each other as a brain that uses Gestalt would, but to the existing 3-dimensional basis of the sense of touch.

This automatically means we have difficulty differentiating sounds that are near from sounds that are far, objects that are near from objects that are far; seeing depth requires Gestalt and our brains do not have that ability. That is why we are clumsy as infants and young children. It is not our body that is clumsy, but our body's movement when it comes to its relationship to the objects we see and hear around us. It is more difficult for a child with Autism to learn the distance between his/her body and all other objects that surround it because our eyes are not able to see the depth of field in the same way as the eyes of Neurotypical children!

In some ways, this lack of depth of field makes us fearless because it does not arouse in our brains the typical response of fear the same input would in a brain that operates mainly on vision and hearing. Our clumsiness of movement is a symptom of a brain that learns to relate as a WHOLE to its environment through the 3-dimensional sense of touch instead of the 2-dimensional (plus Gestalt) way the Neurotypical brain uses. Once we learn to relate to distance, speed, movement through the sensation of OUR WHOLE BODY, through the input that enters our brain from the whole surface of our bodies (aided by the less able senses or sight and hearing), we learn to function within our environment as well as Neurotypicals.

The ways we use to learn and master this ability also follow a different path than Neurotypical brains. Through stereotypical movements of body, hands, head, and legs/feet, through waving of hands in front of our eyes, through rotation of objects within our visual field; we teach our eyes to see and recognize changes in depth of field we cannot otherwise see!

That is also why we do poorly in sports – we cannot catch a ball not because our body is clumsy or slow but because OUR EYES MISJUDGE THE DISTANCE between our hands and the ball!!! The reason we can't separate sounds whether they are near or far, or the voice of a person standing next to us and a person in a room next door is based on the same principle and problem. Our brain takes input from our eyes and ears as 2-dimensional and keeps it as such instead of turning it into 3-dimensional. Without Gestalt, our sight and hearing are as flat and linear as can be. We use WHOLE body sensation to create the 3-dimensions we need from these senses.

Many find ways to learn depth through different activities. I used to bounce a ball against a wall for hours and hours until I could successfully coordinate my eyes to see the correct distance and tell my hands where to aim and catch. Some others use different sports or hobbies (like origami) that take flat surfaces and create 3-D images, teaching the eyes through movement of the hands (the 3-dimensional sense of touch) how to recognize and record the depth of field within space.

Autism and Neurotypicality, the two Human Species

Unlike all other species, we believe humans are all the same. They are not. Our lives had once been spread out over wide open spaces, allowing each of the two kinds to roam free and live in peace and harmony. In many cases, we used each other's specific abilities to our benefit by recognizing some of us had abilities others did not, and some could see possibilities where others could not!

The two species now live piled up together in closed spaces, in over-populated areas and within a system of laws and rules that does not take into consideration specific differences. We are like the two sides of a coin now lying flat on one side, hiding the other. The hidden side is what was diagnosed many years ago as Autism. Autism is not a dysfunction of the brain or an abnormality of human development. It is a basic but fundamental difference of how our brains are built and function.

Autistics, as they have been labeled, think in 3-dimensions using as primary sense touch and tactile input we receive. Other senses, such as sight and hearing, function less well because our brains do not use Gestalt. If they do, they use it in a very limited and almost dysfunctional way. Thus, our brain sees the forest with its 3-D basis and then engages our other 2-dimensional senses to see the details and add them to that basis. This allows us to notice details more easily, see tiny differences that would otherwise go unnoticed, disengage parts for better and deeper learning. Our brains need to do this microscopic observation because they are set to function in a hostile environment and even a tiny difference can prove lethal.

Neurotypicals, as Autistics have labeled those who labeled them, think in 2-dimensions, using as primary senses sight and hearing. Added to these is sense of touch, the basis of Gestalt, since tactile input creates the holographic or holistic connection of all 2-dimensional input coming into the brain from the eyes and ears. This means the Neurotypical brain sees details first then combines them together to see the whole. Seeing the forest instead of engaging in details of trees allows the Neurotypical brain to gather a different set of information about environment and relate to it in a different way. The Neurotypical brain is set to function in a non-hostile environment and see and recognize safety as a given.

I call this the difference between the hunter and herd.

The Autistic brain is the hunter, set to recognize differences that will help it seek out and “contact” ones it sees as fit for survival. We stand aside, observe and seek specific traits in others around us before we seek contact. A good hunter knows when to “attack” and when not. A wrong move can result in an injury that can render hunters useless and unable to hunt any longer. This will lead to certain death. Even though we hunt, we do not hunt to kill. We hunt to connect.

We seek and search to find others similar to us or with traits complimentary to ours, to connect and add these to ours. More traits equals more tools and more tools equals better survival. We are the hunters of fellowship, friendship, and human contact. We do not herd, we co-operate as equals with equals. That is why we are very selective with whom we will co-operate and create a collective of traits and tools, abilities and interests. This co-operation MUST have a solid basis on equality and respect between the parts that form it. Only under such circumstances can co-operation be in perfect balance!

The Neurotypical is of the herd that finds safety in groups, numbers, uniformity; ignoring (willingly or not) the differences to ensure homogeneity within the group to which it belongs.

Within the homogenous group, Neurotypicals also seek traits of similarities and differences. Here the reason is very different. In a herd, not all members can be equal. A Neurotypical brain seeks 3-dimensionality within a 2-dimensional herd by creating a hierarchy in the group. The way the Neurotypical herding brain connects is not that of equality but of dominance, levels and castes.

This model has shaped our existing society and become the primary way of acceptable behavior. In a homogenous group, hierarchy is based on details that show each other the position of the person on the hierarchy ladder. Wealth and possessions, objects of luxury, fashionable clothes, and fancy cars - all are attributes equally important as the intellectual markings of degrees, titles, positions, and the respect these bring. All are necessary attributes to mark the hierarchical position of the holder and separate him from the herd.

To the Autistic brain, such attributes seem trivial and useless; while for the Neurotypical brain, the behaviors we need to develop our brains seem stereotypical and equally useless. The two kinds of the Human species have turned their backs to each other and one dominates the other. What is normal has been established by those who hold the hierarchy - leaving the other (Autistics) at their mercy. While they are no less abnormal than Neurotypicals, Autistics are now used as prey to feed the herd's ever-increasing hunger for wealth, domination and power. The herd has now become a pack of hyenas, and hunters are lonely lions at the mercy of hyenas' feeding frenzy. How much longer?

Cherish forever what makes you unique,
because you're really a yawn if it goes. - Bette Midler

We have to dare to be ourselves,
however frightening or strange
that self may prove to be.
- May Sarton

A very small degree of hope is sufficient
to cause the birth of love. - Marie-Henri Beyle (1783-1842)

Hold fast to dreams for if dreams die,
life is a broken winged bird that cannot fly. - Langston Hughes

We must be willing to get rid of the life we've planned,
so as to have the life that is waiting for us. - Joseph Campbell

Creativity is inventing, experimenting, growing, taking risks,
breaking rules, making mistakes, and having fun. - Mary Lou Cook

Opportunities to find deeper powers within ourselves come when
life seems most challenging. - Joseph Campbell

The greatest gift you can give to somebody is your own personal
development. I used to say, "If you will take care of me, I will
take care of you." Now I say, "I will take care of me for you if
you will take care of you for me." - Jim Rohn

The following was written by Patty Hastings while she was a senior at Hockinson High School in Brush Prairie, Washington and was completing a senior culminating project through which she was promoting autism awareness. “Having lived and worked with individuals with autism, I've composed narratives based on my experience, knowledge, and beliefs. The encouraging message relayed by my written works has significantly inspired my peers and I believe your readers would respond similarly.”

Love of a Room

By Patty Hastings

A cardboard box, larger than me, bumped along the wooden panels of the stairs and hit each step jingling from the objects inside. It squeaked to a stop by the bedroom door. I stepped over blanket mounds to pull back the curtains. Gauzy August sunshine streamed through the window. Outside, I saw the fresh green roof of our house, a roof we’d both sat on immersed in stars but with different purposes and reflections.

My brother, William, was usually in this room, quietly wrapped up in covers. Today, he was out. In fact, everyone was out except me.

Some brown cleaning supply was finger-painted on the wall by his bed, which acted as a canvas for his anxieties and boredom. The floor was gritty with dirt, sand, and corn chips. Clothes were piled on the dresser. I swept the grit away, scrubbed the grime away, coughing up dust and cleaning toxins. I folded blankets and clothes, putting them into dresser drawers.

Spraying a flowery mist, it sieved into the air, the floor, and my thoughts. Images of children spraying William with air freshener, as though he were just another putrid object, spun in my mind. Injustice burned my eyes, but since I seemed to be cleaning it away, replacing it with activity, the sensation cooled. The thoughts fell with the mist.

I stopped my labor only to eat and sleep.

The box stood outside the room as though defiantly hesitant to enter. Shuffling in it and digging through treasures - things that’d lost their playtime novelty and that still held value in my sentiments - I gave them to him. I uncovered kitchen trinkets and crafts throughout the house, such as empty jars that he could therapeutically twist, and organized them into storage boxes I’d owned and doodled on since I was little.

I pinned his birthday cards to the wall, including one I'd made with communication board pictures. Objects were strung from the ceiling and pinned in place: a skunk purse, a Christmas mitten, a toy wrench, and a cardboard star. Frog posters, candy-striped wall paper, poster board, and construction paper were pasted to the walls, their whiteness fading behind the bright surfaces that welcomed doodling and writing practice. I wanted William to transform his own room, to better understand his capacity.

Working swiftly, almost in a trance, the entire renovation took two days. On the first day, I had William sweep or throw garbage away so that he could improve his own room and see it. However, the second day, the contents of the cardboard box and I alone made it unlike the room he'd known for 22 years.

Suddenly, I heard a door creak open from downstairs, the starch sound resonating in the soft hum of my work. How would my parents react to something I'd done on impulse? William's clogging steps bounded toward me. How would my brother react?

"Autistic people do not react well to change," textbook authorities reprimanded me.

My thoughts shifted to "Thinking in Pictures" by Temple Grandin and all of her accomplishments, her brilliance and her fortitude.

Maybe William would find comfort in the visuals. He'd absorb the scene, love the scene.

I couldn't expect radical change. I couldn't expect a miracle and, honestly, I didn't want one.

My breath, my satisfaction, and confidence were held in those few enduring moments before he pushed open the familiar door to reveal unfamiliar surroundings. His eyes narrowed. As William touched everything, a gentle smile played on his face, making his cheeks round, handsome, and colorful like the bright hues on the walls. His smile wasn't pasted or contrived. I knew it was real.

He used the paper puncher, doodled on the green construction paper, and then curled up in his neat bed. "Sweet dreams," I thought, tired and happy myself. I felt equal to him. We both had rooms with colors and materials. We both looked at the celestial bodies churning above us.

If you limit your choices only to what seems possible or reasonable, you disconnect yourself from what you truly want.
- Robert Fritz, motivational author

Review of Leeann Whiffen's *A Child's Journey Out of Autism*

Having just completed this fascinating true-life story about Leeann Whiffen, her husband, Sean, and sons Drew, Clay and Judd, we are still unsure just how to review it.

Leeann takes the reader's heart and mind and spirits on a very personal, heartfelt journey into the life of a young family trying to deal with and find answers to and eventually solve the enigma of and recover their son Clay from autism.

The family, led by Leeann who felt misled by her son's first pediatrician is not satisfied with the concept that autism is incurable or untreatable and thus, they set out to do all they can to negate the idea. Having been on a very similar journey albeit at a much earlier date in time, we were touched by Leeann's strong motivation and devotion to do all she could to help Clay.

From ABA to RDI to Floortime to CARD to DAN protocols and many other biomedical and dietary interventions, Leeann and Sean spent every bit of money available to them to support their son's treatments/therapies, in the process helping other families and children and becoming open public advocates for improved and increased governmental support of these somewhat controversial techniques.

More than a story of advocacy, however, this is a story of unconditional love and devotion - a story of insight into despair and hope - a very individualized tale of a family who did what many would deem undoable (unthinkable) even and turned the lemon they felt life had given them into very sweet lemonade.

Although Leeann questioned her son's progress and the likelihood of his "recovery" on more than one occasion, it is to her great credit that she never gave up and unstintingly worked for the day she would get her child back.

Whether one agrees that autism is curable or incurable or should be cured in the first place, most agree that most effectively treating symptoms that interfere with living the best possible life with autism should be a goal we all strive towards!

By Sharisa Joy Kochmeister and Jay Kochmeister

Let me tell you the secret that has led me to my goal: my strength lies solely in my tenacity. - Louis Pasteur

It is truly said: it does not take much strength to do things, but it requires great strength to decide what to do.
- Chow Ching

Shasti McLaughlin
Intuitive, Certified Reiki Master/Instructor
Pranic Healer, Level II; American Sign Language Interpreter

SPECTRUM

They say our children have "ASD"
They've placed them inside of a “spectrum."
I don't care what they think
what they speculate
As the labels don't say to accept them.

"They don't see it like us, they don't understand"
they warn as they push all their plans.

Their reformations, their therapies,
their diets, their research,
their opinions
Are placed in our laps and
pushed down our throats
'Til we've spent money by the millions.

So I stopped for awhile and watched my girl
I've noticed there's some things about her...

They blow me away as I look in this way
I'm amazed
and I wonder...

If I didn't have her, would I have managed
to see the world in this way?

What I thought was black and white
hey- maybe it's not-
maybe it's actually grey.

There are some things important,
they matter a lot,
and others
well, they just don't make sense.
I watch my daughter
her expressions
find inquiry
in her face
Questioning without voicing the words
perplexities of this human race:

Like cross every "T" and dot every "I"
it looks nice but explain to me *WHY.*

I like my "I" capital without any dots
it looks so much more decided!

Let people do it the way that they like
if they did, we'd be less divided.

"You don't understand..?" she'd say,
"Let me explain the meaning behind what was said."

There are rules that make sense,
like don't run into the street
when the traffic is heavy and dense.

But his yanking the pen out of my hand,
placing it again and telling me "Like THIS."
takes the joy of the experience
of figuring it out
out of my hands and right into his.

Sure, I may take longer to get the idea
do it as well as you may take a bit.

But pause for a moment, give up the pen
and leave it right where I put it.

Watch for a moment, give a hint or two;
but what worked for others, people like you
is not what I'm going to do.

Watch awhile longer, and see me succeed.

Call me "so clever"
"amazing" or "brilliant."

It really won't matter to me,
'cause if you're paying attention

it was you and not me
who learned something back in that moment.

I did a new way, a creative new way
a way that made much sense to me.
Without caring or worrying about
what you would think
or whether
you'd get it and see

Those paths that I and others like me are varied
they're sparkling
they're new

That without this "spectrum"
I'm on in or under
This way I found to do
you and others like you would never have
conceived, perceived or viewed.

So Ha Ha! Look what I've done-
I've brought us here back together.

You've looked, you've listened
you've learned

You changed your perspective a bit.

You and I *aren't* so divided, we're equally good -

it just took you a while to get it.

Song of the Flower by Kahlil Gibran

I am a kind word uttered and repeated
By the voice of Nature;
I am a star fallen from the
Blue tent upon the green carpet.
I am the daughter of the elements
With whom Winter conceived;
To whom Spring gave birth; I was
Reared in the lap of Summer and I
Slept in the bed of Autumn.

At dawn I unite with the breeze
To announce the coming of light;
At eventide I join the birds
In bidding the light farewell.

The plains are decorated with
My beautiful colors, and the air
Is scented with my fragrance.

As I embrace Slumber the eyes of
Night watch over me, and as I
Awaken I stare at the sun, which is
The only eye of the day.

I drink dew for wine, and hearken to
The voices of the birds, and dance
To the rhythmic swaying of the grass.

I am the lover's gift; I am the wedding wreath;
I am the memory of a moment of happiness;
I am the last gift of the living to the dead;
I am a part of joy and a part of sorrow.

But I look up high to see only the light,
And never look down to see my shadow.
This is wisdom which man must learn.

**People deal too much with the negative, with what is wrong.
Why not try and see things, to just touch those things
and make them bloom? - Thich Nhat Hanh**

Being a Parent of a Person with Autism and Realizing You Have the Same Syndrome!!

Jay Kochmeister 10-08 Revised 7-09

For the past 28 of Sharisa's nearly 31 years, she has had a label other than just "person" – a label I had no idea of the meaning of when it was first stated, a label that once I researched it, seemed to imply many things. "Autism", I read, was withdrawal from reality, withdrawal from socialization, inability to experience and understand emotions, a kind of "black hole" from which there was no hope of return. Sharisa had been a verbal infant from six months on. Then, suddenly, language disappeared and other than the word "Daddy", she seemed incapable of any verbalization. "Daddy" became an all-purpose word – as a growl to express anger, giggly to express joy, gloomy to express sadness. I thought to myself: "If she doesn't experience emotions, why does she cry, laugh, sing, hum, scream? If she's incapable of socialization, why does she cling to me so tightly and smile at my parents? If she's withdrawn from reality, what does "Daddy" actually mean to her and why is it the only word she seems regularly capable of uttering? If there's no hope for a future, how will I (we) go on? Will she know her sister, know holidays, feel joy, learn, speak and live rather than merely exist? What did I do wrong and how can I fix it? Can it even be fixed? What the hell will I do?"

I became depressed, despondent, diminished as a person. I had no idea how I could help her and almost every parent always thinks they can/should help their child.

Years went by with a succession of schools, occasional spoken words, multiple tests and diagnostic labels, countless educational planning meetings, numerous therapies, many pontifical statements that she'd *never* progress and I should be prepared to "someday put her away". I watched her younger sister Amy learn and grow, socialize and thrive, defend her big sister, play with her, accept her for who she was because that was the only Sharisa she'd ever known. I, on the other hand, had known another Sharisa – a happy, smiling, inquisitive baby, very social, very intelligent, eager to learn and explore everything; and I held tightly to the hope that *that* Sharisa was locked somewhere inside and if I could just find the right keyhole, door, window, treatment, prayer, bargain with the devil, I could rescue that inner Sharisa. I was unable to accept there was no hope whatsoever.

I did what's commonly referred to as bargain with God, shop around for therapists, fight with school districts, question professionals, and learn as much as I could including going back to school for a Master's degree in Special Education so school districts couldn't tell me they were "experts" and I was "just a parent" who knew nothing about "special needs". I was a single parent raising two daughters at least part of that time, and handled both their special and typical needs every single day; but without that degree I could not possibly have had the knowledge required to understand “special needs”.

Despite all the diagnoses and prognoses of doom and gloom, I managed to hold on to hope. Despite years of tears and fears, I held on to dreams. Through it all, I held on to not just a memory of the Sharisa that was, not just a vision of the Sharisa that could someday be, but always the Sharisa I nurtured, cared for, sang to, read to, loved every day of her life.

A decade went by and suddenly Sharisa became a teenager. On her 13th birthday, she “twinned” with another girl from our temple so that she could be “bat mitzvah”. As she stood beside me on the podium and I read her Haftorah for her, she kept smiling and looking at me as if she clearly understood. At the end of the reading, she looked over the pulpit and smiled at the large crowd of people who knew her and didn’t know her, many of whom had tears in their eyes, some of whom had tears rolling down their cheeks; with me beside her filled with pride, wonder, awe and feeling this huge lump in my throat as my eyes also brimmed over. After the ceremony, we took her to her favorite restaurant to celebrate with friends and her joy was palpable. I sat wondering how someone whose IQ was tested as south of 30 and as low as 10 could possibly enjoy this so much.

Several weeks later, a young woman named Eila, whom Sharisa had met that summer at her “special” school and actually liked, asked if I’d be willing to let her assess Sharisa for some newfangled, not yet controversial process called “Facilitated Communication.” I’d heard about this process for about a year and really believed it would never work with Sharisa, but clinging to a shred of hope that hardly matched my mountain of trepidation, I said: “Sure, you can try it; but I’m almost sure it won’t work with Sharisa. After all, she can’t even read!”

Shortly thereafter, I was forced to eat those ugly words of doubt as I witnessed for myself that not only could Sharisa read - she could understand, reply, think, learn, grow exponentially and enjoy doing all of those.

She brimmed with questions about everything from science to religion, had been writing poetry and music in her head for years, her “inappropriate affect” was actually tears of sadness or pain and laughter in reaction to things that struck her as funny or jokes she told herself, and we could carry on a conversation.

Suddenly, her intelligence tested at a higher level because she was allowed and, yes, even encouraged to reply by typing. Suddenly, her social skills grew huge wings. Suddenly, she wanted to know everything about everything, asking questions and following them up with more questions, reading dictionaries, thesauruses, encyclopedias and books of all kinds. Suddenly, she could tell us when she was in pain, where the pain was, and ask for something for it rather than tantrum in frustration. Suddenly, she was telling me jokes, writing tons of poetry, eating like she was starving after being underweight for so very long. Suddenly, I had not only the daughter I had craved but a friend whose company I truly enjoyed. Suddenly, her sister had a sister and friend whose company she enjoyed. Suddenly, my life began to have a new purpose, a greater meaning, a new direction to help others find their “missing” children, even if those children were already adults. Suddenly, the speech therapist who had pronounced that Sharisa would “never communicate” went for training in Facilitated Communication and started using it at the school Sharisa had once attended and the psychologist who had tested her IQ at 10 found himself unable to even look at Sharisa typing.

Six months after starting to type, Sharisa did her first public presentation/ training and enjoyed every single moment of it. Two years after starting to type, she started seventh grade at age 15. A year after that she was in high school in 9th grade and soon she could type without facilitation.

Three years after that, it was community college with another three years to an Associate’s degree with honors in Humanities and Social Sciences. Subsequently, Sharisa and I moved from New York to Lakewood, Colorado, a suburb of Denver; and in four more years, she had a dual Bachelor’s in Sociology and Psychology. Through the years, she continued to write, train people, appear on television and in newspapers and journals, be helped by therapies of all types, and become more and more social. She met President Clinton at the White House at age 19 after having voted for him at age 18. She became an advocate, activist, leader, author, composer, editor, board member, and the president of an international autism group.

We went to many conferences, and met many people with and without autism; and I, who already knew I had ADHD and strongly suspected there was a strong autism gene on my father’s side of the family, found I felt more like and more accepted by people on the spectrum than I was and ever had been by so called “neurotypicals”. I took a good, long, piercing look at my childhood “shyness” and preference for being alone and reading books seven years above my grade level, my checkered job and romantic history, my need for structure, my own lack of “normal” social skills, my wide-ranging yet non-focused intelligence and interests, my vast creativity, my obsessive-compulsive tendencies, my anger, and my ability to adapt to almost anything and anyone and I began to suspect that gene hadn’t skipped me on its way to Sharisa. I am now finally ready to accept/admit that I, too, am on the spectrum – in fact, I’m quite ready to accept my “differences” and embrace my “uniqueness”.

At last, I feel like not only the proud parent of someone on the spectrum but a proud member of that exclusive and very special club called “Autism!” Apparently, the following poem was more real than I was at the time!

As I Grew
JLK 1997 Revised 2009

As I grew
I knew
I was different
From the others -
All the sisters
And the brothers,
All the fathers
And the mothers
All around me
Who surround me
And confound me -
In my never-ending puzzle
With no obvious solution;

AH, so this is evolution!
And my life's a revolutionary
Construct and/or Concept -
Not a question or an answer,
Just a Concept and/or Construct!

Nobody can give you wiser advice than yourself. - Cicero

A perfect parent is a person with excellent child-rearing
theories and no actual children. - Dave Barry

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

Hateful is the power, and pitiable is the life,
of those who wish to be feared rather than loved.
- Cornelius Nepos, Roman author, 100–24 B.C.

People deal too much with the negative, with what is wrong.
Why not try and see things,
to just touch those things and make them bloom?
- Thich Nhat Hanh

Somewhere from birth until this very moment,
you made a commitment to be the very best you could be.
Are you?
- Bob Perks

Sensory Smart Techniques for People on the Spectrum

- By Lindsey Biel, M.A. OTR/L, Co-author, *Raising a Sensory Smart Child*

Bio:

Lindsey Biel, M.A., OTR/L is an occupational therapist specializing in pediatrics. She is the co-author of *Raising a Sensory Smart Child: The Definitive Handbook for Helping Your Child with Sensory Processing Issues*, with a foreword by Temple Grandin. Through her private practice in New York City and the NY State early intervention program, she works with infants, toddlers, and school-age children with diagnoses including sensory processing disorder, developmental delays, autism spectrum disorders, physical disabilities, learning disorders, emotional disturbance, and other challenges. Formerly an occupational therapist for the NYC Department of Education, she has worked with children in elementary, middle, and high schools, As an evaluator for the Center for Assistive Technology, she evaluated and trained students of all ages for assistive technology. She is a popular speaker, teaching workshops to parents, teachers, therapists, and other professionals across the country. She is a contributing writer to the *Autism Asperger Digest Magazine*; OT Consultant to TRP Wellness' OT at Home and OT at School DVD series, narrated by Kim Hunter; and OT consultant to Integrations/Abilitations/ Sportime, a family of therapy and educational catalogs. Lindsey says the new edition that's coming out at the end of August will have a special chapter on sensory issues and people with autism and a lot more information for teenagers and adults. The new edition is available for pre-order on Amazon now! Visit her website at www.sensorysmarts.com to see more about this wonderful book! - Sharisa Joy

Lindsey Biel

Fluorescent lights blind me.
My teacher smells like Drano.
My feet hurt when I'm barefooted.
I can't hear you if I look you in the eyes.
Grandma's food makes me throw up.
Walking into the mall is like being in the first row of a heavy metal concert.

These are some of the experiences people with sensory challenges have. Everyday experiences that others take for granted may be difficult, sometimes impossible, for a person whose nervous system processes sensory information in a different way.

Sensory integration refers to how a person registers, processes, and uses all the various sensations coming from within the body and the environment. All of us learn about and comprehend the world through our senses. We see things, we hear things, we touch things, we experience gravity, and we move around. All of this sensory input works together to give us a reliable picture of the world and our place in it.

Children and adults with SI dysfunction, more recently relabeled sensory processing disorder (SPD), experience the world differently. They don't take in and use sensory information the same way. They may have problems perceiving some of the incoming sensory input or linking these inputs together so that all of the information makes sense. And because their brains and bodies struggle to make sense of their experiences, they can have significant difficulties with activities such as learning, playing, eating, socializing, self-care and even sleeping.

For a child with significant sensory issues, walking into a classroom can feel like walking into a rock and roll concert. Such a child may be able to see and hear the fluorescent lighting, a chair being moved on a bare floor may sound like nails on a blackboard, other kids may smell like a fish market, the carpet may feel like quicksand, and walking into the playground may feel like being on a merry-go-round. What seems normal to us can easily overwhelm a person with sensory problems. It takes a lot of energy to keep it all together for such a child. Add academic and behavioral demands at school or at work and you can see why such a person would have a hard time.

At school, students with sensory problems have particular difficulty during circle time, transitions between activities or classes, in the cafeteria, in gym class, recess and in many other situations. Their brains and bodies just can't handle the barrage of sensory information. More than likely you will see such a child going into sensory overload and having a total meltdown or simply tuning out. In a work situation, an employee may find that intolerable sensory experiences such as a noisy colleague in the next cubicle or even a cleaning product used make getting the job done a major challenge.

People with sensory problems may show hypersensitivity, hyposensitivity, or mixed reactivity. Hypersensitive people have strong reactions to sensory experiences that are out of proportion. They tend to isolate themselves and either tune out or tantrum in response to overwhelming sensations. The person who is mostly hypersensitive tends to be a sensory avoider. In order to cope with a barrage of noxious sensory input, he or she may withdraw and become self-absorbed or even act out if the experience is intolerable. The hyposensitive person is often a "sensory seeker" who is always on the move, and may enjoy rough play, loud music, and frequently smell, lick, or throw, or bite or hit even when he's not angry because obtaining intense sensory input helps him stay tuned in. Most people with sensory issues are oversensitive to some sensations and undersensitive to others. Much depends on issues about sleep, food, stress, predictability, and so on.

Common Signs of SPD:

Over- or undersensitivity to touch, sounds, sights, movement, tastes, or smells

- Bothered by particular clothing fabrics, labels, tags, etc.
- Distressed by light touch and/or unexpected touch
- Dislikes getting “messy”
- Resists grooming activities
- Sensitive to volume and frequency
- Distracted/distressed by ambient noise
- Easily overloads visually
- Squints, blinks, or rubs eyes frequently (may be a sign of a vision problem)
- Gets dizzy easily or never at all
- Constantly on the go or avoids movement
- Craves or avoids particular tastes or smells
- Very high or very low pain threshold

Problems with vestibular (movement) and proprioceptive senses (body sense)

- Poor fine and gross motor skills
- Poor body awareness and motor coordination
- Poor eye-hand coordination skills
- Poor motor planning (praxis)

Oral motor and feeding problems

- Oral sensitivity
- May drool excessively, have poor latch
- Avoids foods most children enjoy
- May have speech/language delays

- Poor attention and focus: “tunes out” or “acts up”
- Uncomfortable in group settings: does better one on one
- Developmental delays, learning, and organizational difficulties

Sensory problems are frequently a “co-morbid” symptom of diagnoses such as autism spectrum disorders, attention disorders, Cerebral Palsy, Down Syndrome, Fragile X, developmental disabilities, bipolar disorder, anxiety, and other mood disorders. There is a high incidence of sensory problems in children adopted from overseas institutions, premature infants, and in those who have experienced birth trauma, prolonged hospitalization, or exposure to heavy metals.

It’s estimated that there’s one child with SI issues in every regular education classroom, or roughly 10-15% of the population. In a classroom of students on the autistic spectrum that figure is between 50- 80%. In a study of adults and children with autism, researchers at the Geneva Centre for Autism in Toronto found that 80% are hypersensitive to touch, 87% to sound, and 86% had visual issues. Thirty percent reported taste or smell sensitivities. “High functioning” autistic people such as Temple Grandin write eloquently about their very severe sensory issues. Temple wears old soft shirts under all her clothes, and turns her underwear inside out because she can’t tolerate the seams. Certain sounds, like nails on a blackboard, aren’t just annoying—they feel like a dentist drill hitting a nerve. Some people have very severe problems with visual processing, even though they can pass an eye exam. Some act as though they are blind when they

are in a strange place, and others have problems with visual whiteouts, which can be like seeing snow on a vacant television channel. Fluorescent lighting may be intolerable because many autistic people can see and hear the rapid flicker.

Some people use their peripheral vision due because visual distortions are reduced when they look out of the corners of their eyes.

What to Do

Get Expert Help: **Fortunately, a great deal can be done to help children and adults with sensory problems. The first step is to get expert help, which usually consists of evaluation and treatment by an occupational therapist who has specialized training and expertise in this area. The OT's interventions will be designed to increase the person's ability to handle incoming sensory input and to link it up with other sensory systems. It is very important that you or the child's parents and other caregivers carry over recommended therapeutic exercises and activities to achieve maximum effectiveness.**

If the child is under age 3, the parent can ask the pediatrician for the name of a local early intervention (EI) agency. Unfortunately, some pediatricians are not knowledgeable about early intervention, so the parent may need to contact the state EI office for a referral to a local agency. For EI offices in your state, go to www.sensorysmarts.com and look under "*How to find an OT*." For children age 3 and older, parents can contact your local school board.

Adults with sensory challenges may also work with an OT who specializes in this area. You can find such an OT in a private practice, an independent clinic, or in a hospital. You can go to www.spdnetwork.org for a directory of OTs, physical therapists, speech language pathologists and others who are experienced in helping people with sensory challenges.

Feed Sensory Needs: **The second step is to implement a "sensory diet." A sensory diet is a schedule of activities designed to meet sensory needs and it has very little to do with food. Just as you don't wait until dinnertime for the nutrition you need for the day, you also can't wait until evening to feed sensory needs. You've got to keep full all day so you feel calm and alert and tuned in. Even if you received OT five days a week, it's not going to make as profound an impact as getting well-thought out sensory input from morning until night. While a sensory diet needs to be carefully individualized for each person, a large section of our book, *Raising A Sensory Smart Child* is filled with ideas and suggestions for creating and implementing a sensory diet. The book provides sensory diet activities for babies, toddlers, teenagers, and adults.**

Most sensory diets include a lot of vestibular (movement) and proprioceptive (deep pressure) activities that ground a person in his body by pushing joints together. This might include wheelbarrow walking, jump on a mini-trampoline, push a stroller or weighted shopping cart, bounce on a hop-it ball, playing tug of war, play catch with a weighted ball, climbing stairs and marching, wearing a loaded backpack and so on.

Massage using long, firm strokes can be very soothing, as can more playful approaches like making a sandwich out of sofa cushions or pillows with your body as the "peanut butter and jelly" (or whatever sandwich ingredients you like).

Tactile exploration should also be included: use Play-doh (kids) or Sculpey (adults), explore textures and toys. Eat crunchy foods like pretzels and celery sticks, chewy foods like bagels and dried fruit, salty foods and sour foods too. Blowing bubbles and whistles are great too—even for adults! There are many wonderful oral self-soothers such as chewing gum, sucking thick liquids through a straw, or using a "chewy" such as a chewy tube (for kids) or a chewable gem necklace designed by dentist Dr. Bloom (kids through adults). We have a huge section on sensory diet activities for children, teens, and adults in *Raising a Sensory Smart Child.*

***Rethink activities and environments:* All too often, we ask people to fit into our home, school, and work environments rather than asking if we provide spaces that are well-designed for that person. Making simple changes in the home, daycare, work, or school environment can make a big difference in a person's ability to focus and learn. Here are just a few ideas:**

- **Avoid fluorescent lighting. Use natural lighting when possible. If you can, use a table lamp at eye level to cut out some of the visual flicker and glare from the overheads.**
- **Most parents have too many toys and books out which can overwhelm a child. Select a few toys your child enjoys to encourage exploration and creative play and put the rest in opaque storage bins. You can rotate items so they always stay interesting. For adults, keep the visual field uncluttered so you don't get overwhelmed.**
- **If someone says his ears hurt, believe him. After making sure this person (or you) doesn't have an ear infection, speak with an OT or audiologist about an auditory desensitization program. Meanwhile, feel free to use ear plugs (pediatric size for kids or regular ones for adults), headphones, or ear muffs during painfully loud situations such as during fireworks, fire drills, crowded shopping malls, and so on. Do NOT wear them all the time or they won't be effective.**
- **Cut out clothing tags and labels. Buy seamless socks. Wear well-laundered clothing washed with perfume-free detergent. Cotton and polar fleece are often most easily tolerated. Be flexible about what is worn. Try wearing well-tolerated fabrics next to your skin, beneath less comfy textures.**
- **Bring along acceptable foods to parties and family gathering, despite raising a few eyebrows. Social events are not the time to try new foods. Better to focus on social interactions than worry about food issues.**

We offer many other environmental recommendations in the book.

Helping with Transitions

Many people on and off the spectrum have difficulty with transitions between activities that require them to shift attention, process new instructions, and plan the movements needed. Here's a few ways to help:

- **Increase predictability. Review the schedule of activities verbally and using a picture schedule. This helps explain the sequence of activities, and mentally prepare for changes.**

- **Always use clear directions. Avoid using confusing idioms such as “hold your horses” or “bite your tongue.” A concrete thinker takes what you say literally. If you are the concrete thinker, find out what all of these peculiar phrases actually mean!**
- **During clean-up, assign a concrete two-step task using simple directions, e.g., get all of the silverware from the table and put them in the sink. If your hypersensitive child is playing with a group of children, allow her to help clean up on the edge of the clean-up chaos such as to neaten up blocks in the corner. As an adult, you can volunteer to do a task that is within your comfort zone.**
- **Use transition times for movement to help children reorganize, including jumping jacks, wall push-ups, wheelbarrow walking, yoga stretches, etc.**

See therapy catalogs such as Integrations (www.integrationscatalog.com) for a wide variety of toys and equipment that make the world a more comfortable place for kids and adults with sensory issues.

For more information on sensory issues, sensory diet, modifying environments, dealing with work and school issues, handling behavior issues, and more, see *Raising a Sensory Smart Child: The Definitive Handbook for Helping Your Child with Sensory Processing Issues* by Lindsey Biel, OTR/L and Nancy Peske. Or visit www.sensorysmarts.com.

Call-out box:

15 Tips for Calming

1. **Dim the lights if possible.**
2. **Lower your voice, any music, or go to a quieter place.**
3. **Teach the child to breathe deeply 10 times at a time he *is* calm. Learn it yourself too.**
4. **Avoid overheating that often happens when the nervous system gets overaroused--remove a sweater or go near air conditioner or fan.**
5. **Change where you or the child is located. For example, in a shopping mall, he may need to go to a quiet area where there is little to look at.**
6. **Offer the child a bear hug or cuddle or rhythmically, firmly rub back or press downward on shoulders. Hug yourself if it helps you.**
7. **Drink some water or suck on like a hard candy. Crunchy food like pretzels can also soothe, as can an oral comfort item like a “chewy.”**
8. **Bring the child to a less busy part of the room for a few minutes—not as punishment, but to enable the child to self-regulate.**
9. **Listen to calming music using headphones.**
10. **Take the child to a “cozy corner” to relax. This space may have a bean bag chair, soft lighting, and a book or a soft toy to enjoy until he regroups.**
11. **Have the child (or you) sit in a rocking chair or bounce on a ball chair.**
12. **Help the child (or you) do wall push-ups or chair push-ups.**
13. **Use a hand fidget like a Koosh ball.**
14. **Go outside for a few minutes to jump around and get the wiggles out--or climb up and down stairs.**
15. **Repeat a soothing phrase over and over such as “It will be okay” or “everything is alright.”**

Bio:
Martina Robinson is an artist, activist, and an academic
who lives in Belchertown, MA and is soon (hopefully)
to be of Sommerville, MA (near Boston).

Recollection

I fall on knee during first full day
of latest activist journey,
and assume I'm fine-
a trifle achy and extra spastic as a result,
but fine.

I expect pain to dissipate,
be all but nonexistent tomorrow
But when I try to stand
hours later sudden, searing pain
in knee that rendered me immobile
and in need of the second bathroom-based
rescue of the day.
Minutes later, I lie breathless in hotel bed,
packing injury in ice.

I force myself
to remember Kerri Strug,
still so tiny in the Atlanta Olympics,
despite her 18 years-
a gymnast, part of the Mag 7-
an unstoppable sporting force.

My brain recalls her
on broken ankle
thundering down the runway,
flipping and twisting battered
body over the vault,
and landing- stick- on both unmoving feet.

She helped win US Olympic team gold,
the only one we've ever won,
but much less important than the
liberty I've come to here to seek
for those still trapped behind
institutional walls all over our nation.

“The Friendship Doctors” column is written by Linda H. Rammler, M.Ed., Ph.D., who works for the University of Connecticut Health Center's University Center for Excellence in Developmental Disabilities. She has assisted in developing and providing ongoing support of friendships for children and adults of all ages with autism spectrum differences and has provided training to school staff members in how to do the same. Linda supports FC users and participated in developing the Autism National Committee's Position Paper on Facilitated Communication. Although she does not have a diagnosis of autism, many of her friends do, including the co-author of this column, Jacob Pratt, who is the Executive Director of the Autism Spectrum Differences Institute of New England, Inc. Jacob uses FC and frequently gives presentation to parents, staff groups, and colleagues about numerous topics including friendships.

If you have questions about friendships (your own or others), please submit them to *asdi-ne@comcast.net* and put "The Friendship Doctors" in the subject line. We regret that we are unable to respond individually to your submissions but will do our best to get to all eventually or by clustering those with a common thread or which seem of a more urgent or broadly applicable nature.

Here's this edition's column:

Dear Friendship Doctors:

I am a school psychologist and I am appalled that anyone, especially one of my colleagues, would tell a parent a child, autism or not, can live without friends! I love a lot of your suggestions from the last issue and plan to implement them next fall. I am concerned, though, because I run a weekly "Lunch Bunch" -- several of them actually -- and I've seen kids who participate develop real friendships. Are you saying "Lunch Bunch" is wrong?

Signed, One of the Good Guys

Dear One of the Good Guys:

You caught us with one of the major problems with overgeneralization!!!

As we said in the last issue, the usual scenario for "Lunch Bunch" is that nondisabled kids get to go talk to a supervising adult and each other while a student with a disability chows down in silence. While we acknowledged that, rarely, a genuine friendship may develop, we did state that, given its very nature (YOU have a disability and the REST OF US are being nice enough to join you and/or really like the supervising adult and/or really hate the caf anyway), "lunch bunch" make meaningful and long-term connections exceedingly rare. And we also questioned who only has friends every other Tuesday when "Lunch Bunch" meets?

As far as we’re concerned, nothing that gets kids together is necessarily “wrong” if it leads to genuine, mutually respectful, reciprocal, enjoyable, equal relationships or however else “friendships” are to be described as long as they REALLY work for all parties. What we were trying to say was that Circles of Friends and some of the other strategies we listed *increase the probability that these meaningful social connections between students with and without autism will occur.* And that things like adult presence, group names and identities that may not be age-appropriate or otherwise “cool,” other motivations (e.g., escaping the caf, hanging out with a pleasant adult), and hierarchical relationships that are not interest-based can both *lessen that probability and actually create barriers to real friendships.*

If you’re worried because “Lunch Bunch” was a promised service in a particular child’s IEP, here are some things you can do to make sure your efforts have the desired effect:

1. **CHUCK THE NAME. It may still be “Lunch Bunch” on paper but let the participants come up with their own group identity. High school students, unless forming something like an Animé Club, are often cool with no name at all. Kindergartners have come up with some really neat names like “The Three Guys Club.” One group we know called themselves MER-MAC (the initials of the six girlfriends - when others asked what it meant, they said it was because they were all really mermaids and then burst into giggles!). Think of how the name will broadcast over the school’s PA system and how a shy, self-conscious kid would respond best. "Rebecca, time for 'Lunch Bunch'" versus "MER-MAC is now meeting in Room 17." (By the way, this same advice applies to "Best Buddies" - another program for which we have similar concerns!)**
2. **DON’T JUST INVITE OTHER STUDENTS YOU KNOW TO BE IDEAL ROLE MODELS OR WHO REALLY NEED TO HAVE FRIENDS OF THEIR OWN. Invite other students who have a real reason to be there with one particular student – i.e., they share a common interest with the student who has autism, they live in the same neighborhood, they are in the same classes, they have a wide circle of friends themselves, etc.**
3. **DON’T JUST SIT THERE AND EAT!!! Plan for activities that are play-based but non-competitive and/or based on the interests of the child around whom the “bunch” has been convened. Consider sponsoring a project on which the kids can work together (e.g., hat/mitten drive, planting a school garden).**
4. **DO SOME PREP WORK. Consider reading an age-appropriate book or chapter to the student’s class or grade about autism either during the first session or apart from the actual lunch period. As a school psychologist, you undoubtedly already have training in how to introduce and sensitively discuss topics of a wide variety with kids who are the same age as those in the school you now work in. This forms a referent and a reminder to all students if issues regarding “autistic behavior” come up. Along the same**

lines, consider having ALL participants share information about themselves – warts and all! -- because that's what friends do. Can all participants, for example, write a "getting to know me" book or develop a PowerPoint presentation?

5. MAINTAIN SUPPORT by replenishing the group if it dwindles, introducing more friendship-building activities, being sensitive to changes in individual interests, personalities, circumstances, etc.
6. GET PERMISSIONS (as we described in our first column) to share participants' names and contact information so "out of school" connections can flow from those in school. For example, ask the principal to send home a generic letter asking parents of ALL children for permission to release the names of their children to parents of kids with disabilities throughout the school who may not be able to communicate relevant information about classmates to their parents.
7. AVOID RECOGNITION AND AWARDS. If you look up "Lunch Bunch" on the internet, you'll find that some organizations (e.g. the Character Education Partnership, http://www.character.org) and many schools give special recognition to students who have "given of themselves" by volunteering for "Lunch Bunches" around the nation. This reinforces hierarchical relationships – not friendships – and a lot of other negative (e.g., "poor lonely kid with autism") connotations.

Making and keeping friends (especially really interesting, humorous, caring, sensitive, loving, and all the other good things that friends with autism can be!) should be its own reward.

In friendship,

The Friendship Doctors

Vision without action is a daydream.
Action without vision is a nightmare.
- Japanese Proverb

When you are content to be simply yourself
and don't compare to compete, everyone will respect you.
- Lao Tze

For him who has conquered the mind, the mind is the friend;
but for one who has failed to do so, his mind will be the
greatest enemy.
- Bhagavad Gita

Real generosity toward the future
lies in giving all to the present. - Camus

Don't look to become a person of success,
look instead to become a person of value. - Einstein

How I found Peace of Mind with Asperger's Syndrome.

(Written by Stan Hood, electronics technician
turned university student of psychology,
Christchurch New Zealand. July 2009)

Around October 2008, I received the best news I have ever had in my whole life: I was formally diagnosed with Asperger's Syndrome. All of a sudden, everything made sense. Have you ever heard the expression "nothing has changed but everything is different?"

That was/is me. And am I ever grateful to have finally discovered, at the age of 63, who (or should that be, "what?") I am.

Hopefully, what follows may be of interest to some readers. The original intention, as discussed via e-mails with the editor, was to tell a little about myself and share my story of Asperger's and how it manifested in my own life. But the deadline arrived before I could come up with anything cohesive or anecdotal. Perhaps if I say nothing, she will not notice that instead of a story, I have substituted a series of unconnected "glimpses" of my life. These peeks at some of my behaviour patterns are taken from a letter I wrote in evidence to the doctor who undertook my formal Asperger's diagnosis. At the time I wrote that letter, I had self-diagnosed for Asperger's and was secretly hoping to have this officially confirmed (the hope was because Asperger's was the first explanation I had come across in six decades that fitted what I knew I was).

I love being an Aspie. Many months after receiving written proof that I am one, I still happily share that knowledge with anyone who cares to listen. Would I be as delighted to share my special way of Being if I were a younger man? Difficult to say. At my age, it is a pleasure to not have to care what anybody thinks of me. This comment is not borne of bitterness or anger. It has everything to do with the facts that, after 45 years of working life in a high-tech profession (electronics) that I loved, nobody can do anything to hurt my career path (it's gone and done with!). Likewise, nobody can hurt my family with possible taunts (divorced long ago, and son in his 30s).

So please, have a rummage through facets of my Aspie life, offered to you in no particular order. I like to think that just maybe, here and there, you might have a slow smile of recognition as you see aspects of yourself, too.

When people talk with me, I tend to take them literally. I have done this for almost half a century that I am aware of. It has caused misunderstandings aplenty, although now, fewer than it used to. It is just as well we Aspies can remember lots of trivia for decades. How else could I have acquired such a huge intellectual store of knowing "when-to-take-somebody-literally-and -when-not-to"? Neurotypicals seem to get by with a single mysterious rule they have which allows them full comprehension of how to interpret conversation without needing a big memory storehouse to run everything past first.

As a child, it was thought that I was slightly deaf, but tests by a public hospital audiologist of the time, using different tones, decided that any possible slight hearing loss was of no concern. Nonetheless, I continued to be slightly "deaf" in most situations. Many years later, in my 30s, I stayed briefly at a remote farmhouse in a very quiet part of the countryside. I was amazed to find that I could hear a vehicle on the approach road when it was still about 8km away. So much for being "deaf". But I still continued to have difficulty hearing people in social situations. Apparently, some Aspies can exhibit a kind of deafness which doesn't have a lot to do with the sensitivity of the ears to sound waves.

Later, in my 40s, I passed the complex series of hearing tests required to get my Student Pilot's Licence, thus once again proving, according to scientific instruments, that my hearing was OK. Now, many years later again, I finally have acquired some genuine industrial deafness. At last, a measurable excuse for what my hearing, de facto, has been like for decades.

Sounding me out: for years, when I have been asked my opinion of a subject I may know a little (or more) about, my response has been "yes and no", which frustrates the questioner. The questioner generally knows my little personality foibles. He or she knows that a full report is about to come from my lips covering the history, and both sides of the argument, and an understanding that both sides have legitimacy. Those who know me also know that they will have difficulty turning off my report half-way through!

My superior at my last job would try in vain to limit my response to questions by asking me, tell me BRIEFLY about the technical situation. I couldn't. My lifelong difficulty of not knowing how neurotypicals prioritise information in their minds would not let me be brief. To this day, when I try to be brief, it misses the "mark" so often that I then am criticised for leaving out important information.

Sometimes my friends would ask what they should do about a social situation which is worrying them. This would be a situation which in my own opinion has not yet revealed itself sufficiently. Therefore, I could not make an assessment of what they should do. I frustrate my friends when I respond (as I have done for years) by saying, "let it unfold". This is a personal coping mechanism, for two reasons: one, I cannot (dare not) draw conclusions based on what I perceive as insufficient information, and two, I have always been too easy to feel very stressed by a perceived new or strange situation looming ahead of me. Therefore I make a conscious decision to remind myself constantly that I must remain calm at least until ALL of the information is in. Only then is it possible for me to make rational decisions about the situation.

For decades, I have felt that I was just slightly "disconnected" in some way from normal humanity. Like my consciousness was somehow not "plugged in" to whatever it was the rest of the human race appeared to be in. Partly, this feeling was with me because I could not understand some of the reasons why some people would want to do some things. Therefore, I began a regime of hobbies and interests I thought I might like to do until what I thought of as "real life" came along and then I could plug into "real life" and feel complete like everybody else appeared to be. There was often a suspicion that some interests of mine were pointless, but doing something staved off boredom while I waited around for "reality". Yeah, that sounds nuts, I know, but I bet I'm not the only Aspie who has had these feelings.

I do not like noisy environments. I find supermarket shopping stressful, so I go late at night when all is quiet. Once, many years ago, my firm took we employees to a night club in our capital city, Wellington (New Zealand). I completely failed to appreciate any worth in being there. In fact I felt that everybody must surely be driven catatonic by the racket. Therefore I reckoned that people who went to nightclubs must be very stupid to want to do that to themselves.

There was a lady I had a relationship with for about six years. She would always ask me where we should sit when we went to social ballroom dances. I would always reply "where-ever you want" which always annoyed her. She thought I did not care, whereas I cared about her very much. She could never understand, although I explained it every single time, that it was not because I was not interested in social company, it was because the noise of the dance music, with my perceived "deafness", always meant that I could not hear a word which any of our friends we may meet, would say to me. Therefore I would have to sit quietly if I was not actually up dancing, and I would hope I nodded in the right places during the inevitable conversations, always started by others. I would try to be sociable at least to some degree, but the perceived circumstances meant I could not be. A coping mechanism was to simply explain to our acquaintances that I had a hearing problem, and yet I still worried that they may not understand why I appeared to be ignoring them.

For decades as an adult, I was told I was too nice, too caring, too compassionate. I don't understand how kindheartedness can be construed as a negative thing. But many people, both emotionally close as well as more casual acquaintances, said the same about me. Don't neurotypicals have strange ideas of what is good and bad in life?

I have been married twice. My first wife made comments like "you have a persecution complex", and I would respond with "no, there are some people out there in the world who really do persecute me". My perception was, that there were some people who appeared to enjoy annoying me. To be charitable, I would now say that such people simply did not realize just how much their probable innocent banter hurt and confused me inside.

I was about nine or ten years old when I realized that during the usual schoolyard banter of boys, I was feeling a lot of stress, and yet they appeared to be immune to those feelings of stress. This set me to thinking over the very long term that I needed to find out how they did that (i.e., coped with such amazingly high levels of stress, at least as I perceived it), so I could do it also and therefore make life much more relaxed, i.e., nearer normal, for myself. Aside from developing a number of what I consciously call my "coping mechanisms", I have not yet arrived at the core reason for my feeling things so much more deeply than normal humans. And so, I still cannot do "normal" banter, it will often come out wrong and I so easily cause offence.

My second wife sometimes said that I was "devoid of emotion". She wanted to see me "out of control" as she put it, but I was having none of that. I needed to be in control of my emotions, so that my seething cauldron of highly stressed emotions would not cause me to look foolish with inappropriate social responses.

The lady of my last relationship said a similar thing. She wanted me to be spontaneous, and face each day like it was my first. Neurotypicals appear to believe that this is a great way to enjoy life, but I dare not let myself do it. The hard-won coping mechanisms of years, are what keep me in equilibrium. I cannot afford to pretend daily that I must learn to cope from scratch all over again. Being spontaneous when one has learned hard lessons for the better, has to be akin to self-flagellation for Aspies, does it not?

My employers: for many years I thought I had a succession of bad-tempered bosses. It was actually an astrologer (when I was in my 30s) who pointed out that I was projecting a stiff, inflexible and probably all-knowing approach to my employer, which was probably being perceived as arrogance (but in reality, I was always very eager - anxious, actually - to please by doing my job very well). I was told by the astrologer to overdo it a little with formal pleasantries and respect to my superiors, and that appeared to help the boss/worker relationship. It was always a conscious challenge over decades to remember to overdo (in my perception) my polite subservience to my boss. In this way, the boss would perceive my behaviour as appropriate. It usually worked for me, but I then had a continuous worry over how much "over-the-top" politeness was too much before it slipped into caricature which would have the opposite effect.

Star Trek is my favourite television programme. I like it because it is full of aliens who have to try and use logic and cold intellect to understand the emotive ways that humans have. You can count me with the aliens on this one. Maybe one day a UFO will come and take me home (the UFO is a joke, right?).

Well, those were some snippets of life from somebody who has lived for over six decades knowing he was different, but not having a name to put to the difference until less than a year ago.

A couple of months ago, at university, I told a tutor that if a "cure" (I don't really like that word when referring to Asperger's or autism, because it implies an "illness", and we are certainly not ill!) was ever found for my Asperger's syndrome, I would refuse it.

University? Yes, at the dawn of my Third Age, I decided to throw in my job and go to university, starting this year. Funny, the liberating effects of a desired diagnosis of Asperger's syndrome. So far this year at university, two papers, two final exams, passed with a B+, and an A. Not bad for someone who hasn't studied for half a century. All Aspies are good like that, we are a smarter species (Homo Aspergiens, perhaps? This is another joke).

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

William Keeley’s
“A View from the Inside”

I am a verbal, high functioning adult autistic. As a child, I was considered severely autistic. When I was born, my mom knew that there was something very different about me. As a baby, I would stiffen when held or touched. The only way I would eat is if I were laid down or propped in a position. As a young child, I would bang by head constantly, especially at night. I would also engage in violent behavior such as hitting people, biting (including myself), etc. At that time, very little was known about autism or even its existence. My mom took me to many, doctors, hospitals, and psychologists to find out why I was different. She was told that I was severely retarded and emotionally disturbed, and worse yet, it was recommended that I be institutionalized. However, my mom saw things in me that caused her to disbelieve that I was retarded. For example, I watched my brother learn to walk, and then I would not make the mistakes he made. Later on, I would have a fascination with opening combination locks by ear. I would learn things quickly except eye contact, talking, and social skills. I would understand and do things mom asked me to do, but I would do nothing for strangers when instructed. My mom watched a television show that featured a child like me, and she learned that that child had something called "autism." Finally, my mom was able to take me somewhere where she could learn how to teach and train me. When I was growing up, there was no ABA (Applied Behavior Analysis), and Occupational Therapy was very rare. The training I received was from my mom, my immediate family, and quite a bit from the plain ole school of hard knocks.

So far, I have made it through adulthood without any government assistance. I have worked in many different fields, and had many different jobs. I worked as a dishwasher, prep cook, farm hand, member of the U.S. Navy, electronics technician, grocery clerk, computer technician, computer programmer, and even as a salesman. Most of my employers consider me a good worker. As an adult autistic person, I have spent many years learning how to act like neurotypical people, and I can do so under many different circumstances.

I am self-educated in many different areas including the Bible, history, locksmithing, computer science, bee keeping, carpentry and many others. I learned how to do these things from reading books, watching videos, using the Internet, and asking questions from other people with the same interests. As far as school is concerned, I graduated regular high school in Florida, I completed the Naval Nuclear Field "A" School (Electronics Technician section), and graduated a local community college earning a degree in Electronics Engineering Technology. Although I have been relatively successful in formal classroom education, I would much rather learn on my own. All in all, I must say that I have not done so badly for someone who was labeled "severely mentally retarded."

Currently, there are many others out there on the spectrum who are married, hold down jobs, and live independently. I have held down many jobs and lived away from home while I was in the Navy. I have many abilities and can do plenty of different types of work. I am limited mainly by stereotypes autistic people face. Hopefully, that will change as more and more people are deemed autistic. As our recognized number increases, society will be forced to acknowledge us and hopefully, our abilities.

The artwork and poem below are by Kimberly Dixon, a dear friend of mine who uses keyboard communication and lives in Texas.
In Kimberly's own words:
"I am in my twenties. I like writing poetry and stories. Friends help me cope with my disabilities. (I have a seizure disorder.) Freeing up time to chat with friends online is my goal this year."

Blooms of Joy

Freely lovely flowers grow
Spelling independence with their show;
Petty problems flee
When beautiful blooms I see.
Sunlight glistens on dewy petals
And flowers shine like bits of metal.
Many flowers dance in the wind
Teaching me to depend
On God for my life
Asking Him to end my strife.
Teach me, Lord, how to bloom
So my life shines for you.

In Closing:

Fascination is one step beyond interest.
Interested people want to know if it works.
Fascinated people want to learn how it works.
- Jim Rohn

Our greatest pretenses are built up
not to hide the evil and the ugly in us,
but our emptiness.
The hardest thing to hide
is something that is not there.
- Eric Hoffer

It still holds true that man is most uniquely human
when he turns obstacles into opportunities.
- Eric Hoffer.

Words, when written, crystallize history;
their very structure gives permanence
to the unchangeable past.
- Francis Bacon

Miracles happen every day.
Not just in remote country villages
or at holy sites halfway across the globe,
but here, in our own lives.
- Deepak Chopra

Practice the philosophy of continuous improvement.
Get a little bit better every single day.
- Brian Tracy

Permanence, perseverance and persistence
in spite of all obstacles, discouragement, and impossibilities:
It is this, that in all things
distinguishes the strong soul from the weak.
- Thomas Carlyle (1795-1881)

Every problem has a gift for you in its hands.
- Richard Bach

Endurance is the crowning quality,
and patience all the passion of great hearts.
- James Russell Lowell

Every man feels instinctively
that all the beautiful sentiments in the world
weigh less than a single lovely action.
- James Russell Lowell

Time, whose tooth gnaws away at everything else,
is powerless against truth.
- Thomas Huxley, English biologist, 1825-95

Will and I could hardly wait for the morning
to come to get at something that interested us.
That's happiness.
- Orville Wright

Blessed is the man who, having nothing to say,
abstains from giving us wordy evidence of the fact.
- George Eliot

Creative activity could be described as a type of learning process
where teacher and pupil are located in the same individual.
- Arthur Koestler

Integrity without knowledge is weak and useless,
and knowledge without integrity is dangerous and dreadful.
- Samuel Johnson (1709-84)

The more we refuse to buy into our inner critics
- and our external ones too -
the easier it will get to have confidence in our choices,
and to feel comfortable with who we are.
- Arianna Huffington

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

Imagination is more important than knowledge.
Knowledge is limited.
Imagination encircles the world.
- Einstein

There's nothing that can't be done
If we raise our voice as one.
- From "We've Had Enough":
by Michael Jackson, Rodney Jerkins III,
LaShawn Daniels, Carole Bayer Sager

Closing Words of Gratitude from Jay Kochmeister
Part-Time Copy Editor and Full-Time Father:

I would very much like to thank, on behalf of Sharisa and myself,
all of the writers and artists who contributed their work to this issue
and all the subscribers who make this labor of love truly worthwhile.

In our effort to bring joy, love and healing
to a very non-united world,
we are truly moved by you all and your desire to do the same.

Lack of understanding has reached pandemic proportions
and to turn that around will require a Herculean effort -
but we truly believe that caring, sharing, hope, joy and love
will bridge the chasms between us, heal the wounds of the world
and change the energy from negative to positive.

We ALSO thank everyone for your prayers, wishes & healing energy
while Sharisa was hospitalized for 10 rather harrowing,
terrifying days and nights.

It demonstrated how
despite the various religions and belief systems involved,
people who care can unite in a common concern
and compassion is far stronger than illness,
disease, medicine, and needles.

Lastly, we want to invite people to contribute
your thoughts and feelings about our magazine
to a special section in the August issue
that will be out around the end of August.
If you can send these by August 20th,
it would be greatly appreciated.

With love to you all,
Sharisa, Jay and Carol Kochmeister ☺