

**The Voices and Choices of Autism
Volume 1, Issue 1
June, 2009**

**Learning to Exist with Hope and
Joy In A World
That's Not Always Your "Friend"**



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The Voices and Choices of Autism

- An Insider View

Volume 1, Issue 1: June, 2009

Sharisa Joy Kochmeister,
BA Psychology and Sociology
Creator, Publisher, Editor-In-Chief,
Author, Advocate, Consultant
sharisajoy@yahoo.com

I used to be retarded
But now that's out of fashion,
So being a true genius
Is my only real passion!
SJK

Thought is the blossom;
language the bud;
action the fruit behind it.
- Emerson

Welcome to the premiere issue of
"The Voices and Choices of Autism"!

Right now, I am the editor-in-chief, head writer and publisher; a few hats to be sure - with an assist from Jay Kochmeister, M.S.Ed., Stephen Shore, Ed.D. and a very esteemed and capable advisory panel!

Our mission is to expand understanding and acceptance of autism, people on the spectrum, and the idea that this is not a disease to be cured; but rather a way of living and being that should be understood and supported as needed; and then only if the people being supported are active participants in the support they receive.

It is our goal to give those on the spectrum and those who care and advocate for them an open and widely read forum in which to share, learn and feel free to express in a positive, open and hopeful manner.

Panel of Advisors/Consultants:

Jay Kochmeister, M.S. Special Ed.
Author, Advocate, Creative Consultant,
Copy Editor, Professor, Presenter,
Trainer,

Stephen Shore, Ed.D.
Co-Creator, Author, Advocate,
Educational Consultant
<http://www.autismasperger.net/>

Brian R. King, LCSW
Asperger's Ambassador, Social Worker,
Consultant, Speaker, Author
www.ImAnAspie.com

Judy Endow, MSW
Author, Consultant, Advocate, Speaker
<http://www.badgerinternet.com/~bobkat/bio.html>

Linda H. Rammler, M.Ed., Ph.D.
ASDI of New England
Advocate & Consultant
http://www.autismdifferences.org/index_files/whoware.htm

Jacob Pratt, Executive Director, founding member and consultant-trainer for ASDI of New England

Mark Romoser Cum Laude, Yale
Hawaii Centers for Independent Living
Legislative Advocate, Presenter,
mromoser@yahoo.com

Alyson Bradley, New Zealand
Advocate - Aspergers Parallel Planet
www.asplanet.info

Robert L. Harriman, Ed.D.
University of the Pacific
Major: School Administration
Cognates: Curriculum, Research,
Psychology, Educational Administration
& Teaching; 2007 - President-
Founder, The Global Learning Co.
<http://www.segarama.com/index.html>

Travis Breeding; Author, Entrepreneur
Pursuing a bachelor's with a double major in music education and trombone performance at Indiana University
<http://www.travisbreeding.webs.com>

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Sharisa Joy at Work



This is me, communicating via keyboard, an often but not always effective method for people without verbal speech to communicate their feelings and thoughts to an otherwise unknowing world.

About Me:

(For those who know me & don't) I'm Sharisa Joy Kochmeister: professional author of poetry and essays; published and performed composer/lyricist; graduate of The University of Denver with a 3.6 GPA and a dual degree Bachelor's (with honors) in Sociology and Psychology; professional speaker, consultant, award-winning trainer and advocate in the areas of disability rights, inclusion, and augmentative and alternative methods of communication; President of AutCom (The Autism National Committee); Executive Committee member for the C.D.D.C. (Colorado Developmental Disabilities Council); member of W.O.W. (Watch Our Words) Colorado; on the Panel of Spectrum Advisors of A.S.A. Autism Society of America and a

member of the board of advisors of Autism Perspective Magazine (of which I am Editor-In-Chief) and several other advisory panels. I'm a future social psychologist and/or educator studying autism and other disabilities and continuing to advocate for children's rights as well as the rights of all people with and without so-called disabilities.

Oh, and by the way, I have multiple disabilities, including Cerebral Palsy, autism, epilepsy, being non-verbal and requiring a keyboard to communicate and a trusted assistant to ease my way.

I've been to The White House and met President Clinton; received awards for advocacy and community service; written a fairytale about autism to help people understand; and writing my autobiography: "My Life As A Zero And My Life As A Hero."

I've been a high school and college literary magazine writer and editor. I have a list of other accomplishments too long to mention that I'd be more than glad to share with anyone interested who chooses to e-mail me at:

sharisajoy@yahoo.com
or sharisajoy@aol.com

Remember:

Even the stars we think we see
are not what they appear to be!

Ring the bells that still can ring.
Forget your perfect offerings.
There is a crack in everything.
That is how the light gets in.
- Leonard Cohen

**All children are gifted;
some just open their
packages later than others.
- Anonymous**



My Paternal Grandparents (1941)



**Dad, Me, My Sister Amy,
And ONE Wonderful Niece named
Lily! 11/2008**

**IF I HAD A VOICE Sharisa Joy
1994 Revised 2009**

**If I had a voice
I'd shout sometimes
So that everyone would hear:
People are people
Even if they seem strange,
I am not something to fear.**

**Other times
I might whisper so softly
I could hardly be heard,
But if you try to listen,
You'll understand every word.**

**If I could say
What I need to say
And get people to listen to me,
They'd understand
That understanding
Helps make people free.**

**People need to listen and know
That all I say is true.
I don't have a voice
To speak out loud,
So I share thoughts with you.**

**Read or hear my words
And know the way I feel within.
I'm trying so hard
To say what I feel,
And this is how I begin.**

**If I had a voice like others do,
You'd probably listen to me;
But it's hard to make you
Hear what I think
When my words are just
Something you see.**

**If I had a voice
I'd shout sometimes
So everyone would hear:
People are people
Even if they seem strange,
I am not something to fear.**



**Me, Amy AND Adorable Lily!
11/08**

FUTURE DREAMS Sharisa Joy 8/2/97

Deep in my soul
There are songs to be sung;
Tunes of the ancient,
Rhymes of the young.

As I begin my sweet journey of love
My soul is inspired within from above;
And I can dream
My sweet dreams,
Future dreams;
Dreams never cease -
Dreams filled with peace.

All of my life I have waited and craved
For angels to come
So my soul would be saved;
Now I know angels all live deep within,
So far inside
Where my thoughts all begin
And I can dream my sweet dreams
Dreams filled with hope
Teach us to cope.

Now that my dreams have
All planted their seeds,
Into the future is where my path leads.
And I am finding
The dreams that are mine
Glow from within me
And make my eyes shine,
Each time I dream my future dreams -
Dreams where I soar,
Dreams where I fly higher than sky.

Though I may stumble
And fall on my way
I know I will get
To the place where I may
Be fully free and enabled to feel
That my sweet dreams and I
Are all finally real.

**ODE TO ACCEPTANCE
Sharisa Joy 1997**

See me as I am,
Not as I appear to be.
Read between the lines
And what you'll find is me.

Look past your prejudice
And open up your heart.
Accept me as a whole
Rather than just one part.

HEARTSINGS SHARISA JOY 8-1-94

My song is deep within my soul,
A song of peace that makes me whole.
Strands of joy, love and hope.
Songs to heal and help me cope.



Amy, Sharisa & Marnie - Sisters



Today, let your heart dance.
You will find no shortage of
dance partners,
as your feet join in.
And your eyes. And your smile.
And every part of your body
and your feelings.
Let your heart dance all day long.

- Unknown

Society and "Diversity"
(A Brief Rant by a Frustrated Adult - Seeing "Red")
By Sharisa Joy
6-13-09, Updated from 9-08

In the larger scheme of things, I have now lived more than half my life in the world of communicators and October 10, 2008 marked my re-birthday, the day I began communicating via typing at age 13 in 1991. Thirteen years of tantrums having been my only real way to communicate frustration had shaped me into a teenager that people feared. Did they know that I also feared myself? My screaming hurt my own ears, my wailing was so infantile, my inability to make my needs known was so frustrating, and my behavior was extremely self-destructive as well as socially disruptive and destructive. I was a force to be reckoned with, much stronger than I appeared at 69 pounds and 4 feet 9 inches. When adrenaline flowed, I seemingly had the strength of the "Incredible Hulk" without his ability to <choke> control his rage. While I had never truly hurt anyone, their fear was palpable and it fueled my anger against my plight.

These days, as a calm and rational <rolling eyes and looking innocent> adult woman, I have managed not to have tantrums. While the occasional rage (the psychiatrist prefers to call them "frustration") attacks I have now are far worse than any tantrum, I am learning to control them and not allow them to control me.

I am, after all, expected (and expect myself) to act like a neuro-typical adult (note the word "act" AND all of its possible meanings). Usually, I manage to pull it off in a way that could win Oscars, Emmys and Tonys. There are times, nevertheless, when my rage gets the better of me, when my frustration and anxiety fuel my actions, when my dyspraxia fails to stay under wraps, when I flail and wail and attack!

Afterwards, of course, I feel contrite; but during an attack there are feelings that defy description, emotions that defy definition, and anger that defies explanation and/or understanding. I am a thermonuclear meltdown personified. I have seen myself in mirrors when this happens and I look as frightening and frightened as I feel.

What causes my rage (frustration)? In general, as well as I am able to pinpoint it, it's mostly related to feeling negated. When people ignore me, put me down, deny the reality of who I am, the need I have for understanding, the fear I have of losing the ability to type and once again becoming non-communicative, I quite clearly "lose it". While I can't say exactly what this "it" is that I "lose", its sudden disappearance threatens my humanity and my sanity and I stop being the me I have chosen to be and revert/regress to something far less that I have trouble even recognizing.

When I witness discrimination based on difference(s), I take personal umbrage and there is no flight but plenty of fight within me. When I hear people saying people with autism need to be "cured", I refuse to feel like some kind of "untreated meat" and I react. I say "cure ham, not people!" I don't have a disease - I have a set of disabilities that cause unease - especially for me! People may not like the way I react; heck, I don't even like the way I react; but it's part of who and what I am and the essence of Sharisa is something that cannot, will not, should not be changed - and certainly not something to "cure"! Treat what ails me, by all means; but don't fail me by denying who I am!

So please, take your talk of curing and defeating autism and do not foist it upon me or anyone who feels autism is not a disease. Additionally, please accept and respect us for who and what we are, for what our autism has helped us be, for the value members of society and teachers of the neurotypicals we long to and deserve to be! Enough said for now - but feel free to react and respond - I welcome healthy debate.

Mindburn

6-13-09 by Sharisa Joy Updated from 7-27-08

**Lightning streaks cross the skies...
Burning fires in my eyes,
Brightly blazing liquid fire
Takes my senses ever higher
Than I've really ever known
All the years that I had grown...
Aloof, withdrawn and so alone -**

**Silently screaming so no one could hear,
Tearlessly crying so none knew my fear,
Endlessly hoping that someday I'd see
The purpose of living this life given me -
Fearlessly taking the deepest breath
While I laughed in the faces of danger and death -**

**Wondering always
If anything real
Truly existed
To make me feel,
And care to share,
And want to give
A damn about whether
I'd die or live.**

Stephen Shore, Ed.D.

Diagnosed with "Atypical Development and strong autistic tendencies" and "too sick" for outpatient treatment, Dr. Shore was recommended for institutionalization.

Nonverbal until four, and with much support from his parents, teachers, wife, and others, Stephen is now a professor at Adelphi University where his research focuses on matching best practice to the needs of people with autism.

In addition to working with children and talking about life on the autism spectrum, Stephen lectures, presents and consults internationally on issues pertinent to education, relationships, employment, advocacy, and disclosure as discussed in his books *Beyond the Wall: Personal Experiences with Autism and Asperger Syndrome*, *Ask and Tell: Self-advocacy and Disclosure for People on the Autism Spectrum*, and the critically acclaimed *Understanding Autism for Dummies*.

Dr. Shore serves on the I.A.C.C. (Interagency Autism Coordinating Committee), Board of Directors for Autism Society of America Unlocking Autism, Board of AutCom (The National Autism Committee) and various other autism-related organizations.



Stephen & Friends "Down Under"

Rethinking Autism: Moving from a Deficit Model to Making Strengths Count

Whether a family member, co-worker, or in an educational situation, the thought of a person with autism often results in the consideration of the weaknesses they may have. What this article proposes is moving away from a deficit model when considering persons on the autism spectrum or with other difference. Rather, focus should be on finding ways to employ the strengths – as done with everyone else – towards building a life of productivity and fulfillment as a contributing member to society.

...We're sorry to tell you... ... He will have difficulties making friends, communicating in a way that others can understand... ... Maybe a sheltered workshop or supported employment... ...Well... some people with autism do go to college, but it's not something you should expect...

A parent just finds out that their child is diagnosed with autism. An educator learns that a student with Asperger Syndrome is entering her classroom next

week. A manager hears from her supervisor that a person on the autism spectrum is joining her workforce. After recovering from the initial shock the parent gets a verbal download from the clinician of all the things their child will not do or face significant challenges accomplishing.

Educators read the IEP and in discussions with the special education teacher learns the student's weak points and challenges. Managers wonder what possibly expensive accommodations will be needed and will the person be able to do the job effectively?

Umm... Let's try this again.

He took apart and reassembled watches as a toddler... ..Might this mechanical ability be useful later on? ... She's kinda quiet, but will spot a typo in a page of text with barely a glance... ..Interesting... he seems to know everything about earthquakes and how to keep safe... I wonder if he could give a presentation on this subject to his classmates given that the school is located in an area frequented by earthquakes?

The previous paragraph contrasts with the first by emphasizing what the person on the autism spectrum can accomplish rather than focusing on what she can't do. One important barrier preventing people with differences from achieving success is that the diagnosis of autism and other conditions is based on a deficit

model stressing weaknesses. However, the challenge facing us is finding ways to use the characteristics of autism in positive meaningful ways.

Let us suppose a young verbal man on the autism spectrum has a deep interest for train schedules. His passion runs so deep that he has memorized the entire transportation schedule for greater Aspergia, which is located on the Isle of Autism. One of this person's favorite activities is to find out where a person lives and then explain to them all the ways they can get between their home and various point of interests using public transportation. In addition to memorizing the schedules, he also knows all the junctures where one can connect to the next bus or train to continue a journey to its destination. He clearly articulates the directions in a no nonsense manner. Talking about "just the facts" on getting between destinations puts him on top of the world. Might this passion and skill with navigating a public transportation system be useful somewhere? Might it be that if he were to work in a train station he could provide answers to lost patrons even faster than his coworkers who have to look up the information in a manual?

Those of us on the autism spectrum are characterized with extremes in our skill sets. While the challenges may run very deep; properly harnessed, our strengths can bring us productivity and fulfillment as we reach for the stars.

Autism and the spectrum. It may be broader than we think:
by Donna Williams

Dear Donna Williams

my name is Marco Del Bufalo, I'm an autistic boy preparing his graduation thesis on autism: "communication in handicap".

I attended the conference held in Rieti in 2000 and I was very impressed by your division of autistic people in three categories:

- autistic;*
- normal autistic;*
- autistic-normal*

Now I belong to the first category and, as I would like to mention your approach in my graduation thesis, it would be vital to have from you more information on the second category: who is really a normal-autistic?

Hi Marco,

I believe I spoke of

- Autie,**
- Autie-Aspie,**
- Aspie**

meaning some people:

- have only features of autism,**
- features of both autism and Asperger's**
- only features of Asperger's.**

I also don't think there is one normality, so I'm a normal person in my world but to others maybe not in their world.

But there could be

- Autie,**
- Autie-nonAutie,**
- nonAutie**

categories in which some people are

- globally effected by their autism,
- effected in many ways but not all (ie like the autistic basketball player,... there's nothing autistic about playing basket ball and this was where he excelled)
- those who have never been effected by autism.

So for example, I used to be mostly Autie because there was little my autism did not effect I had severe meaning deafness, was object blind, context blind, face blind, had social emotional agnosia, I was quite Alexithymic. I also had gut, immune, metabolic disorders, mood, anxiety (including severe Exposure Anxiety), compulsive disorders, so pretty much everything was effected.

But by late childhood I had developed understanding of categories and lists and by adulthood, I had developed an Aspie's intellectualism so between age 11-19 or so I moved from Autie to Autie-Aspie (an 'Aspinaut') and especially by my 30s, some areas of my life were not overtly effected by my autism for example, typing, expression through music and singing, ability to paint, sculpt, gardening, eating. So those things are relatively nonAutie but still influenced by my autism (ie its hard for me to change task and go outside to garden, my diet is altered because of health issues, I paint and sing about autistic experiences etc).

And my ability to converse and manage closeness and most self help skills is now sort of Autie-nonAutie meaning it is still often clearly effected by my autism but my autism doesn't dominate my communication extremely any more (it did until age 9 but then only dominated these functions by about 70% by my teens and about 50% by my 20s but only by about 30%-50% by my 30s and maybe only by 20-40% now in my 40s. If I were to come of medication, drop diet, skip things like Glutamine and omega 3s, leave off my tinted glasses which allow me to see things as a whole, and stopped using signing and objects to track thought and speech, I'd struggle far more by the end of 3-30 days, so my ability to function beyond just 'autism' depends on my ongoing

use of adaptations. And, my adaptations are specific to the contents of my autism 'fruit salad'.

I will never have a 'non autistic' personality and a lifetime with autism has shaped how I learn, think, process information, but we all have differences, and mine will always be 'autistic' but in terms of functioning, I experience far less frustration and disability directly resulting not from differences but from incapacity and it was parts of my autism 'fruit salad' which had caused those but in lesser doses, not too big a problem. So in big doses my autism 'fruit salad' stuff caused incapacities but in smaller doses more like differences.

Remember that the means of one's progression and capacity to move beyond one's autism depends on the 'fruit salad' of each individual's autism. By addressing all my pieces of 'fruit salad' the degree of my autism is far less so doesn't dominate every aspect of my functioning now. It really comes down to each person's journey and I chose to use adaptations. Other people may feel they are content with a greater degree of their 'autism' dominating their functioning but I wasn't. That doesn't mean I hate autism. It doesn't mean I glorify non-Autism. It just means I don't have carers and don't want them and although lots of people help me learn things or assist me in new things or in patterning or getting used to new adaptations, I have a personality that lives for autonomy.

Warmly,

:-) Donna *)

--

Donna Williams, Dip Ed, BA Hons.
Author, artist, singer-songwriter, screenwriter.
Autism consultant and public speaker.

Ever the arty Autie.

<http://www.donnawilliams.net>

<http://www.aspinauts.com>



ABOUT THE AUTHOR:

Brian R. King is a Licensed Clinical Social Worker in private practice in Naperville, IL in which he brings a unique threefold perspective to the world of Asperger's. Brian is not only a single father of three sons on the Autism Spectrum and has a practice focusing exclusively on working with Asperger clients and their families. Brian is also blessed with Aspergers himself.

Brian has become known worldwide for his positive approach to Living the Asperger's experience and is dedicating his time to serving as an Ambassador between the Asperger and Neurotypical communities. His goal is to help both communities learn to better communicate, appreciate and cooperate with each other in a spirit of mutual respect.

Through Brian's books, website and online discussion group he has become a Positive Force for Asperger's. You can learn more about Brian and his work at:

www.ImAnAspie.com

"Teach Me About Asperger's" by: Brian R. King, LCSW

I'm often asked by my clients "How do I teach my child about Asperger's?" My response is "You don't, you teach them about themselves." When it comes to understanding Asperger's the greatest source of information comes from increased self-awareness.

It is important to help a child understand what works for him/her and what doesn't. Any child has strengths and challenges and that is something they will always have in common with any other human being. Their challenges will likely be in areas that other people find easy and their strengths may be in areas that are unique and highly specialized. You can either teach your child about these things in terms of Asperger's or you can teach them as a way of helping them understand themselves.

For example, when I tell people about myself I want them to know all of me not just part of me and Asperger's though a large part of who I am is still only a part. So when asked to describe myself I might reply "I'm a father of three boys, I'm a social worker, I'm An Aspie, I have two brothers and a sister." You see, I simply slip it in there and if asked to clarify it I can do so

in the context of everything else I mentioned. It makes it easier to present myself as more than a label.

I can talk about my interests, the things that bother me, my sensory sensitivities, the fact I don't like surprises or loud noises, etc. I can always come from the perspective of "This is me." This is what I encourage parents of spectrum children to do as well. Educate your children about themselves in their entirety. Do you want your child to become as fully functioning a member of society as possible using all of their gifts or do you want them to see themselves only through the narrow lens of one aspect of themselves?

I'll admit that I'm very open about being an Aspie because I've decided to be a spokesperson and provide opportunities for open and honest communication in order to foster respectful dialogue about what it means to have Asperger's as a component of who I am. But I also emphasize that I am as equally defined by my beliefs, my values, my hopes and my dreams as I am my Asperger's.

When you raise your children on the spectrum, raise them to know and be themselves. Raise them to understand, respect and ultimately take responsibility for their quirks. When you choose to introduce them to the term Asperger's, make sure you give it to them as one of many descriptors of who they are. In the past, the term Asperger's was an automatic label of exclusion. But with the number of Aspies growing, it is now a greater source of inclusion and can even provide a child with a greater sense of purpose as Asperger's can grant a child a unique contribution to the world that is second to none.



THINK OUTSIDE THE BOX!
Sharisa



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The Autism National Committee - www.autcom.org

The only autism advocacy organization dedicated to "Social Justice for All Citizens with Autism" through a shared vision and a commitment to positive approaches.

AUTISM NATIONAL COMMITTEE (AutCom) POLICY and PRINCIPLES REGARDING FACILITATED COMMUNICATION POLICY: It is the policy of the Autism National Committee that everyone has something to say and a right to say it. Facilitated Communication is one accepted and valid way in which individuals with autism can exercise their right to say what they have to say.

"It is hard enough to live in silence without anybody or anything making it harder or more uncomfortable."

- Sharisa Joy Kochmeister, Current AutCom President

PRINCIPLES:

- Everyone involved with people on the autism spectrum needs to be consistently open to and ready for opportunities to listen and to the obligation to explore any and all processes enhance genuine communication and social connections between human beings.
- People with disabilities (including those on the autism spectrum) who do not communicate meaningfully through speech must have an available means of communication that allows their fullest participation in the world.
- All people have a right to communicate using their chosen method(s) and their communication must be respected by others. To communicate is a right, not a privilege.
- People who are denied access to whichever types of Augmentative and Alternative Communication (AAC) they require are denied their basic rights because communication is the basis of all other rights and the means by which those rights can be realized.
- Facilitated communication (FC) is one process to which those for whom this is already a viable form of AAC have an absolute right to access.

- Those who are not yet using Facilitated Communication and who are not speaking fluently have a right to be exposed to, and to receive, competent Facilitated Communication Training (FCT) in addition to being exposed to and receiving training in other specific processes and methods. These, as stated in the American Speech and Hearing Association (ASHA) Guidelines, must be part of a total communication approach that includes speech, signs or gestures, and/or access to low or high technology communication devices.
- The benefit of FCT in leading to FC as an acceptable and valid form of AAC has been established by: (1) the number of individuals on the spectrum who are typing independently today; (2) the studies in which at least some messages were passed correctly; and (3) practical applications when individuals' messages about pain, discomfort, choices, and other personal information have been successfully addressed.
- The primary goal of FCT is always for individuals to achieve independent typing. However, given the complexity of challenges faced by individuals, total independence in typing and demonstrating literacy may not be possible at all times and for every single person.
- Children whose oral language is either absent or delayed for any reason must have access to any and all forms of communication (including AAC and FC) that are necessary and appropriate to enable them to communicate meaningfully in chronologically age-appropriate ways.
- Literacy is essential for an FC user to maximize skills learned through FCT and to become an independent typist. Therefore, literacy must be taught to all students regardless of the apparent severity of their disability. This is particularly true for students with autism spectrum disorders, whose complex movement, anxiety, connectivity, and sensory differences may preclude their demonstrating their abilities in conventional ways.
- At all times, the "least dangerous assumptions" must be made regarding anyone's potential to learn. This is particularly true for people on the spectrum as well as those with other challenges involving communication. To be precise, cognitive potential should always be presumed to exist and a rigorous, systematic, and long-term commitment is required in order to unlock the doors of communication.
- FCT can help enable a person to overcome neuromotor, anxiety, communication, and sensory difficulties and to improve their pointing skills for other forms of communication, e.g., pictures and symbols, along with achieving literacy. However, literacy does not have to be demonstrated initially in order to attempt other methods of communication; including, but not limited to, FC.

- Anyone attempting to introduce FC as a form of AAC must have the minimal competencies articulated in the Facilitated Communication Training Standards. Facilitators, as well as FC users, need to learn the range of technical skills essential to access and use FC reliably and validly with current and potential users. Those who provide training to facilitators, the facilitators themselves, and FC users require and must be provided on-going training, supervision, and support.

- Additionally, facilitators must adhere to strict standards in order to minimize facilitator influence (which AutCom acknowledges may occur), and to assure that all communication is generated and owned by the FC user. Intentionally guiding an FC user to a target is unacceptable under any and all circumstances.

- Funding must be available for FCT, facilitators, ongoing training, and the AAC device(s) each individual requires to communicate meaningfully.

- People with disabilities who use alternative forms of communication should be active and proactive at the local, state, national and global levels in shaping policies and practices of government agencies, professional organizations, and other entities that directly affect their lives. FC must be accepted in policy and practice as an equal choice among AAC opportunities.

- AutCom acknowledges that FC involves multiple forms of support provided by the facilitator, allows the FC user to communicate messages that differ in complexity and usefulness, and is highly individualized and based on the specific needs of the FC user. As such, it does not necessarily look the same from person to person; there is a wide diversity of supports and styles of pointing to targets involved and there is no single rote prescription of how to introduce or use FC. Instead, FCT and FC involve dynamic, active and long-term processes of identifying, implementing, and evaluating communication supports according to the Facilitated Communication Training Standards.

- AutCom supports and endorses the TASH resolutions on communication and facilitated communication, the "Breaking the Barriers" project results, the work of the Facilitated Communication Institute at Syracuse University, and the information on FC reported in the Autism Society of America's journal in 2006 [c.f., "The Advocate", 3(1), 14-22].

- AutCom acknowledges that FC and AAC are methods of communication which may reveal competencies and feelings and thoughts that were previously unassumed and/or unexpressed. We also affirm that all individuals possess unique gifts and strengths

whether or not they need some type of support to assist them in communicating those.

- AutCom asserts unequivocally that there is nothing mystical, magical, miraculous or mythical about FCT or FC. Indeed, this is very difficult and challenging work for both facilitator and communicator.
- AutCom criticizes attempts to dismiss FC on the basis of studies that are poorly designed and/or whose results are incorrectly extrapolated to the entire population of FC users. In particular, we reject over-generalized claims that allege or imply that merely because FC is not valid for some people under some circumstances, FC is not valid for any person under any circumstances.
- AutCom additionally acknowledges the existing body of research points to essential cautions in using AAC (including FC) with anyone who does not fluently and independently speak, sign, or write to communicate. Both genuine, user-authored communication as well as influence by others can occur in a given conversation involving any communicators, even those using oral language fluently.
- Facilitator influence is not an insurmountable obstacle to the responsible and dependable use of FC. Message-passing (in which the FC user communicates information that is not known to the facilitator) is a straightforward way of verifying FC's validity and can be assessed in everyday situations.
- AutCom always welcomes responsible research into AAC/FC using a variety of acceptable, valid, reliable research methodologies and standards. AutCom supports and endorses research that is currently underway as funded, for example, by the Nancy Lurie Marks Foundation. AutCom also notes that the American Psychological Association and other organizations have not precluded continued research into the use of FC.
- AutCom affirms that FC has already proven to be profoundly beneficial in the lives of many people by opening the door to reliable, trusted, and respected symbolic communication for the first time.

“As for FC, it is a tool I use to get where I wish to go. Just as a voice is used to those who speak.” – Jenn Seybert

Selected resources/references:

Attwood, Tony, Ph.D., internationally known expert on Asperger Syndrome [c.f., foreword in Blackman, L. (2001) *Lucy's Story: Autism and Other Adventures*. JKP;

Attwood, T. (1992), “Movement disorders and autism: a rationale for the use of facilitated communication”. *Communication*, 26(3), pp. 27-29.]

Crossley, Rosemary and Borthwick, Chris. (2002), What Constitutes Evidence – “Why the debate about facilitated communication is important for ISAAC”: Paper written for the proceedings of the Seventh Biennial ISAAC Research Symposium, Odense, Denmark.

http://www.fc2000.dk/Artikler/What_Constitutes_Evidence.pdf

Cable News Network (2005). CNN Presents: Facilitated Communication Studies.

<http://www.cnn.com/CNN/Programs/presents/shows/autism.world/fc/studies.html>

Kasa-Hendrickson, Christi, Ph.D., educator [c.f., Kasa-Hendrickson, C. (2006). “Typing to Communicate: Understanding Facilitated Communication”. The Advocate, 3(1), 14-22.]

Damasio, Antonio, M.D., internationally known physician and neuroscientist.

Donnellan, Anne, Ph.D., internationally known educator and autism expert. [c.f., with Martha Leary, CCC-SLP. Reg CASLO (1995): “Movement differences and diversity in autism/mental retardation”. Madison, WI: DRI Press.]

Facilitated Communication Institute at Syracuse University (2000). Facilitated Communication Training Standards. Syracuse, NY: author.

<http://www.inclusioninstitutes.org/index.cfm?catID=8>

Greenspan, Stanley, M.D., pediatric psychiatrist. [c.f., Lecture 8: Review of the Model, Basic Course on the DIR®/Floortime™ Training on-line course (2008)].

Maurer, Ralph, M.D., psychiatrist. (Collected works).

Pratt, Jacob (2008). “Teaching Your Support Staff How to Understand Your Autism Using the MACS Approach”. Rocky Hill, CT: ASDI/NE.

Shevin, Mayer & Schubert, Annegret. “Message-Passing: Part of the Journey to Empowered Communication”.

<http://www.inclusioninstitutes.org/index.cfm?catID=30&articleID=53>

Kochmeister, Sharisa Joy, B.A. (dual major in Psychology and Sociology), AutCom President & FC user/independent typist.

[http://sharisa-](http://sharisa-kochmeister.blogspot.com)

[kochmeister.blogspot.com](http://sharisa-kochmeister.blogspot.com); http://blog.360.yahoo.com/blogtveq9NMic6dhDvPf_YYFDh8M;_ylt=Aq7RhI69A5CUWAV9eU3IJ6.kAOJ3

Weiss, Michael, Ph.D., behaviorist [c.f., Weiss, M., Wagner, S.H., & Bauman, M.L. (1996). “A validated case study of facilitated communication”. Mental Retardation, 34, 220-230; “Evidence Based Behavior Management,”

www.revolutionhealth.com/blogs/michaelweissphd

AutCom invites anyone with questions about this policy and its principles to contact the Autism National Committee using the website at: <http://www.autcom.org/contact.html> or:

The Autism National Committee

P.O. Box 429

Forest Knolls, CA 94933

Linda H. Rammler, M.Ed., Ph.D.



The Friendship Doctors column is written by Linda H. Rammler, M.Ed., Ph.D., who is a consultant to several organizations at present, including the Autism Spectrum Differences Institute of New England, Inc., and 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.

Jacob F. Pratt



Jacob is the Executive Director, founding member, and consultant-trainer for the Autism Spectrum Differences Institute of New England, a 501(c)(3) organization that applies comprehensive, innovative, evidence-based approaches to celebrate strengths and support movement, anxiety, communication, and sensory differences of individuals with autism spectrum disorders of all ages at home, school, and work, and in their communities. Previously, he was a consultant-trainer for Rammler & Wood, Consultants, LLC. As a brilliant person with significant movement, anxiety, communication, and sensory challenges associated with autism who also uses alternative communication, Jacob is firmly committed to breaking down barriers so that others have the same opportunities he has had to participate in inclusive education, meaningful employment, and self-determined living in a real home in his community.

Jacob receives rave reviews for his poignancy, thoughtfulness, and humor and has given numerous presentations across the country, taught sections of graduate level classes, and been invited back by many participants in his trainings.

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.

Dear Friendship Doctors:

I'd really like my autistic son, who uses facilitated communication and is "fully included" at school, to have friends. He types at home about how lonely he is and how left out he feels. His school is very focused on academics and, after his last PPT meeting, the school psychologist (who has her Ph.D.) pulled me aside and said something like, "I wouldn't worry too much about him wanting or needing friends. First off, you need to be realistic: This is what autism is all about. Secondly, he's very popular already. A lot of kids say 'hi' to him in the hallway at school and he participates in our weekly 'Lunch Bunch.'"

Is she right and are we dreaming? Or is there something I can do to help support him in reaching out to other kids and have them reach out to him? I am afraid they will stop allowing him to use FC if I push too hard on this other issue of him having friends.

Signed, Lonely Kid's Single Mom

Dear Single Mom:

AAARRRRGGGGGHHHH. Let's debunk some myths right away. Working backwards, "Lunch Bunch," where the usual scenario 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, is not the same as having friends!!!! Rarely, a genuine friendship may develop but, 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. Plus, who only has friends every other Tuesday when "Lunch Bunch" meets?

Which leads to the second myth about the meaning of "hi": Since when is hearing "hi" an indicator of popularity and since when is popularity equated with having genuine friends? It more likely is merely an indicator that there are a lot of kids in the school who are aware your son exists, know his name, and, at minimum, are polite enough to say "hi." A place to start, for sure, but not by any means dealing with loneliness or feeling left out. Besides, being "fully included" means "having a sense of belonging" (see works by Kunc, Davern, Maslow, and others) which is clearly not your son's experience. Unfortunately, many professionals (like your son's school psychologist, apparently) subscribe to what we think is THE MOST DANGEROUS MYTH: That difficulty making and keeping friends in traditional ways equates to a lack of desire for, and/or lack of ability to have, the kinds of meaningful social connections we call "friendships."

Here are some facts as we know them:

You didn't say how old your son is which is good because people with autism of ALL ages almost always want and need friends, regardless of "what kind of autism they have" (i.e., classic, PDD-NOS, Asperger Syndrome, etc.).

People with autism, just like people without autism, can always learn more skills related to "social-emotional intelligence" and they can do so without autism-specific "social skills training!" What's important is that EVERYONE has chances to do this because this intelligence, not academic prowess, is the single best predictor of adult success across a variety of measures (see, for example, work by Daniel Goleman and Peter Salovey, among others).

Further, as is the case for people without autism, children and adults who have an autism label may define friendships in ways that work for them and not according to someone else's definition. Just try to Google "friendships+definitions" to get a sense of the lack of consensus in the world at large!

The short answer then is that **YOU ARE ABSOLUTELY RIGHT ABOUT YOUR SON'S NEEDS BASED ON WHAT HE HAS ALREADY TOLD YOU!** The corollary is: Neither you nor your son is dreaming. (As an aside, another short answer is that, if they are allowing him to use FC for academics, school staff better not take it away from him because you as his mom are asking for an individualized education program that addresses meaningful social connections!!! If they try, we may need to have another discussion about legal rights...)

So, back to your concern with a longer answer:

The reality is that you and other adults (and even kids) in his life may have to do some extra work to support your son's friendships, particularly in what sounds like a "not very socially supportive" school environment. This is because school environments are where many children and youth develop the majority of their meaningful social connections and typically offer the largest pool of potential friends.

Here are some ways to encourage friendships that we find work for FC - using kids with autism as well as others who may use other forms of AAC, sign, or speech and, as we said before, regardless of "what kind of autism they have":

1. Enroll your son in other supportive and inclusive activities outside of school that are either based on his interests or are things in which you would have enrolled him if he did not have autism/use FC. Even if you have to go with him at first, make sure you teach the other neurotypical participants to address him directly and that they **MUST** wait to give him time to communicate back to them. Once they discover his personality, the rest usually takes care of itself! In the best of all possible worlds and depending on his age, one or more of the kids may even volunteer to be his facilitator(s).
2. Encourage your son to tell school staff how he feels. Often, one of the jobs of school psychologists is to work with socially neglected or rejected kids (including those with no labels at all) who are sad because of their lack of friends. Then, this doesn't become an autism issue but a "lonely kid" issue. The person in charge of helping kids "fit in better" can use the same strategies for your son, but with continued use of his form of communication. Sometimes this means sponsoring a project on which these kids can work together, assigning them as mentors to younger kids, or making sure teachers assign them valued jobs in the classroom. It will also give your son a chance to develop some self-advocacy abilities with your support!
3. At the same time, we would make sure to give lots of information to the school psychologist and others who embrace the myths we hope we shattered above. At least then, they may be less inclined to be "gatekeepers" and either intentionally or inadvertently prevent your son from having friends. There are many ways to keep debunking those myths but here are some that have been successful with school staffs (NOTE: be sure to honor any copyright conditions, of course!):

Show staff videos about friendships among people with autism. A good example is "Inside the Edge: A Journey to Using Speech through Typing", which stars Jamie Burke. In this, he talks about his goal of being a "cool kid" not just a smart kid. Although there's a lot of junk on YouTube, there are some short clips that also make the point like: www.youtube.com/watch?v=pvBue08ohH0, which is only 2 and a half minutes long! You can also fast-forward to the really important part of Jamie's or others' videos and actually show them at your next IEP meeting.

Give staff readings, notably first person accounts by people with autism who quite clearly articulate their desire and need for all kinds of relationships including friendships. If staff says there is no time, use the index in such books or collections of first person accounts (e.g., *Autism and the Myth of the Person Alone*) to find excerpts about meaningful relationships that you can photocopy, highlight, and leave in staff mailboxes!

Bring them professional books/chapters on children with autism and social connectedness. Again, if they say they don't have time to read them, photocopy a relevant page or two and use a highlighter to prove they are wrong! You can find books/chapters on developing circles of friends (q.v., <http://www.inclusion.com/books.html>) or meaningful social connections (q.v. Paul H. Brookes Publishers) in many places. Always preview your selections to make sure they convey the message you want and don't just reinforce the stereotype.

We know as a parent that you spend time on line! Find and printout any articles, blog entries, etc., which again prove your case. You can leave these in the teacher's lounge or coffee table (with or without your name/son's name and phone number) in the main office, too.

Volunteer to read an age-appropriate book or chapter to your son's class or grade about autism. Again, always read these first before making your choice. There are some books with lovely titles that convey the wrong messages (e.g., about having to be in a special class for autism).

4. If friendships don't happen naturally for your son, you must continue your MOM advocacy! You got the school to use FC with your son. Now it's time to educate them about addressing his social-emotional needs in his IEP. For example, tell them you want a "Circle of Friends" in his IEP.

There are many ways to do this as follows:

Have a social-communication goal with objectives that have your son interact socially with peers at natural times during the school day. Natural times include but are not limited to cooperative learning opportunities in class, lunch, recess, "flex times," or study halls. To meet this goal, the school district will have to provide supports and instruction instead of leaving your son to his own devices while other kids are socializing. These are not times for adults who facilitate with your son to be taking breaks!

Educators working with your child are supposed to be "highly qualified" and "trained" to meet his unique needs. Insist that there be a PPT recommendation that the district either send staff to conferences/workshops where friendships are discussed (AutCom and TASH often have strands related to this topic), bring someone into the district who has the necessary experience (e.g., people with autism themselves like Stephen Shore), or do a self-study using the types of reading we mentioned in #3 above.

Most IEP forms have a place for commitment of staff resources. Make sure the time of the school psychologist, counselor, special educator, social worker, or other support staff is dedicated in this place to forming and continuing to support a Circle.

"Support from friends" can be listed among instructional strategies as can "participation in supported collaborative team projects/group work/study circles."

Children with IEPs have the same rights to participate in any extracurricular or co-curricular activities as their classmates without IEPs. Make sure this valuable time is used for your son to make social connections, not to get additional academic support that he may not need anyway!

5. Be, as many parents of typical kids are, your son's personal social coordinator. Again, some tried and true ways to do this well:

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. This way, when your son expresses an interest in befriending "Jason" or "Patrick" or "Jamalia," you can ask the principal how to contact their parents (or, if older, the students themselves) to arrange an out-of-school play date or get-together. If your principal is resistant, remind him/her that this is a 504/ADA "leveling of the playing field" for kids who may not be able to ask for a friend's telephone number, call the friend, and/or arrange an age-appropriate get-together himself.

"Hang out" and get to know other parents (either at school or at your community activities) and invite them and their kids to do something with you and your son yourself.

Help your son write a "getting to know me" book or PowerPoint presentation and ask his classroom teacher, if other kids don't do the same thing as part of the academic program, if he can share this information with the rest of the class. Ask to be present when he does this and make sure you distribute your name and phone number to classmates in case they want to invite themselves over or invite your son themselves.

If you don't already know it, you need to learn what's age appropriate for friendships so you have the right kind of expectations for your son. For example: Preschoolers are friends simply by playing together when the adults know how to engage the child with autism. Their friendships come and go. All you need are a bunch of REALLY FUN AND ATTENTION-GETTING (but short) THINGS TO DO.

Elementary schoolers tend to have common bonds like enjoying kickball versus the swings supplemented by living in the same neighborhood as/sitting next to/being in the same cooperative learning group for much of a school year. Or they may attend out-of-school activities together and share similar interests in school (like excitement over science projects).

Children before and during puberty have complex relationships because the factors governing friendships change so frequently as they mature. Be ready to explain this to your son so his soul is not destroyed when someone he has as a friend moves on and be ready to help him connect with someone else. Also be prepared either to be the coolest parent on the planet or make yourself scarce: Having an adult around can be a deal-breaker! Almost all parents (except those of the kids who set the governing factors or who are flexible and good-natured enough to "go with the flow") spend a lot of time during these years supporting their children's often tumultuous social lives.

High school student's relationships, like adults, tend to be highly interest-driven and "marked" by defined group identity and/or intimacy (as in being each others' "go-to" people when conflicts with other peers result). The biggest barrier at this age is scheduling given other commitments and transportation.

We could go on and on but that's why we have this column. We hope many other parents or individuals with autism themselves will submit questions about friendships for future issues of this magazine. When we can't answer them personally based on our own experiences, we will always check with other experts - people with autism themselves, parents whose kids have friends, or other (para)professionals we know who are way cool in this department - for ideas!

In friendship,

The Friendship Doctors



A.N.G.E.L., Inc.

*Autism Network through Guidance,
Education, & Life*

WHO IS A.N.G.E.L., Inc.

Est. in 2000 by Jennifer & Jim Larson, parents to a son diagnosed with autism only a few years prior, with a simple goal. To provide support to local families who were going through the same challenges as they were. We saw firsthand the great need for this type of network due to the lack of resources and information about autism in general, and the treatment methods available. As with any growing organization, we have gone through several changes over the years. At the end of 2006, the organization had a name change from ANGEL- A HELPING HAND, to A.N.G.E.L., Inc. (*Autism Network through Guidance, Education & Life*). We are a registered 501 c 3 non-profit corporation governed by a board of directors consisting of 10 members. We have many "ANGELS, Angels" throughout the state, and have a chapter in Racine.

Our mission is simple. Support children with autism and their families by providing:

1. Funding for needed therapies
2. Education of autism spectrum disorders and related biomedical and behavioral interventions
3. Create Networks of parent-to-parent and parent-to-community resources.

We also changed our focus from school districts to individual families in need. 100% of money collected goes to the educational

and grant programs. Grants are awarded on a quarterly basis to Wis. families who have a child under 18 with autism. Grant applications are available on our website. Direct funding to schools is no longer available.

WHAT ANGEL OFFERS:

Angel, Inc. is a non-profit 501 C 3 organization started in 2000, which offers financial and emotional support to Wisconsin families who have children diagnosed with Autism. Angel is staffed completely by volunteers. Angel offers compassionate guidance to parents of children with Autism, as well as individual grants of up to \$500 for payment of treatment, which is not covered by insurance companies or Medicaid. We hope to inspire a caring community partnership providing early intervention for each child and family touched by Autism. **SUPPORT GROUP MEETINGS and CONFERENCE OF HOPE:**

Where parents, teachers, caregivers or anyone affected by someone on the autism spectrum can come and share their stories and know they are not alone. We have speakers and many resources available.

Networking parents to parents and sharing resources is essential to families. Sharing is caring!

SOCIAL EVENTS:

We do Date Night or Day Out for parents, where businesses donate their facilities and watch our kids. We also plan outings for the whole family. It is important to get the whole family involved because of the high divorce rate in special needs families. We create opportunities to do things together as a family.

FUNDRAISERS:

2009 events:

January 17th Indoor Walk for Autism – *Changing Autism one step at a time*
Feb 28th Music- Wine-Charity.
April 17th ROCK for AUTISM Concert
Puzzle piece awareness sales
Bowl 4 Autism TBA
June 20 Bushys in Muskego Golf Outing
June 20 Step up to the plate against autism & treasure hunt in Fort Atkinson
Sept. 12th Cruise for Autism (cars & motorcycles) House of Harley, Mil.
Sept. 19th Metric Century Ride 4 Autism – *Breaking the cycle*
November Shop for Autism {TBA}
Nov & Dec ANGEL Calendars and puzzle piece ornaments sale
Many other small fundraisers are done throughout the year, and can be found on our website.

GRANTS:

On a quarterly basis ANGEL gives grants to WI families with children affected by autism for needed therapies and treatment. We feel parents know their children best, so we believe in “treatment of choice”. FOR EXAMPLE: You may have a non-verbal child and want extra Speech Therapy. Or a child may have sensory issues and Occupational Therapy would help. Some children have a lot of issues with their immune system or dietary problems and you may ask for services at Autism Recovery Comprehensive Health (A.R.C.H.) Medical Center. If approved for a grant, ANGEL sends grants to the provider of your choice and you are then notified. In 2007 ANGEL granted \$56,859 to 130 families, with children affected by

autism. 2008 ANGEL has granted 143 families, \$66,381. We hope in 2009 we can continue to beat our last year’s record!

BIGGEST CHALLENGE:

Not having enough funds for the entire grant requests ANGEL receives. Donations can be given at angelautismnetwork.org or you could donate items for raffles done at ANGEL events or volunteer your time at an event. Ask your family, friends, and co-workers to donate. Together we can make a difference in the lives of these children.

An ANGEL STORY:

ANGEL helps woman with nephews who have autism

By Marci Laehr Tenuta

Journal Times

Monday, January 12, 2009 3:59 PM CST

[Burlington couple sees promise in autism bill](#)

RACINE COUNTY — When her younger sister died suddenly last February, Patty Turner’s life was turned upside down.

Not only had she lost her sister, she was also now responsible for being a parent to her three nephews — who all have autism. “I was overwhelmed and scared,” said Turner, 51, who up until then had been a single woman with no children of her own.

But with the help of ANGEL Inc. — a statewide autism organization that offers education, support groups, advocacy and grants for therapy, which often isn’t covered by insurance.

— Turner and her nephews are putting together a life that works for all of them. They still struggle sometimes, but they are adapting.



Brian, 24; Michael, 12; and Kyle, 13, are in the care of Patty Turner, center, after Patty's sister died suddenly. Turner, 51, Kansasville, became a mom after assuming responsibility for her sister's three children - all diagnosed with autism. (Journal Times photo by Scott Anderson/Buy this photo at <http://www.JTreprints.com>)

Autism is a developmental disability that affects language development and social skills. There is a wide range in the autism spectrum, from mild to more severe.

Turner said her oldest nephew, 24-year-old Brian Bailey, has severe autism and is living in a group home. The younger boys, Kyle Turner, 13, and Michael Turner, 12, live with a foster family in Racine during the week and stay with their aunt on the weekends.

The arrangement isn't perfect, Turner admits, but it is the best solution they could come up with currently. She lives in the Town of Dover, and would have to change the boys' school if they moved in full-time with her. Also, Turner works second shift, so Kyle and Michael would be with a baby sitter five days a week if they lived with her. "I'd be home when they are sleeping," Turner said. "I could drag them out here, but who's going to watch them? I didn't want

the kids shoved off to the side and ignored."

Instead, Turner is trying to make the best of her time with the boys. She's learning how to work on things with them, has taken them fishing, to the playground and to ANGEL group events. They've participated in the Special Olympics, and this summer she was able to send them to a therapeutic riding camp through a grant from ANGEL. "The kids were just thrilled," Turner said. "It was the first time they had ever been on a horse."

Throughout the past 11 months, Turner has also been able to turn to Cindy Schultz, who lives in Racine and has a son with autism.

Schultz is the southeastern Wisconsin advocate for ANGEL.

Anytime Turner has a question about something or needs information on a particular autism topic, Schultz has been able to help her. "She's been just wonderful," Turner said. "God bless her. I didn't know anything. She's a wealth of information."

Because of the support ANGEL Inc. has given to Turner and her nephews, she will join hundreds of other people Jan. 17 at an Indoor Walk for Autism to benefit ANGEL. It will be held from noon to 4 p.m. at the Aurora Wellness Center in Burlington.

"I am very grateful for ANGEL for helping me fill the void in (Kyle and Michael's) life," Turner said.

She believes her sister, Carol Bailey, would be proud of her sons.

"The boys were Carol's life, now they have become my life," she said. "The boys have made many gains over this year and Carol would be very proud of them. I know I am."

CHILDREN HELPED BY ANGEL:



Jennifer@angelautismnetwork.org

Cindy@angelautismnetwork.org

www.angelautismnetwork.org

Alyson Bradley Bio:

My name is Alyson Bradley. After discovering myself to be on the autism spectrum later in life and have other associated conditions, a few neurological including being diagnosed with Aspergers, I guess you could also say I am intellectually disadvantaged, having dyslexia and dyspraxia and other differences... Shortly after I was diagnosed, my son Stuart Bradley also was diagnosed as being on the Autism spectrum; and unknowingly I have grown up surrounded by Autism spectrum disorders; many of my extended family are now starting to be diagnosed, a lot less common than any of us think.

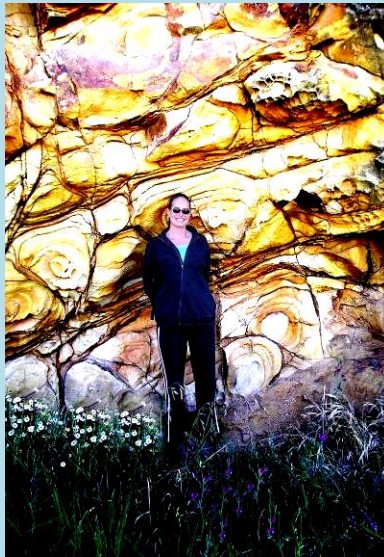
At first, I didn't know which way to turn. I started to read and read some more, looking for answers, and over the last few years I have done extensive research and have now set up my our web site and support forum, my web site shares my journey and others and I have found the more I reach out, the more I heal and get to understand self:

Aspergers Parallel Planet (bringing together those of us who are differently able)

<http://www.asplanet.info/>

AsPlanet forum (read, share, ask or have somewhere you feel understood and matter)

<http://www.asplanet.info/forum/>



Autism Awareness Worldwide

Is the Key to Our Rights

By Alyson Bradley - May 2009

My name is Alyson Bradley. I have Aspergers and other neurological differences; for me while I know so much is already being done, so many people advocating, there also to me seems to be 3 sides - those on the autism spectrum, parents of children on the spectrum, and everyone else; many still trying to figure while reading many conflicting views. At times to me it feels like those on the spectrum and parents of children on the spectrum are in different groups. I have been working alongside many parents; and while at times frustrating, yes, we have differing views and see from different points of view, we all want the same thing and I feel it's vital we all really listen to each other. While I continually listen to the non-ASD community, I get the instinctive feeling many would like to stereo-tape my lips!

There has to be a middle ground. I have started an ASD exchange of conversations because instead of fighting we need to start talking; until we can build bridges among ourselves, the message to the wider majority will continue to be conflicting and confusing for many. This is not easy as I continually find myself trying to restrain the real me, my real thoughts, so others will listen and not write me off as some ranting loony... something of course I am not, but for some reason my differences seem to scare some, many would prefer I conformed and continued to pretend to fit in, for who of course then only the non-ASD individuals...

Here in New Zealand, I have helped to instigate the first ever annual autism awareness fun run. I have Aspergers, and the core group of other mothers have children on the spectrum. While we did not always agree, I feel working closely with those that do not fully understand really helps; and I am so proud of the other mothers as we all have children on the autism spectrum... when we started, no one thought we would achieve much, but together we achieved so much more than any of us ever imagined.

The day itself opened my eyes; for me one of my most special moments ever, I felt so allowed, alive and all I can say right now is brilliant - every child, individual came together, we planted a seed and it grew so much more than we could have ever imagined... I saw so much joy and at the finish line so much pride, well over 1,000 nearing 2,000; do not yet know numbers but that does not matter, hardly a child sensory overloaded and the odd child that did we had a resource for that, it was a place and a chance for many just to be and I felt so privileged to have been able to help arrange such an event... it has opened my eyes to see that there really needs to be many more events that are inclusive, where parents can just relax and not worry and every difference is allowed. And it was great to feel in the majority myself, surrounded by like-minded individuals. I felt a real connection, sense of belonging and feel this is what my daily life should be like - not a continual struggle, written off at times as a misunderstood difference.

I will quote just some information from one of many conversations with a parent of children on the autism spectrum I have connected with on my own journey to help raise awareness and the response I feel incorporates an important point:

"These are important words. There should be more inclusive events that are created where differences are allowed. There needs to be more interaction with the world. In the early 1990's, the autistic/mentally disabled community group members came up to us to hug and invite my son and I over to their group. People in our community were taken aback. It was nice for the first time for our family to be able to belong to a group. When my husband and I hug these disabled members other people were shocked. Eventually others started greeting them. By interacting with normal people their status improved. In a few years the disabled were allowed to participate in church activities like pass around the collection baskets, ushering etc. Their differences were ignored. Regular people treated them as capable.

It was the visibility with other people that changed attitudes. Today in our community people don't see the disabilities. They see the abilities even in adults that can't speak or who do things differently." From a friend I connected with on my own journey, good positive awareness often can have positive outcomes, personally I am tired of fighting, yes I will stand up but also feel it is just as important to at times work alongside those we do not agree with; as often this is where we can have the biggest impact, not easy as myself I have found extremely stressful at times, and I can get a little people overdosed sometimes and just want to hide away, but this is my world also.

I feel this sums up the huge tasks ahead for the ASD community: "It is a paradoxical but profoundly true and important principle of life that the most likely way to reach a goal is to be aiming not at that goal itself but at some more ambitious goal beyond it." – Arnold Toynbee.

But to me, days of togetherness, being out there and realizing that so many in the community want to understand, want to know gives me so much hope for the future and for my own children.

For myself at times as one door opens 10 seem to close, the tide is turning slowly, but at times I feel like I am chipping away at a mountain that may take more than my lifetime to shift. So I feel it's vital to unlock many individuals' isolated existence; worldwide awareness is needed, as up until now many ASD individuals do not even have the key to their own lives. I so agree with the NAS quote: "Nothing about us without us", but to add we all need to be more inclusive and exchange information, help those still in the dark see through our eyes, and it gives me hope that many want to and are starting to listen.

My quote: I will dip whatever I want into my tea... as my way may not always be right in your eyes or your way, but its mine, why does it bother you! So I cannot help but wonder as I continue to hear those that question most, who are they really questioning, but self. And I have heard it said truth goes through 3 phases, it is ridiculed, denied and finally made self-evident.

With so many brilliant autistic individuals advocating, I cannot help but wonder why so many continue to bully and discrimination so obviously against the wider autistic community. Many schools fail to support autistic children and until at least all children get support many adults will continue to be afterthoughts!

I feel EDUCATION is not meeting the needs of most ASD individuals full stop. There is a huge lack of adequate services for ASD individuals' education; employment and life... I feel there will only be real change with worldwide recognition, quality services and consistent knowledge.

Yes, there are some good examples of things that are going on; but speak to another parent, individual and their experience will be completely different to the next. I see it often as the nice compliant families getting the most support, those non-autistic I individuals with autistic children and often that way they do not need to really involve the autistic community, give us a voice or listen... when will others let their children become adults like us?

Autism, and similarly Asperger syndrome, can be lifelong developmental disabilities that affect the way a person communicates with and relates to other people. Yes, some individuals need a lifetime of specialist care and others can live relatively independently and are left to do so, but often when their individual needs are not understood, not allowed, and the majority rules, we are forced to comply with or isolated and forgotten...

No one seems to want to listen or care, so it leaves those of us like myself, who to be honest could do with some good intelligent support. The only support I seem to get is from non-ASD individuals telling me I have to be and act like them, but not really listening or understanding our real issues in life. So the only choice for me is a never-ending fight for our rights, instead of being given a chance like everyone else in life...

The biggest problem for most of us I feel, be it education, employment, lifestyle or anything else is others trying to tell us what our needs are, without really including us or only if on their terms...!

So what can we do when I continue to hear about discriminating and bullying, those of us trying to reach out and speak out. It seems if not on other people's controlled terms, if others do not like what we say we... for myself and many it seems we get abusive emails, pushed aside, put down and/or even blocked from some sites... it shouldn't have to always be on everyone else's terms, how we think, speak out, do things and act.

I am on many committees and so want to bridge gaps, help others understand, but continually feel some individuals from some groups while we agreed to disagree on many things, at times I feel like I am only listened to on non- ASD terms... continually being told "that's not how we do things, you cannot say that, you should not say that, you should not do that...." and it is evident certain people on many committees and groups can be at times very discriminative against me. This includes professionals, preferring to just dismiss what I say, not listen if do not communicate in/on their terms... I feel that at times I am being sent to exile. I feel like a token autistic individual most of the time, and feel it's more a matter of others having to include us, than wanting to... where I live in New Zealand anyway - only and nearly always on their terms!

This of course long term is beginning to affect me mentally and physically; many do not seem to want to make any allowances for our needs or understand what real support we need. There are, of course, a few brilliant individuals and ASD advocates here, the ASD community and of course my AsPlanet members on my forum are brilliant mostly and continue to give me the strength to do what I do. But I am also aware many individuals do not get the support they need, let alone fighting for our rights... all fighting their own battles!

So sometimes I feel my only option is to remove myself from mainstream society, but feel that would be 10 steps back... We have such a long way to go as a minority community, I do feel this has to be a worldwide issue as people are quite often in transit and can affect anyone whatever race, religion etc... while the amazing strength from the Autistic worldwide community helps me stay strong and here for you all, I cannot help but feel at times all the odds are stacked against me sometimes.

**My Autistic Child,
Through the Eyes of a Parent –
1/9/09 for Siobhan
As Written By Her Mother:
Jocelyn Plowey of Woodland, TX**

Only people who have an autistic child can possibly know how it feels to hear the news of his or her own child being diagnosed with "Autism Spectrum Disorder"... how your world crumbles under your feet, how your heart wants to stop the very moment, unable to block out what you had just heard. This was how I and I am sure was the same way my husband felt when we heard the devastating news. He was probably more in denial than me, for my motherly instinct was that something was wrong. At first, everything appeared Ok. Our daughter Siobhan, an energetic infant, full of smiles, growing lovely in all aspects, developing to her age, was able to talk, at least two word sentences, memorized her ABC's, counted to 10 (even backwards), then at to a point to 20, knew some basic colors and shapes before the age of two. Then, at some point, her progress stopped and she started going backwards, to the point where she stopped talking altogether.

Her pediatrician (fearing the worst) recommended a child psychiatrist who gave us the news; Siobhan has "Pervasive Developmental Disorder" (PDD), a type of Autism.

PDD... what's that? What causes it? How can we fix it? I had the "gut" feeling and had seen the change in sudden behavior and withdrawal in words and from people, (even her close family members). These were some of the signs of Autism. I recall that trying to get her to say "juice" was a four hour struggle with crying and tantrums, and her only pointing towards the refrigerator while refusing to say "juice" (which she loves, drinking 1 carton of juice a day); then just simply walking away and curling up on the sofa. Most of the time, I simply couldn't get her to do anything; she was always in a "quiet state" - staring.

Siobhan would not make "eye contact", but sometimes would respond to her name in a quick glance to us. She was very quiet, kept to herself most of the time, but yet couldn't keep still, jumping up and down. Her food appetite had changed; she evolved from a child willing to try new things to an extremely picky eater. She wouldn't interact with babies her own age while she was in a playgroup, kept clinging to me or played in a corner by herself. These were some of the changes that had me wondering "Why?"

Siobhan was a healthy baby otherwise; we lives a normal healthy life, with no wild lifestyle, that could have caused damage to my baby or me. I had previously had two normal deliveries of two healthy baby girls before she was born. We were told it was not our fault as parents, and that the cause of autism remained unknown.

Siobhan's School Lessons At Present:

Since school had started in August 2006, Siobhan has attended Special Education Classes. When she started, she was unable to talk, communicate and socialize. She was in her own little world and surroundings. Through training conducted by a dedicated staff of teachers, speech and occupational therapists, she gained the foundation to cope with words again and gained some social skills and behavior skills. Along with this, she had some basic lessons in understanding the concepts of things around her, helping her in a visual way by using "picture cards". This has been the main focus point in her life, which led her to understanding more things in details.

She then went on to a different public school in 2007- 8, attending Kindergarten at age 5 with regular kids, as well as being in a Special Education class with therapists assisting her. She was able to further develop more skills to deal with her learning disabilities and put them to use. As parents, we were pleased with the achievement she had made in two years and had seen a tremendous change of who she was and who she is at present. She had made sufficient progress towards her I.E.P. goals (as stated in her school curriculum) in Cognitive Skills, Language Skills, Social Skills, Speech and Fine Motor.

The training, however, also exposed other problems of which we were not aware. Siobhan has a slight problem with her Fine Motor Skills; she is unable to use her fingers to grip a pencil to write her letters. We understand this can be a problem related to her Autism; most autistic children have difficulty writing or simply don't want to write. She'd rather spell her full name out loud or on the keyboard. Another cause can be lack of muscle movements of her fingers; but with proper techniques in using objects to control the finger muscles she can become able to write. A list of objects was sent to be used as practice at home to help her finger muscles. She is making an effort in tracing her letters, mainly the beginning of her name and numbers. She sometimes tries to write on her blackboard at home. She can write a 0 + X -

Lately, after entering 1st grade, she is improving on her fine motor skills, by drawing lines, using a scissor to cut straight lines and holding the pencil to be able to write her name. She now can spell her numbers from one to three and count by 2, 5, and 10. She can identify living and non-living items as first, middle, last; identify some coins; hours of the day; temperatures as hot or cold; people or workers in a community; repeat short stories with pictures or using words and sentences, as well as responding to questions. She is at the stage where she can recite a bit of her school pledge and wants to be involved in any school activities performing in front of an audience. She looks forward to seeing her parents in the audience, doing her best for us. She is advancing towards reaching her goals as shown on her first school Report Card as an "excellent student".

Beside this, her school lessons are coming along fine, having some knowledge (from an earlier age) to apply to her school lessons as well as having social skills, in which she is now interacting with kids her age. She

now has a best buddy at school that she relates to. More class hours have been extended to suit her abilities of learning level, which are increasing rapidly, and her behavior is also improving.

She sits well while listening to guest speakers at school. She is now able to participate in group sessions with regular children, doing "show & tell" and read in front of the class, as well as listen and respond well to questions. Her reading and spelling are amazing along with her computer skills. These are her greatest strengths. She has done well in phonics, in which she says the name of an object and tells you the beginning of the word or tries to spell it. This helps her with her speech, in which we are using more reinforcement in prompting her for more words to be used effectively in communication, as suggested by her speech therapist. She is saying four to six word sentences. She is a very observant child, willing to explore and learn more. Her memory level is well beyond expectation, which helps her in her visual learning as well as processing from her senses; enabling her to cope and understand things around her, leading her towards becoming independent.

She has mastered the basic techniques of doing things for her age group, such as putting on her shoes and clothes (but she has trouble sometimes with her pants buttons), using the potty, (had fully mastered the potty at age 4½) tries to brush her hair, loves dressing up, and now carries her purse everywhere she goes, saying "let's go to the store". She is now into playing with dolls and toys that she had once lost interest in, and loves to give her doll a bath. She had mastered washing out her mouth when using toothpaste. She tidies her room by saying "cleanup", and "pick up your toys" after playing or wiping up a mess.

She enjoys being among kids and watching or playing with them. She likes birthday parties, mainly the balloons, bubbles and singing the birthday song (although she will not eat the cake or food). She participates in Halloween, dressing up in costumes and doing "Story Book School Parade", sometimes like a "mermaid", other times like a "snow princess". She loves going on school field trips.

She recently took a class photo, which for the first time came out wonderful, with her looking into the camera smiling. (I guess, seeing the other kids doing so motivated her). This made us very proud, seeing how well composed she was. We were so touched to see how well (shyly) she walked up the aisle to obtain her given diploma without any assistance, how well she participated in the graduation ceremony and the end of the marching parade, enjoying herself jumping up and down. She looks so intelligent in her graduation photo.

Summer-Break:

Over the summer break, Siobhan showed a bit of confusion about her changes of days of the week referring to weekends earlier as days off from school, and later adjusting well to every day - changing the calendar daily. She can't wait for school to start again saying "where is my friends", "I don't see my friends", I know my friends at school". She understood school would start in August. To our surprise, on the 1st of August, she

woke up early, got her school bag saying, "it's August, it's time for school, come on". I had to inform her that August 25th is when school starts, so she kept counting the days leading up to the 25th of August.

Siobhan turned six during the summer break, (well aware her birthday was coming up) and had adjusted well to new changes, new places like being to a "big screen movie theater" for the first time, the circus, concerts, water parks/ pools and the Space Center (she talks about space, the moon a lot – like her father going to a mission in space when he travels abroad, although she knows he comes back in an airplane. What an imagination! A sense of humor!

Lately, she has been asking for her friends, pretending her friends are in front of her, talking with them, even to some sort of objects (mainly her purse), expecting the objects to respond to her. She sometimes takes out her frustrations on these objects, which seems to calm her down. She does miss her friends and school which could have led to some frustrations at home, having a long summer break.

Christmas Break:

Siobhan is beginning to understand what Christmas is all about. She had a wonderful Christmas. She had started early playing her Christmas music and looking at her Christmas videos, "Charlie Brown Christmas Story", and "The Wiggles Christmas show" which has become her favorite, though she did not care for it last year. She took photos with Santa, which she has never done before. She loves posing in front of the lights and decorations for photos. She had been surfing the Internet for her Christmas presents, which had given us a clue to what she wanted. She was all excited when she discovered she was given what she wanted, this made her day! Her three favorites presents - a Leap Frog/Lespster2 handheld video game with a first grade level in writing and drawing and Dora Snow Princess Wii game along with her lighted Disney Princess Castle. She learned quickly to operate the video game and Wii, the new learning activity/motion sport game.

She experienced "ice skating" in the ice rink and "roller skating" as well as discovering "snow" for the first time in her life – rather "fallen snow flakes"; she was so happy running around catching the snowflakes in her tiny hand and feeling the icy cold breeze against her face. What a joy to see her excitement! She loved dancing with the tune "Frosty the Snowman" while watching the dancing water fountain displaying colorful lights. She was on her best behavior entertaining her aunt and cousins visiting, she mingled so well with them, and they were so impressed with the improvements in her behavior. She realized school was about to start again after all the decorations had been taken down and was asking to see her friends. She was so full of excitement going back to school again!

Siobhan's Developing Personality:

Siobhan has evolved from a quiet introvert, unwilling to engage in any social interaction to a lovable child, full of energy, always laughing and bonding with her family. She likes to tickle you or wants to be tickled.

She's full of hugs and kisses, holding our face in the tiny palms of her hands, saying to us "are you okay mommy," "it's all right", "don't worry", "sorry mommy", with a sincere expression. She now can be somewhat demanding, saying, "Let's go now", "it is time" "come on mommy", but it is much better than the non-speaking introvert we once knew her to be. Lately, she acts out like a mother figure, saying very loud pointing to her older sisters, calling their names, saying: "Come downstairs, come eat now", or sometimes "Go bath now, it's time to bath now". "Go sleep".

In the mornings, she will knock on our doors and say, "get up, it's time to wake up". She will help her Dad to make coffee in the morning and set the table for breakfast, placing mats, cereal bowls and cereal boxes for each of us. She helps me to make her breakfast by getting her bowl and using a wooden spoon to cook her eggs, saying "circle, we making a circle". She also likes to help her sister make cookies and cakes. She did try a bit of the cookie, but refused to eat later.

Despite all her demands, though, she is sweet and mannerly, now regularly using the words "please", "Thank-you", "You are Welcome", "Blessed You", "Excuse me", "Sorry", "I", "How are you", "Good Morning", "Bye" and "See you Soon". She loves to greet people (by their names if she knows them) and be among people; crowds and loud noises don't bother her any more. She wants to be involved with everything around her and with her family. She loves feeding our dog.

She loves music, dancing, singing a bit to words of nursery rhymes and dancing to its music. She also says a few learned sentences on the Karaoke, about herself. She loves most of the time watching TV and surfing the Internet doing videos. She loves learning from her favorite videos "Dora the Explorer", learning new Spanish words and applying the words in the correct context. She has demonstrated interest in learning to play an instrument, including the piano and violin.

She loves school, and looks forward to riding the school bus. She enjoys being outdoors and experiencing nature - birds, butterflies, squirrels, dogs, fishes, waterfalls, trees, simply feeling the breeze against her face while walking through or riding her bike on the pathway on which she had learned to ride in three days after Christmas. She loves going to the park, playing ball, trips to the mall, pet shop and children's museum. Sometimes, it seems she loves her trips too much because she does not want to go home, even after several hours. We have no problem going on long rides on vacations, (don't want to stop at our destinations, just keep going; we have yet to try her on an airplane). She enjoys being in a hotel. She sits with us in open restaurant, but not for too long.

At home, she's well adjusted to daily routines, makes changes on her own, relaxes and plays on her own or with her sisters (now teenagers) imitates them or gets into mischief with them like playing around with their stuff "giggling" and just having fun! She enjoys watching family movies at home and had an interest in seeing a movie at the movie theater, *Wale* - a clip she saw on the Internet. She was so into the movie, giggling, sitting still most of the time; smiling and happy she was there. My heart filled with joy just watching her, glad to see how well she "fit in

the crowd", as I supposed, would a "normal" child. As a reward, she went to her favorite restaurant with the waterfall, and this just made her day!

She now enjoys the 4th of July "fireworks", saying "Happy 4th July/Happy Birthday" USA, but still gets confused as it is supposed to be a party asking for the balloons and where are her friends. Siobhan has become a "chatter-box", "loud", always moving around, in a hurry, wants to help around the house, or do things herself, a perfectionist – saying "try again" if she does it wrong. Her imagination has expanded; so does her choice of words used.

Siobhan still has her challenges. She gets frustrated easily; demonstrates symptoms of "Obsessive Compulsive Disorder" (like closing & opening doors, putting on lights in certain rooms and lately getting frustrated (sometimes) if her clothes get a bit wet. She had started a new habit of putting down and moving things to put back in the right spot like a few of her personal things. She will get moody if something is missing (her attached toys) if she can't find it immediately. Or she will walk to & fro twice to go and sit down to eat; this is fairly new. She is still a picky eater; however, she did ask us to buy "Tyson Chicken Nuggets" which she saw the kids eating on the TV. She will take a bit or sometimes eat a good piece. She did this with animal cracker as well as marshmallows. These are the only snacks she will try on her own.

She insists on using the public bathroom wherever we go. She reacts abnormally to over-stimulation and jumps in place or makes "goggling noises", flapping her hands and crossing her eyes, as a reaction to the stimulation. She reacts if you take off her socks, must have her socks on all day, even at bedtime! Sometimes, she reacts if I am (mom) not around, will go into a tantrum for a short time; she is still attached to me and wants all my attention, so we have to sometimes hug as a family so she doesn't get jealous.

The challenges, however, are taking a back seat to the progress she has made. Her tantrums are getting fewer when she goes out, I suppose she is aware it is not acceptable; lately instead of getting into a tantrum for something she must have at the "electronic store", she quickly pointed a "no-no" finger at her Dad when her Dad was putting back a certain toy she desired. Saying "Daddy No"/"No Daddy", with a stern face as "you dare not put the toy back".

Going to the doctor is less stressful lately, for she shows no tantrums, acts as "normal as can be", listening and responding to the doctor and playing with her electronic toy while waiting for her test results. Before diagnosis it used to be a "struggle" with the family having to be there to try to hold her down for examinations with her yelling and running around. A huge challenge, which we had been waiting for, was when she surprised us by drinking a few mouthfuls of orange juice and milk; she seems to like the milk more. She did eat a few bits of my birthday chocolate cake and tried the strawberry toppings as well. She was so excited when she tried it! She seems to want to try new food items.

Most of her obsessive and repetitive actions, she no longer does. She no longer lines up her toys. She no longer obsesses over bottles or a

certain bottle of lotion she wants us to buy when we go to the supermarket and looks for it in the shopping cart. She no longer flushes the toilet twice. She no longer screams at shows on television that somewhat trigger her mind; she simply walks away or would rather watch her favorite "Disney Shows", of which she is now into more movies for her age group. She is also into playing with her toys and dolls. She now chooses a book and her school reading book to read at bedtime; before it was 10 sets of books that had to be read in order at bedtime in which I couldn't forget a word on the page for she had it memorized. She stopped using "The End" after each sentence or story. Now I can read her one story of her choice or choose one or simply lay my head on her pillow for her to sleep when she wants me to do so, saying "Goodnight, I love you mommy".

She is getting closer to her father, and wants him to carry her to bed, saying "Good night Daddy, I love you", and also says goodnight to her sisters, giving each one of them hugs and kisses. She will sleep through the nights and seldom gives trouble in the morning for school.

She has fewer tantrums in public places, mainly the book store, which she didn't want to leave after two hours of being there or must have had a book to take home. She loves going to the supermarket, will help pick out her food items; sometimes she will show some tantrums in which we have to quickly stop shopping. She has her favorite stores she must go to. Often when she gets in the vehicle she will tell us "seat belts, so we can be safe" and puts on her seat belt herself.

One of her "biggest" challenges, I must say, was when I had to stay overnight in the hospital, how she would react to us being apart for the first time. She astonished us, by cooperating in doing her usual stuff around the house, asking, "where is mommy", "let's go pick up mommy at the doctor", "No store, No buying, we have to pick up mommy now". She did not go into tantrums, just waited for a long time, accepted the idea that mommy was coming back, and then fell asleep. She was happy to see me the next day, showing no resentment. This made me so proud of her!

Another "big Challenge" is how "well-observant" and independent" she has become by using my cellular phone calling her father at work and conversing with him. Asking him "Daddy, this is Siobhan, how are you?" "Where are you?", "when you coming home?" I was so surprised to know she did this on her own, and later on watching her speaking to her aunt conversing on the phone with her.

Siobhan's Journey:

Siobhan has come a long way without the help of medication or specialized medical treatment. We are proud of her achievements, her ability to learn, her strengths, her struggles within a world she was locked in when she was diagnosed in May 2006 with PDD. Before being diagnosed she was a "shy/quiet" girl afraid of the world and its surroundings, not understanding or fully grasping the associations of things for several reasons. She had to rely on the comfort of her parents, mainly her attachment to her mom and the focus of her books and TV, and her room where she dwelled most of the time.

She was unable to communicate and socialize with other people around her. At present, because of her achievements in reaching towards the mainstream she is aware of who she is, as being in the family and being among people who love her and wants to do things like other people. She's also aware of dangers around her, how to be careful, and how to take her time.

Our life as a family has changed from the time we discovered the word "autism" as applied to our beloved child, a child we had watched yet were somehow in denial about, even while seeing the situation before our very eyes. We went through struggles, frustrations, bringing laughter and tears of joy in trying to understand the world and mind of our "autistic child". Her two older siblings (much older) had it more difficult dealing with her, but grew to understand her and the symptoms that come with being an "autistic" person. This makes them closer to her, treating her with more love and attention; likewise as equal to them.

Siobhan is a child who is trying desperately to come out of her World to meet us halfway for acceptance in society. We support her with all our love, guidance, being there for her; for she is a special and unique child set in her own autistic ways, enjoying life, looking on through the mirrors of our eyes, waiting to be embraced for who she is.

Pictures of Siobhan and Jocelyn:



Groundbreaking Novel Pairs Baseball With Autism

Frank Nappi's new baseball novel, *THE LEGEND OF MICKEY TUSSLER*, goes where no baseball novel has ever gone before. Sure, there is plenty of good old fashioned hardball, lots of baseball jargon and feel good descriptions that every baseball fan can appreciate. But this story is one that has never been told before. Set in the minor leagues in the late 1940s, this remarkable tale tells the story of a pitching phenom who must deal with a different set of circumstances, heretofore unexamined in books such as this. In short, young Tussler despite notable baseball prowess, suffers from what we now identify as autism.

The story is a well crafted, artistic account of what may or may not be an improbable occurrence, one that will both inspire and engender understanding and compassion, particularly for those touched by autism. Michael Thomas Tussler, "Mickey," is serendipitously discovered by baseball lifer Arthur Murphy, manager of the minor league Milwaukee Brewers, a real life affiliate of the then-Boston Braves. Like many who suffer from autism, the teenager possesses a remarkable talent: throwing a baseball with great velocity and pinpoint accuracy. Murphy's discovery is indeed a fascinating one.

"He stood," Nappi writes, "with his back and left foot flat against the side of the stable, watching in amazement at the young farm boy, standing next to a curious pattern of crab apples in the dirt – firing one at a time from one hundred feet away into a wine barrel turned on its side." Murphy watches for a while, eventually engages the boy in light conversation, and convinces him to try his "trick" with an actual baseball. Much to Murphy's delight, his initial impulse is proven correct.

"Murph's eyes widened like saucers. His breath was gone again. Then, in the flatness that followed the euphoria, Murph knew, just knew, that he had stumbled on something special."

Murphy, whose team is struggling, manages to secure the lad's services by appealing to the greed of Clarence Tussler, Mickey's abusive, no-account father, who incidentally treats his wife just as poorly. The signing of Mickey is a God-send for Murph, for he has been warned that if he does not turn the season around, his position as manager will be terminated.

Arthur Murphy takes the boy back to Milwaukee, where Mickey is greeted by his new teammates about as well as one could expect. We've all read books such as Steinbeck's *Of Mice and Men*, or seen movies such as *Rain Man*, in which an unenlightened society treats those who suffer from these conditions with indifference and condescension at best and downright contempt at worst. That mentality is only exacerbated in the traditionally politically incorrect environment of the locker room. Mickey is subjected to all of the usual hazing associated with the "new kid in town." His hat is

hidden, socks destroyed, and his shoes are nailed to the floor. In addition to this abuse, he must endure a daily barrage of insults and invectives, all at the hands of teammates and opponents alike who are either scared of or intimidated by the boy's incomprehensible talent.

Fortunately for Mickey, there are a couple of good guys to look out for him, including Arthur Murphy, the doddering assistant coach Farley Matheson, and Mickey's locker mate Pee Wee McGinty, a little shortstop with a big heart.

The book follows the fortunes of the team and their new teammate Mickey, who continues to have a fair amount of trouble adjusting to his new situation while away from the routine and comforts of life back home. It is at these moments that the reader gets a real glimpse into the world as seen through the eyes of an autistic person. It is not the safe, predictable place that most of us enjoy. Rather, it is a frightening, oftentimes emotionally debilitating prison of sorts, replete with all kinds of treacherous pitfalls that the boy is unable to navigate. This is when Nappi is at his best.

Through Mickey's haunting recitation of his favorite poem "Silver," to his love for his pig Oscar, the reader becomes one with the fragile, ill equipped Tussler as he tries desperately to negotiate situations about which he has no understanding. The book is an excellent reminder that we all need to be mindful of special needs individuals when they cross our path. Perhaps New York Yankees superstar Alex Rodriguez said it best when he proclaimed, "I see all kinds of challenges facing kids today, and this book does a very good job of treating gifted kids and teenagers with sensitivity and understanding in coping with and meeting these challenges."

Nappi, who has taught English and Creative Writing at Oceanside High School in New York for twenty years, published his first novel, *ECHOES FROM THE INFANTRY*, in 2005. *ECHOES*, which is based loosely on events described to him by several WWII veterans, is the story of one LI WWII veteran who struggles his entire life with the insidious residue of war. The book, Nappi said, came as an outgrowth of a WWII Veteran's Day Speaker program run through his interdisciplinary class at Oceanside. Like *ECHOES*, *THE LEGEND OF MICKEY TUSSLER* was influenced by Nappi's experiences in the classroom, and by observing what he calls "so many remarkable autistic young people with whom he speaks every day." The creation of his title character is, by all accounts, a composite of many special individuals.

Whatever the formula was, readers will agree it works. Mickey Tussler is certainly an endearing character. Like many special needs children, Mickey is genuine and soft-spoken. He possesses a simplicity of the heart that distinguishes him as someone for whom we all want to root. The legend

that Frank Nappi creates for us is one that transcends the baseball diamond into realms that are far more universal.

"I wanted to tell a special story using baseball as a vehicle," Nappi said. "Sure, the baseball storyline is compelling, and at times a lot of fun. Baseball is a great game. But as is the case with all good fiction, there needs to be, beneath the surface, something universal, something poignant that touches the reader at his core."

Clearly, this remarkable story fits the bill. Parents of autistic children, as well as those of us who know someone with autism, will find this a story that celebrates resiliency in the face of adversity, all the while throwing a spotlight on the many amazing things that special needs kids and teens are capable of doing. It is a deeply complex look into the plight of the underdog, and a sobering reminder that everywhere we turn, and perhaps where we least expect it, there exists these diamonds in the rough. All we need do is look.

As a father of two handicapped sons playing in the Little League Challenger Baseball program, *The Legend of Mickey Tussler* connected with me in ways you can't possibly imagine," said Mark Snider, a reader who offered his praise for the Nappi's novel. Snider's comments have been echoed by many other parents and friends of autistic children, many whom Nappi has met during speaking engagements at local SEPTA meetings and Challenger Baseball events. It is this mystique and emotional appeal of the story that caught the eye of Jason Koornick, Executive Producer at "Eye In The Sky Entertainment" in Los Angeles, California.

"Shortly after the book was released," Nappi explained, "I received a call from a gentleman who was looking for a baseball property to develop. Jason was very excited. He was captivated by the way, as he put it, 'the story leapt off the pages.' Everyone there is very excited about the prospect of Mickey Tussler coming to the big screen."

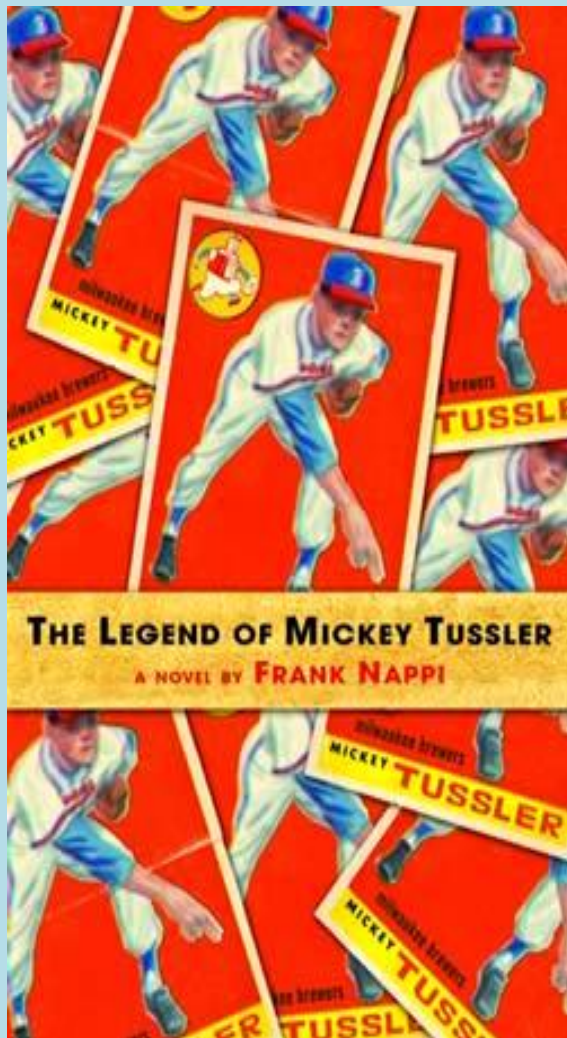
Koornick's company, whose last endeavor was the film *Next*, starring Nicholas Cage and Jessica Biel, purchased the film rights and is presently at work on a screenplay. Nappi said that the screenplay should be completed sometime this winter, after which all eyes will turn to bringing the story to theatres across the country.

Certainly, should the film project come to fruition, the media attention that will undoubtedly accompany the release will thrust Nappi's innovative novel even further into the spotlight. And, Nappi's goal of raising America's consciousness regarding the talents that many autistic young people possess will also be realized. Although there have been countless non-fiction books to hit the shelves regarding autism, very few efforts have been made to cast autistic characters as protagonists in fiction.

Aside from Mark Haddon's bestseller *THE CURIOUS INCIDENT OF THE DOG IN THE NIGHT-TIME*, the autism community has been relatively starved for a quality story that features one of these special individuals. Nappi's novel does just this, becoming a wonderful blend between the classic baseball tale *THE NATURAL* and Haddon's unusual story of Christopher Boone.

As a society, we have become increasingly tolerant of and sensitive to our special needs citizens. However, many would argue that we still have much work to do. Frank Nappi's novel, *THE LEGEND OF MICKEY TUSSLER*, which is available at all major bookstores as well as Amazon.Com, will do much to get us there, as his wonderful protagonist, the loveable, fire-balling phenom called Mickey, becomes the poster boy for all special needs youngsters.

Kathleen Stenson



Frank Nappi, Author



Xenia Grant



Opinion Piece on Adult Research When it Comes to Autism

In 1989, when I went to the Autism Society of America conference in Seattle, one of the speeches I saw was a father talking about his teenage son with autism and what his life would be like in the year 2009. He talked about how this young man had a good job, a fulfilling life in the community with people who understand him and how he enjoyed living life.

Even though the father mentioned nothing about research on autism or how research studies can enhance the lives of people with autism, I have for years been thinking about how there is little research out there that focuses on adults over the age of 21, and how there is next to nothing that focuses on the people with autism who are over 55 and are elderly.

Besides this, very little of that research focuses on how we can deal with our lives in a practical manner, especially when dealing with the sensory issues that all adults with autism face.

And, when a person who is 40 or over 21 finds out on their own that they have autism or might be on the spectrum, they don't have the money or health insurance to even get a diagnosis.

Many of these people have been wondering why for decades why they are different and they read about autism/AS and they find out that is them. But to get an official diagnosis is difficult.

Additionally, research tends not to focus on people over the age of 21, and none focuses on people over the age of 55.

I have talked to some adults with autism, and here is what some of them have to say.

My friend George, who is in his 40s and just was diagnosed as having autism said: "One thing I discovered when I was looking for information about autism like treatments or therapies is that there really isn't stuff out there for adults. It's all geared towards children... and early diagnosis and treatment. It seems like from looking at stuff that if you weren't diagnosed as a young child, there really isn't any hope for you."

Another one of my friends, who lives in Denver says, "It takes so long to get diagnosed as an adult. Especially when you consider that most adults with AS, if they haven't managed to fit in, they have no health insurance. The problems of finding a doctor, getting the testing the diagnosis, etc. etc, etc, leads to a lack of services for the uninsured Asperger's person, especially with the lack of support services it prevents us from fully participating in life."

This same friend also said, "If they had support services, they (meaning AS) would make excellent employees."

One of the things I suggest is that all 50 states have at least one diagnostic center that caters to adults and the issues that we face.

I envision that there will be centers like this in big cities and in small rural areas and that practical things like how to deal with sensory issues, life on the job, how to keep house, and other areas of endeavors are worked and dealt with.

And that at least 10% of the employees who work at these centers have autism themselves and that the ideas on how to help autistic adults come from people with autism themselves.

An adult of 21 has different issues than a person who is 45. And a 45 year old has different issues than someone who is 65 and older.

Not only that, but some of us adults who are autistic are married, have kids, jobs, mortgages, etc, and the issues that they face are different than the 21 year old who just graduated from college, high school or some other educational program and that person faces different things than the 36 year old who lives in a group home and is learning basic self-help skills.

There needs to be autism research for those who are over 45 years of age and research is needed for those who are elderly.

Geriatrics and autism are going to be the new high frontier of research that will grow in the next few years.

After all, kids grow up to be adults and adults age and become over 65 and those who are over 65 become older, and that means dealing with issues such as arthritis, eye problems, heart issues plus other physical things that elderly people face.

Additionally, all the research into social skills and how to be more social won't help one iota if we have sensory problems/issues that make life hard to live. How can a person who is sound-sensitive to the tiniest sound be able to get a job and work in a noisy office?

I am a big believer in research into the practical aspects of life, and one of these areas is how to deal with our various sensory sensitivities.

Along with this, some of the people I have quoted touched on the area of employment and I believe adult research needs to go into how we autistic people can be good employees in environments that best support our needs, and how employers and other non-autistic people can help us be the best autistic workers possible.

In Denmark, a company called Specialisterne employs people with autism because it gives us a chance to use our skills in the IT field. They are an example that can be replicated to all parts of the world. I wish there were more companies like Specialisterne out there.

Dr. Temple Grandin says there needs to be "research into treatments for sensory sensitivities because these problems can be debilitating. They (sensory problems) can make it impossible or very difficult to function in normal environments such as offices, restaurants and sporting events. And there is no way a person can be social if they feel like they are inside a speaker at a rock concert. Also another big problem is fluorescent lights. And to some ASD people the room will be flashing on and off like a discothèque. That would be impossible to work or study in this environment." She ends up saying, "Sensory problems are very variable. One individual will have sensitivity to fluorescent lights and to another individual they will have no effect. One of the problems with doing research on sensory issues is that they are so variable."

I, for one, agree with what Temple says. I may not have a problem with fluorescent lights, but I will never go to a concert or a basketball game because the noise is too intense and all-encompassing. That means that if my friends or family decide to see the Nuggets play against LA in Game 4 of the finals, I can't go because the noise would be too much for me. How can I be social when the noise would feel like torture?

Many of us on the autism spectrum live out our lives that way because we have bodies that don't deal with the post-industrial American environment well.

Where are the practical research and the papers that are produced that can help adults cope with our sensory difficulties?

Where is the literature on how someone who wants to work for a computer company but can't commute to work because he/she can hear the flicker of fluorescent lights and how that can be dealt with?

Where is the research in how someone with autism who wants to go out and be social, but can't because his/her sense of smell is so strong that the odor of the average human body is too much to take?

Or that clothes are too itchy to wear for long periods of time because it causes intense pain of the body?

Yes, every person with autism deals with variable sensory issues, even within the same person.

A good example is me in that I have almost no sense of smell (unless it is really strong), but the cry of a baby on the bus is too much to take; but I grin and bear it because I keep my instincts at bay.

Many of us on the autism spectrum feel "cheated" that so much research is into kids and people under the age of 21. Many of us who are over 21 feel neglected and forgotten.

Where are the specialists who cater to and focus on adults? Maybe there needs to be college/university (undergrad, graduate and Ph.D.) programs that focus exclusively on the issues that we adults face.

Maybe one of the ways to create that is to give tax incentives to those who study adults over 21 and when they get their degrees have their student loans paid off and forgiven if they work with adults for over a year in the practical areas of life.

And I am not the only one who feels this way; my friend Jean Paul Bovee of Kansas City, MO who is autistic and married said, "Focus for many years has just been on the children with autism but not enough on adult issues. And the focus has been on cure and fix instead of helping people be the best they can be as people on the autism spectrum. And we are adults much longer than we are kids. And services for adults with autism are much harder to find."

My friend Tim, who lives in Aurora, Colorado says, "We just want acceptance and be accepted like everyone else. We want to be treated like everyone else with respect and dignity."

Carol, who lives in Denver, says, "In my experience therapists have an attitude that autism is strictly a childhood disorder. And I think that comes straight out of the DSM-IV. Some of us autistic people manage to survive beyond the age of 18. The specialist who diagnosed me with autism, was working in the STEP DD program to learn more about bi polar disorder (many of us on the spectrum have other diagnoses besides autism), she was surprised to learn that I met all the criteria for Kanner's (classic) autism. Psychiatrists that I have had since then have tried to make a claim that autism is a childhood disorder and therefore that I can't be autistic - when I heard that, I fired them. I learned through some of my own research that people with autism should be given psychiatric medications at a much reduced rate like basically one quarter to one third should be of what normally should be expected. "Carol said about SB-244 (an autism insurance bill) which was signed into law on Tuesday June 2 by Governor Ritter, that this "is a perfect example of kid-centric thinking in autism."

And the problem is not only in Colorado, but all over the nation. Even in big cities like New York, adults with autism are having a hard time getting diagnosed and having a hard time getting the proper help because of the "kid-centric" thinking in the autism world.

So many of us who are over 21 are having a hard time finding a place and a way to live good lives because of the paucity of services that are out there.

And what about those who are considered on the more severe side of the autism spectrum? What about practical research that can help them to better their lives?

I have read letters to the editor in Britain's National Autistic Society about adult children with autism who need high levels of support and what is going to happen to that person when the parents are gone. What about them - not only in the UK, but in this country?

Many states do not have enough services for adults and Colorado has a long waiting list for adults who need services and it might well be the 22nd Century before some of them get any services at all.

And then when there are cutbacks in state budgets, people with disabilities, especially autism, are the ones who are most affected.

Ondrea of Rhode Island says, "I wanted to let you know how it feels to be an adult diagnosed with autism. It isn't easy being an adult diagnosed with autism, let alone a young adult, because I know I am different from some of the people that I deal with every day. Some don't understand what it is like to live with autism, and some don't even want to imagine what it is like. I am living my life the way I am supposed to be by being the best advocate I can be for autism, and I just want more awareness to get out there, especially in the city of Woonsocket. The focus is on kids having autism more than adults having autism. That's how I feel because in Rhode Island, they have a lot of programs and activities for kids with autism to participate in, and they get more help, I feel than adults with autism. Sure, there are few groups for adults with autism, but it isn't enough. Adults on the autism spectrum, of course, need to speak out and have their voices heard so more things can be done. That's what I'm going to keep doing."

I remember being in Seattle in 2000 at the Best of the Northwest Conference and meeting an 87 year old man who just found out he is autistic. This elderly man didn't know for decades things like why he wasn't close to his kids or why he was "socially off" and then to find out in the twilight of life why is a reminder to me why research into adults and especially those who are elderly is so important.

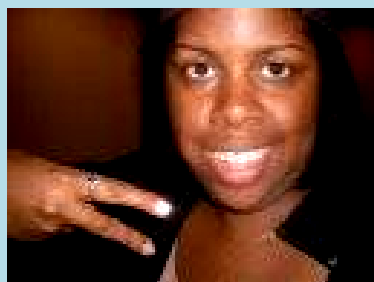
**After all, we autistic people grow up and grow old
and we are here to stay
and research needs to be reminded of this reality!**

From Ondrea, Mentioned Above and Author of the Following Story:

Here is the story on me: I was born in Woonsocket, RI, on February 11, 1981. When I was three years old, I was diagnosed with autism at Bradley Hospital in Providence. I was interested in colors and read on my own at that time but didn't communicate. If I did communicate, I would scream and get upset. There were times when I hated to go to appointments, because my social and communication skills were not there. I hated people, because I simply didn't know how to interact with people at the time. School was especially tough, because a lot of people gave me a hard time. They yelled at me, they made fun of me, they let me down, and some of them were basically two-faced. But I did make some friends at school, which was a good sign (even though it was hard because of my communication skills). I actually enjoyed doing work at school like math and English. I excelled in classes like Computer Science, Journalism, and Spanish (I still use it to this day), because I love writing and communicating with people, even to this day. I was on the Honor Society in High School, and then I moved on to the Sawyer School in Woonsocket (which is no longer there) two months after graduating in 1999. I got a 3.9 average and graduated with an Office Information Processing degree, because I did office work, and I did excel. I am now currently a student at the Community College of Rhode Island (I started in January of 2006), majoring in Liberal Arts-English, since I want to focus on my poetry and stories. I have taken a lot of English classes, including Creative Writing and Introduction to Poetry. I got a 4.0 this semester, which was exciting, because I worked very hard. I do have a lot of poetry and stories, and that keeps me going, in a sense. I am blessed, because God gave me the talents so I could use them to help others, especially sharing my story about autism to parents who have children with autism or people with autism. Of course, not everyone with autism accepts that they have autism, and even though we don't like it, we have to respect it.

There's more to this story, but I don't want to bore you! I hope that this helps you!

Ondrea



How to Interact With Someone Who Has Autism (by Acuariana)

Hector narrates the story:

Hi, everyone. It was a beautiful, sunny Thursday afternoon in Bella Rosa. People were coming in The Pink Rug to get the famous pepperoni, cheese, and sausage pizza that I usually made.

This day was no exception. My girlfriend Raquelle and her older sister Vanessa came to the restaurant and sat at the famous pink bench Raquelle loved so much. They were ready to chow down.

As usual, I greeted them. "Hello, *muchachitas*." I grinned when I saw Raquelle.

"Oh, hello," Raquelle said with a grin while Vanessa waved to me. "We're here for your famous pizza."

I laughed. "I knew you were coming to chow down on it, *mi bella Raquelita!*" Then I noticed that she was wearing a pretty lavender sundress and pink sandals. She looked beautiful!

Vanessa caught me looking at Raquelle and grinned. "Hector, Raquelle felt like putting that on so she could impress you."

I raised an eyebrow. "Um, Vanessa, Raquelle usually doesn't dress pretty to impress anyone!" Then I told Raquelle that she looked beautiful.

"Thank you," replied Raquelle.

I laughed. Then I went behind the counter to start up another pizza. While I was doing that, Vanessa and Raquelle struck up a conversation.

Vanessa took Raquelle's left hand and stroked it. "Okay, *hermanita*, the reason why we came to The Pink Rug is because it isn't noisy or overcrowded, and the people are very friendly, especially *your cute and understanding boyfriend!* Plus they understand about your autism, don't they?"

Raquelle pretended to gasp. "Vanessa! You sound dramatic, *chica!*"

Vanessa smiled. "I'm trying hard not to be dramatic, Raquelita, but Mama and Daddy are helping me how to interact with someone who has autism more than ever before. For example, I have to be patient with you and Juan Carlos. I can't talk down to you both or accept you to be normal like me. I've been to a couple of events about autism with you and Mama, and they taught me more than what I knew."

"Like what?"

"More and more people are getting diagnosed with autism now than ever before. Awareness is out in the open, but it can be done even more. I would want to work with someone who is autistic, because I have a lot of knowledge. But, Raquelita, I have to admit that I don't know everything about autism. I know I have to be sensitive to those who have autism. I don't want to end up like Gladis and Adela Lozano, that's for sure. I mean, Gladis's daughter Isabel is autistic, but Gladis sure ain't sensitive half the time with Isabel, and she's the mother! Jose Alexander, Isabel's father, is more patient and understanding. Patience and understanding is what someone needs to give to people with autism."

Raquelle rolled her eyes. "Believe me; I know about Gladis and Adela. Maybe they need to interact with autistic people in a better manner than they do. They need to be trained, *Vanessita*."

"They need to be much better trained, that's for sure, Raquelle. But Mama and Daddy went to an autism training for parents in Colombia three years ago, remember? Daddy actually knew about it before Mama did, but they chose to go. You, Juan Carlos, and I had the house to ourselves for a week, but Ondrea, Erinne, and Desiree came over to have pizza two days in a row! I thought they were great entertaining us with their skills!"

Raquelle laughed. "Ondrea referred to herself as the Autistic Creative Eeyore by wearing an Eeyore shirt and pink capris; and Desiree showed us her drawings of circles, triangles, and girls' faces. Erinne hooted loudly like usual, but she did help Juan Carlos cook some taco salad."

Vanessa hooted even worse. "At that rate, I thought Erinne could cook better than Juan Carlos!" That made Raquelle laugh a little louder, but not too loud. Luckily, nobody noticed.

When the laughter died down, Vanessa went on. "Raquelle, I thank God that you are my beautiful autistic sister. I love you." She prepared herself for crying.

Raquelle did just that, but she smiled through her tears. "Thank you, Vanessa. Thank you." She got up and hugged Vanessa. It was clear that they loved each other very much despite their differences.

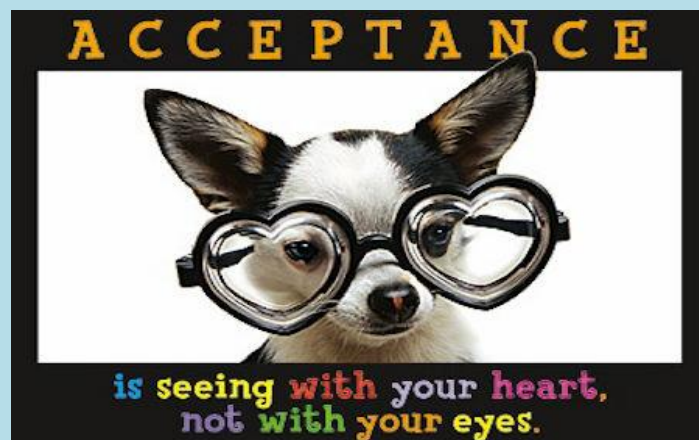
Luckily, I was done making the pizza by then and showed up at their table. "Hi! I am ready to serve you both!"

Raquelle and Vanessa looked in awe as they saw a beautiful and delicious pepperoni, cheese, and sausage pizza cut in 12 equal parts. I also planned on them having mozzarella sticks and Nestea Iced Tea, one of Raquelle's favorite drinks. (Jesenia, another worker at The Pink Rug and Paola's older sister, was going to bring the mozzarella sticks and the Nestea Iced Tea out in a minute.)

"Thanks, as always, for the great service, Hector," Raquelle said to me with a smile.

"While you were making the food, Vanessa and I had a long talk about how to interact with someone who has autism." She leaned over and gave me a kiss on the lips.

I smiled back. It was important that she said that, because I heard the conversation between her and her sister. I knew it was important, because I've dealt with people who have autism, and I've learned how to interact with them. I still have more learning to do (thanks partly to the conversation), but thank God I can say that autism is a part of my life, and it will continue to be until I depart from this earth.



**Living With Autism
by Ondrea Robinson**

**Living with autism is something I have to deal with everyday.
Sometimes I can't express out of my mouth what I have to say.
When I get frustrated, I feel as if no one really understands me.
I wonder if I'm really the person I want to be.**

**Autism is not a disease that can be caught,
But people need to be taught,
Because some think they can be infected.
That's why I feel rejected.**

**Other times I just want to be left alone,
Because negative views I don't have time to condone.
I've witnessed hearing comments that are so rude
And some things about autism that are not true.**

**If anyone thinks that doing all that is fine,
I'll lend a deaf ear, because I don't have the time.
Even though there are times where I feel sadness,
I thank God, because I know I feel gladness.**

**I express poetry to cope with my autism
And see myself in a colorful prism.
Although living with autism can make me stressed,
I know for a fact that I am being blessed.**

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**“When we cannot be sure,
because we have too little information,
we should base our efforts on assumptions
which, if wrong,
will have
the least dangerous effect
on outcomes.”**

-Anne Donnellan and Martha Leary

Judy Endow, MSW maintains a private practice in Madison, WI providing consultation for families, school districts and other agencies. Besides having autism herself, she is the parent of a son on the autism spectrum. Judy does workshops and presentations on a variety of autism related issues, is part of the Wisconsin DPI Statewide Autism Training Team and a board member of ASW. Her first book, Making Lemonade, Hints for Autism's Helpers (2006 CBR Press) shows how Judy has used the lemons of her autism to "make lemonade" in her own life.

Outsmarting Explosive Behavior, A Visual System of Support and Intervention for Individuals with Autism Spectrum Disorders (2009 AAPC) and Paper Words, Discovering and Living with My Autism (2009 AAPC) are Judy's most recent books. She brings a great depth of understanding and compassion to all the work she does. For additional works by Judy please visit Autism Asperger Publishing Company at www.asperger.net



Judy Endow

**On the next 2 pages
there's an excerpt from
an about-to-be-released new book by Judy....
Which looks awesome!**

That will be followed by a review of her current book by me.

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
The Impacts of My Differences Learned Forty Years Ago
While an Institutionalized Teenager

Back Then, when I had launched my new strategy to discover the ways in which I was different from my peers, I imagined that once I had this information, I would simply hide my differences so as to “appear normal,” the criteria for discharge from the mental institution. At the time I never realized that once I had discovered my differences, this information would have an emotional impact on me.

Once I had identified my differences, I began noticing not only when my “different-ness” was showing but also the impact of my differences, both on others and on me. I had expected that I would learn about the functional impact of my differences and then figure out how to hide them so that they would come to have no impact on those around me. So that when staff at the institution looked at me, they would see a “normally acting” teenage girl, which I hoped would result in my discharge.

I never expected that this functional exercise would usher forth a personal, emotional impact. Furthermore, I never expected that I would live in this phase of discovery for several years, even decades, of my life. This phase of my personal journey of discovery saw me through discharge from the mental institution as a teen, and shortly thereafter into postsecondary education and the world of work, followed by volunteerism as a Christian missionary, and a marriage that brought forth three sons – the all-time miraculous blessing of my life.

Come,

journey with me further

so together
we might partake

of that
which I discovered

both the

functional impact
and the

emotional components
that my

different-ness

creates in
this world ...

People Yardsticks

If

you measure me

using your yardstick of life

I will not measure up
to be any inches

I'm not the same

so you can't accurately measure me

in the same way

that you measure

most other people

but since nobody has found

another way to measure

I have come to accept

that I'll always be less

than all of the others

Note: People Yardsticks appears both in the book *Paper Words, Discovering and Living With My Autism* and in the DVD *The Power of Words, How We Talk About People With Autism Spectrum Disorders Matters!* Both publications by Judy Endow are due to be released in July 2009 by Autism Asperger Publishing Company www.asperger.net

Outsmarting Explosive Behavior, A Visual System of Support and Intervention for Individuals with Autism Spectrum Disorders
(2009 AAPC) by Judy Endow
Review by Managing Editor Sharisa Kochmeister

I have known Judy Endow for only a short time and heard her do a presentation only once, but I found her and still find her to be very real, very knowledgeable, very intuitive and very unique in her insights to ASD, Asperger's and behavior.

When Judy asked me to read and review this book, I took it on with a great deal of trepidation - you see, I was trying to outsmart my own extraordinary explosive behavior breakdowns. Talk therapy, diet, elimination of environmental irritants, antihistamines, anti-psychotics, relaxants, pain meds, animal therapy, deep pressure, brushing, relaxation training, breathing, meditation - most of these made a small impact, none of them worked well or for very long and episodes would happen for 30-90 minutes several times a day for weeks and months on end. I couldn't leave the house, couldn't sit still, couldn't type much if at all, couldn't focus, think or concentrate, couldn't be anything resembling what I always had thought of as "ME." I was angry, enraged, frustrated, violent, self-injurious, non-compliant, impossible to comfort, to communicate with, to reach emotionally or physically, avoided even gentle touches I used to crave - totally out-of-control of my body, mind and very soul!

To put it mildly, yet succinctly, my parents were at wit's end - my father who has never given up on me in 30 years was well-prepared for his own breakdown and institutionalization in a psychiatric hospital was looking like the best (if not the only) alternative for me! We were constantly in fear that even previously tolerant neighbors would fear I was being abused and the police would be at our door... hearing the way I screamed bloody heck (family magazine) at all hours of the day and night could even cause someone to summon an exorcist. I was possessed, YES, by my own endless rage and frustration, helplessness and fear, anxiety and adrenaline surges, hyper-stimulated and overloaded central nervous system, chronic pain and rapid cycling bipolar mood swings!

That was me until about a month ago. Now, I am getting better control and better results from calming meds and pain meds (though I hate taking pills - not in my control, exactly). However, I live in constant fear of the return of rage because I am and always have been so unpredictable in so many ways. This is where reading Judy's book comes in - and that is why I want to share this book with everyone and my thoughts about her system.

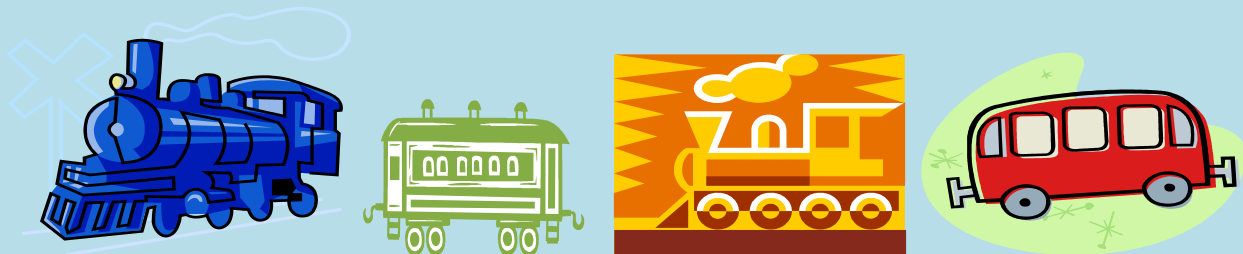
Judy compares explosive behavior to a runaway train heading for an explosion through a four stage process plus a recovery phase and provides a simple-to-use but nonetheless brilliant systematic method of stopping the cars of the train from linking before you get to the third stage - what

she calls very accurately “The Point of No Return”. In this stage, the fight-or-flight response has already been fully triggered and the linkup and explosion are apparently unstoppable. Judy knows this methodology has worked first with her own teenaged son and since then with countless others of various ages. As she informs the reader in her introduction to the book:

“... I've had the privilege of using this train model with numerous individuals on the autism spectrum and their teams of support people. Currently, instruction on using this model to outsmart explosive behavior is part of the Wisconsin Department of Public Instruction Basic Level Statewide Autism Training for school staff and teachers across the state. It has been used for young children as well as adults. It has also been used by non-readers by constructing it totally in pictures rather than using words . . . and it has been found to be effective in both . . . versions.” Judy goes on to point out that: “Teachers reported an increased calmness in their classrooms, as neurotypical students also came to use the train model to communicate their frustrations to peers and teachers.” Judy states: “It is my hope that this model for outsmarting explosive behavior becomes a useful tool for any individual - young or old, label or no label - who struggles with explosive behavior.”

After reading and absorbing this awesome and insightful book, I can truly say that I support and echo Judy's hope, endorse her process, think it should be adopted everywhere asap, and intend to make it part of my own life and my own strategies for coping so I can outsmart my own explosive behavior(s) before the attacks ever return again and will know where to start and what to do to prevent reaching “The Point of No Return” and the inevitable, unavoidable disastrous explosions long before they have a chance to so much as begin!

Go to Judy's site, buy this book, read this book, make it part of your life and the lives you wish to spare the pain of despair and emotional exhaustion of explosive behaviors! My father totally agrees!



Sharisa Joy Kochmeister, June 16, 2009

**The Triple A Connection: Autism, Aspergers, and ADD
By Susan N. Schriber Orloff, OTR/L**



Susan N. Schriber Orloff, OTR/L, is the author of the book *Learning RE-Enabled*, a guide for parents, teachers, and therapists (and a National Education Association featured book), and the *Handwriting on the Wall Program*. Children's Special Services, LLC is the exclusive provider of P.O.P.™ Personal Options and Preferences, ™ social skills programs. She was the 2006 Georgia OT of the Year and the CEO/executive director of Children's Special Services, LLC, which provides occupational therapy services for children with developmental and learning delays in Atlanta. She can be reached through her Web site at www.childrens-services.com or at sorloffotr@aol.com.

What do these words mean? One minute you think, "...well, maybe my kid is just a bit quirky", and the next dreadful sounding words are being tossed at you!

What do you do, to whom do you go, and what do you do *first*?

These are but a few of the questions rambling around in your head, stirring both your heart and your mind.

The first place to start is with definitions. It is imperative to know what the words mean, and what are the similarities and what are the differences. They all involve thought and the ability to organize and utilize information, and with each, motor planning is often impacted and emotional responses are often unpredictable.

The definitions are as follows:

Autism: is a central nervous system developmental disorder that impairs social interaction and produces restricted and repetitive behaviors.

Aspergers: a milder variant of autism. These children often have idiosyncratic speech and generalized clumsiness with motor skills.

ADD:(ADHD - new DSM designation making the terms interchangeable) a central nervous system developmental disorder that impairs one's ability to sustain focus and to retain (immediate memory) information.

Another way to look at this is to diagram what is similar about all three diagnoses:

Diagnosis	Central	Nervous	System	Function	Involved
	Excitation (Amygdala)	Calming (Hippocampus)	Relay messages (Thalamus)	Immediate Memory (Temporal Lobe)	Motor Planning (Cerebellum)
Autism	X	X		X	X
Aspergers	X			X	X
ADD	X		X	X	X

From this chart it is easy to see the similarities. All three of the children (with these diagnoses) are excitable, with short-memory and motor planning concerns. Autistic children are able through self-stimulatory repetitive behaviors to calm themselves while it is more difficult for the other children to do so.

The Autistic Child:

The challenge with the autistic child is to get them to use techniques that are both productive and calming, and that is where occupational therapy comes in and is so essential for these children.

Autistic children "look" OK. There is nothing that distinguishes them from other children - except behavior. And precisely it is the charting of behaviors that aids in their diagnosis.

However, out in the "real world" I have noted that these behaviors, which usually are unfiltered, look like "misbehavior" to the untrained eye. I saw an autistic child have a meltdown by the baggage collection at a large metropolitan airport. And I saw a perfect stranger come over to the mom and admonish her for not being able to "parent her child better".

Teaching these children to self-moderate is a major challenge in raising a child with autism. If we refer back to the chart excitation is both an action and a reaction with these children.

The ADD/ADHD Child:

Since the new DSM-IV (Diagnostic Statistical Mental Health Manual) the terminology has melded into being "ADHD".

What research has found is that whether the child is *overtly* hyperactive or not, the brain is being *physically* hyperactive.

These children are also excitable, but it as if once one has turned on the "on switch" they do not know how to turn it down. Self-calming does not work with these children. They need to actually change what they are doing and be re-directed into alternative activities.

Earmarks of a child with ADD are that they are often:

- Impulsive
- Forgetful
- Restless to the point of disruption
- Prone to fail
- Unable to follow through on tasks
- Unpredictable
- Moody

These characteristics put them at risk for:

- Impaired learning ability
- Decreased self-esteem
- Social problems
- Family difficulties
- Potential long-term effects – such as having to repeat courses in school (not because of lack of knowledge but because they could not retain the information they needed in order to pass; not being able to sustain themselves in one job for a significant amount of time; difficulty making commitments; etc.

What is unique about these ADHD children is that they often find themselves in negative situations and literally have no idea how "all that" happened. Their erratic behaviors become a self-fulfilling prophecy of being the "bad kid". They seem to lack a sense of what is right and what is wrong, living in the moment because attention to the past and projecting the future are not possible especially for the young ADD child.

These are the kids that tend to use "stock and trade" answers to such questions as "why did you do _____? Often responding, "I don't know", "I wasn't listening", and even a more truthful "huh?"

Learning introspection is hard for all children, but for ADD children it has to be taught, re-taught and taught again.

Establishing routines is critical for the ADD child. Changes are not easily tolerated and responses are often explosive. These children tend to be either defensive or oblivious.

But they are natural adventurers, spontaneous loving and often highly creative. The challenge is to channel those qualities so that they can be called upon to problem-solve and to sustain the child in typical life demand situations of home and school.

Children's Special Services, LLC in Atlanta, GA has a US trademarked outdoor sensory program called S.H.I.N.E.TM - Sensory, Hiking, Independence, Novel Experiences that takes 10 children with 5 therapists out into the state parks for high ropes, hiking, rock climbing, canoeing and more. In these out-of-the box environments children learn to act, react and interact with guidance and structure in unfamiliar situations.

The importance of novel teaching situations is cited in many articles about positive ways to effectively teach these "Triple A" children. The importance of outdoor activities, the use of "green space" and more is becoming more popular as alternative learning environments.

At a recent research project conducted at the University of Illinois Human-Environment Research Laboratory suggested the following specific activities for children with ADHD...however in reviewing the list I found it to be applicable to all three diagnoses.

Some of the recommendations of this study were as follows:

- **The more natural and open your surroundings, the more your symptoms will improve.**
- **In other words, you benefit more by exercising outdoors in the city park than working out in an indoor gym. (But if a gym is your option - use it!!)**
- **But you benefit most of all by days spent fishing or hiking in a wilderness area. (or basketball, golf or some other sport that can be played by 2)**
- **Activities for children with ADHD... interestingly enough, the Illinois team found that attention deficit disorder children benefit by having a view of nature outside their windows.**

- In one study, children who had a tree or park outside their windows at home actually got better grades than children did whose windows looked out on a parking lot.
- There may also be some benefit to listening to tapes of natural sounds like waterfalls and trees as well.
- Try to spend as much time as possible outside in natural settings.
- The best way is to break up your day with time spent outdoors. (A good argument against those schools that want to do away with recess!!)
- You and your ADD ADHD child can have your lunch in a park. Take a jog along a lake in the evening. (A "lunch bunch" group at school, weather permitting may be a great idea! And how about building new schools with an atrium!!)

And may *I* add, perhaps as a non-sequitor, that parents limit computer time with their children! This is good advice whether or not your child has special learning issues or not! The number one issue impacting learning in the USA is not ADD. It is not Autism. It is obesity! Too much time spent in front of the computer playing games and having "virtual" experiences.

In spending so much time in front of TV's and computers we have limited our children's ability to experiment and learn vital life/social skills in low-consequence situations.

And while I neither advocate taking or refraining from medication, I thought the following information very interesting.

For parents who are concerned that medication may interfere with the ability to be active a study at Ball State University in Muncie, Indiana, Tony Mahon of the university's Human Performance Laboratory found that ..."the medicine ADD ADHD children take does not interfere with their capacity to exercise."

In deference to whatever "label" your child may have, exercise is good for *all* children! And for families with children who have autism, it breaks the mold of repetitive behaviors. For children with Aspergers it helps create an avenue of increased capabilities. And for the ADD/ADHD child it provides an outlet for releasing energy and movement in a constructive manner.

So get up, get out, get going!

It is good for your body and it is good for your brain!

Selected References

Allison, D.B., Basile, V. C., & MacDonald, R. B. (1991). Comparative effects of antecedent exercise and Lorazepam on the aggressive behavior of an autistic man. *Journal of Autism and Developmental Disabilities, 21*(1), 89-94.

Principles and methods of adapted physical education and recreation (8th ed.). St. Louis: Mosby. Berkeley, S., & Zittel, L. (1998).

Learning Re-Enabled, Orloff Susan N.Schriber, Elseiver Mosby Press 2004

ADD, Autism, Bipolar and Oppositional Behaviors, common disorders, uncommon approaches, Susan N. Schriber Orloff, OTR/L Advanced Rehabilitations Services, Inc. Seminars, Atlanta, GA September 2008

Out of the Clinic—out of the box: the outdoor sensory experience, Susan N. Schriber Orloff, OTR/L Opening Door Conference; American Association of Pediatrics—AMA Bethesda, MD 2008

"Isn't it ALL Brain Based Learning?" The neurology of learning and the impact of OT in both clinic and educational settings" Susan N. Schriber Orloff, OTR/L Atlanta, GA Maine Occupational Therapy Association Annual Conference keynote address, September, 2008

S.H.I.N.E.™--Sensory, Hiking, Independence, Novel Experiences™ A program exclusive to Children's Special Services, LLC, Atlanta, GA CEO/Exec. Director, Susan N. Schriber Orloff, OTR/L website information www.childrens-services.com

Teaching the child with autism in physical education. *Achieving a Balance: Proceedings of the 6th National Conference on Adapted Physical Activity*. Western Illinois

University: Macomb, IL. Elliott, R. O., Dobbin, A. R., Rose, G. D., & Soper, H. V. (1994). Vigorous, aerobic exercise versus general motor training activities: Effects on maladaptive and stereotypic behaviors of adults with both autism and mental retardation. *Journal of Autism and Developmental Disorders, 24*(5), 565-576. Gillberg, C. (1990). Autism and pervasive developmental disorders. *Journal of Child Psychology and Psychiatry, 31*(1), 99-119. Huettig, C., & O'Connor, J. (1999).

Wellness programming for young children with disabilities. *Teaching Exceptional Children, 31*(3), 12-19. Kitahara, K. (1984b)

Positive behavior management strategies for physical educators. Champaign, IL: Human Kinetics. Quill, K., Gurry, S., & Larkin, A. (1989)

Rosenthal-Malek, A., & Mitchell, S. (1997). Brief report: The effects of exercise on the self-stimulating behaviors and positive responding of adolescents with autism. *Journal of Autism and Developmental Disorders, 27*(2), 193-202.

Weber, R. C., & Thorpe, J. (1992). Teaching children with autism through task variation in physical education. *Exceptional Children, 59*(1), 77-86.

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.

**"Sounds Into Syllables®"
by Kayla Cornale**

<http://www.soundsintosyllables.com/>



Most people have a friend or family member living with autism, and I am no exception. I have a twelve year old cousin who is diagnosed with an autism spectrum disorder. Watching her at family gatherings sparked a desire in me to help her find a way to cope with her autism.

As the second eldest of thirteen cousins, I saw how difficult it was for her to communicate and interact with the twelve other children. I thought that if she could learn to read and spell, it would help her to participate more fully in the world around her.

I created a music based teaching system called "Sounds into Syllables®", which is designed to assist children like Lorena with communication and social development

difficulties by teaching them how to spell, read, classify words and correctly identify the facial expressions for six universal emotions.

In February 2004, I began working with Lorena using "Sounds into Syllables.®" My goal was to teach her the alphabet and a series of animal nouns. The teaching system is music based, so her initial fear of the piano keys made me skeptical of any progress.

However, as our lessons together continued and she overcame her fear, I was thrilled to observe tangible improvements. In only four months she had learned the letters of the alphabet, eight nouns and her own name.

Throughout my 4 years in high school I continued to meet with Lorena and she continued to master new words. She ultimately learned all 26 nouns in the animal book and went on to work with the next part of the system which pertained to verb and adjective acquisition, simple sentence construction and emotion recognition.

I am now entering my sophomore year at Stanford University so I am no longer able to meet with my cousin as I did in high school; however she continues to use the system at her school.

Drugs vs. Diet
By Barrie Silberberg

Author of "The Autism & ADHD Diet," Sourcebooks, Inc.



What if the big pharmaceutical companies went out of business because their "star" drug was proven to cause serious and irreversible damage to the human body? What if a change in diet could not only do what the damaging drug was doing, but went several steps further to create a healthier, improved, happier and content body? What if paying a bit more for natural food, rather than supporting the big drug companies, actually lowered your child's overall medical bills and gave you back the child you dreamed about having, so many years ago?

This is not a fictitious story. It is fact, proven the world over,

with success rates at over 70 %, perhaps even higher, with no ill side effects, no health risks, just by eating real, natural, chemical-free food.

I am talking about changing your diet to be gluten free, casein free, dye free, preservative free, chemical free and perhaps also soy free, yeast free, sugar free and maybe even removing some other commonly eaten foods. Some children have allergies, but more have intolerances to the aforementioned foods.

Do not think of it as "taking away" these foods from your child. Think of it as substituting other foods that can make your child feel better, look better, behave better, perform better and fit better into typical environments without an incidence.

It can be done and has been done across the globe, by thousands of families affected by Autism Spectrum Disorders, ADD/ADHD and other disorders.

It may sound crazy at first, but after some detailed research into this amazing phenomenon, you, too will see what thousands of other families see on a daily basis....a miracle.

For more information go to www.puttingyourkidsfirst.com.



Mark Romoser was diagnosed with autism at the age of 4, by the renowned Dr. Leo Kanner.

After attending eight different schools and two colleges, he became a *cum laude* graduate of Yale in 1985. Mark has worked with top researchers in the autism field, including Dr. Fred Volkmar at Yale. He has also worked for Columbia's

child psychiatry department, as well as operating a multimedia computer laboratory for a small private school in Manhattan that primarily serves children with autism.

Most recently, Mark has been involved at Hawaii Centers for Independent Living doing legislative advocacy and creating the Aloha State's first self-advocacy network.

In this process, he has worked with people who have many different disabilities, from every major island.

Mark has presented on his personal experience with autism for nearly fifteen years, primarily on the East Coast, but also in the Midwest, Canada, and most recently in Hawai'i.

Nobody Knows
by Mark F. Romoser

What exactly is it that people with autism can't do, anyway? I have worked in the field of independent living for nearly eight years now, so lots of my friends have disabilities of one kind or another.

Charlene is blind. She can't see. So she has a beautiful black Lab for a guide dog. Cheryl is deaf. She can't hear. So she uses American Sign Language, the language of instruction at her alma mater, Gallaudet University. Lillian's legs won't support her. She can't walk. So she uses a wheelchair. But what can't we do? Nobody knows. And because of that, nobody knows just what to give us in place of the guide dog, ASL interpreter, or wheelchair. So why not focus instead on what we can do? Take me, for instance. I can plot trips on public transit in about fifteen different cities, including a few I haven't been to for years. I can spot a typo on a page before I have even read the sentence in which it occurs. I have even spotted typos in Spanish! (I speak at least a bit of four languages, one of which is Hawaiian.) I can name seven or eight Israeli political parties off the top of my head. And I've never even been to Israel.

If there's information I need out there on the Internet, I can find it in minutes (maybe a half hour on my slow dialup connection at home). And whenever a neurotypical's computer hangs up, guess who s/he comes to for help?

People who are deaf-mute, that is, cannot hear or speak, used to be called "deaf and dumb". Why? Because for centuries, hearing people thought that those who did not respond to their speech could not understand them. It wasn't until the 18th century that it finally dawned on them that maybe these others simply could not hear them. Think of all the Deaf people throughout history who never got the chance to invent the Internet like Vint Cerf, or win an Oscar like Marlee Matlin, all because nobody understood that they weren't "dumb", but simply could not hear. I guess it isn't the Deaf people who are "dummies" after all!

And now with more and more people growing up with autism around the world, it's time for the real "dummies" to figure us out. I am as prone as any neurotypical to "taking the easy way out". Problem is, when it comes to dealing with us, "the easy way" is to stick their heads in the sand and pretend we don't exist or shunt us into "malemployment", a term I coined years ago to describe low-skill jobs such as those in fast-food restaurants that not only don't take advantage of our skills, but put undue pressure on our sensory and nervous systems. To actually work with me, and take advantage of my Ivy League education, technology and policy skills, and vast storehouse of knowledge might actually require effort on the part of a neurotypical employer, in order to handle my rather unusual way of relating to people and events. And we can't have that, now, can we?

I just heard from no less an authority than Lee Grossman, president of the Autism Society of America and himself father to a young man with autism, that we on the autism spectrum have a 94% unemployment rate. You read that right. 94 %. He even backed up that claim with figures from the National Autistic Society in Britain. And of that remaining 6%, I imagine many are underemployed or as I just mentioned, "malemployed". After hearing this, I made sure to hand Lee my business card, since apparently I am one of the few people on the spectrum who has one, yet.

Now and again, one hears figures like "each person with autism will cost society over \$3 million". Really? \$3 million?? I think I might just possibly have the solution for that. To paraphrase Cuba Gooding Jr., "Show me the money!" All society has to do is give me the \$3 million up front, and I'll invest it in nice, safe, tax-free municipal bonds, the interest from which will support me in the lifestyle to which I have become accustomed. That way, society is relieved of the apparently unbearable burden of caring for someone like me - and I am relieved of the necessity of trying to conform to whatever it is that society expects me to be. It's a win-win, all the way around!

I imagine most of you reading this have the same hopes and dreams for yourselves as any neurotypical does: a decent job, a home, a family, maybe some cats or dogs: in short, a fulfilling life. My friends with other disabilities all have those things. So why don't we?

Nobody knows.



The following are all thoughts by Sharisa Joy:

In the greater scheme of things that be,
I'm the only one who needs to be ME.

A war between the sides of my brain
Is often the cause of incredible pain,
But I survive and will get through
Because that's what I have to do!

Have you ever really noticed folks around you?
Have you ever really pondered what's inside?
Have you wondered if the face you see
Is the one that's meant for you and me
That masks the one they simply choose to hide?

If I had a voice, I'd tell the world...
To listen and understand
That being non-verbal and being stupid
Don't always go hand-in-hand.



Darcy Reed

Darcy means "dark and mysterious." Clarisse means "clear and light."

Truly, she is both. In her waking world she is Darcy living on the "severe" end of the autism spectrum, without speech, with different behaviors, differently "wired."

In her dream world she is Clarisse, a famous artist and poet who speaks and has typical behaviors. Luckily, Darcy is able to type with facilitated communication and to paint independently.

In either world, Darcy is a visionary and a genius.

Darcy Clarisse Reed
Poems and paintings
Contact Darcy:
savantness@yahoo.com

War

**Grey brown and red
dark shadows
oppressively read the news
people buried the dream
too deep for tears to react**

**Bewildered in sand
wearing their grief
in tatters,
eyes raised heavenward**

**Peace had no chance
to breathe in red
puddles of war
all hopes
into the sea at last**

**Inside rubble
bodies hold each other
forsaken finally
by their god**

Ghost children scream

**for revenge in the night
Peace never comes.
I Paint My Dreams**

**1.
I paint my dreams
in blue and white**

**2.
My life in green
too dark to see**



**3.
Only purple interrupts
pure possibilities
edges discrete
in faulty shadows**



**4.
Red not enough
in turquoise vortex**

**5.
Orange waits indefinitely
for pink but it never comes.**

**6.
Growing instead
fuchsia petals
against white snows.**



7.
**Purple inside purest
of gold holds orange
hostage at last.**



**Soul cries among
green wastelands
of misunderstanding
into purple night visions**



**I scream too loud
in silence
at the wonder
of the joyous night.**



Tim Academy's Best Practices in Training Autistic Support Teachers
By Judy Horrocks, Ed.D.
Laura Roberts, Ed. D., and Wendy Moran

My colleagues and I spend many hours in public school classrooms observing, evaluating, and honing the skills of autistic support teachers. The following scenario is typical at the beginning of our work with a new teacher.

Ms. Taylor seemed excited about her first day in a special education classroom dedicated to students with autism. Although she had three years experience in special education, she had not worked directly with students with autism. Upon accepting the position, she had read several articles about autism and reviewed all of her student's Individual Education Plans (IEP). She felt prepared to meet each student's individual academic needs. She was also encouraged by the fact that she would have an assistant in the classroom and one of the students would have an aide.

The students began to filter into the room. Sarah was the first to arrive. As she entered the room with her aide, Ms. Taylor cheerfully said, "Hi Sarah, I'm Ms. Taylor!" Sarah repeated, "I'm Ms. Taylor. I'm Ms. Taylor", over and over in a harsh mimicking tone.

A look of disappointment flashed across Ms. Taylor's face, but she persevered. When the other students arrived, she changed her tone to be more business-like. On arrival, Tommy was immediately upset with Sarah's noises and started to cry and flap his hands wildly. The

teaching assistant successfully quieted both Tommy and Sarah with the offer of puzzles. Eventually, all six students were sitting at the table playing with puzzles or Legos, or coloring.

Ms. Taylor had planned a small group to begin each day and it was time to get started with instruction, so she asked the assistant to help get all the students seated in a semi-circle. The students did not want to stop playing and several began to cry and resist removal of the toys. One student left the play area and went directly to the sink and began to play in the water.

Another student hit the child next to him in frustration, which in turn caused that student to begin to cry. The noise level was deafening and the room in chaos. Ms. Taylor and her assistant were both trying to gain control when Ms. Taylor noticed Sarah's aide sitting idly next to Sarah at her desk. When asked to help get the rest of the children prepared for group, she responded her job was only to work with Sarah. Ms. Taylor quickly realized her plans for morning instruction weren't going to work.

Unfortunately, this isn't an uncommon scene for beginning teachers in an autistic support classroom. Often, teachers are overwhelmed with student behavior issues and find themselves managing behavior all day instead of teaching. With proper training,

mentoring, experience and knowledge, however, an autistic support classroom can run effectively and efficiently. When teachers gain expertise and training specific to issues of autism, things go much more smoothly. For example, the following scene took place in a classroom at the Timothy School, which focuses specifically on the needs of children with autism.

On the first day at Timothy School last September, students were greeted at the door by a team of teachers and assistants. Everyone looked eager to see the new students and greet old friends. Each student was escorted to their classroom and allowed to play until everyone arrived. When it was time for the morning group activity, each child was told "Check your schedule." Students moved independently to their schedules and found the top card with a picture of the group activity they were supposed to go to first. They were then prompted, if needed, to go to the group area and find a matching picture. All students were guided to sit down and instruction began.

Teachers who understand communication deficits of children with autism provide visual cues to assist with instruction. This strategy has proven effective because it keeps students' attention and provides non-verbal students with a means to actively participate. What made the difference? Special education teacher preparation classes often don't equip autistic support teachers for the challenges of this population.

There are numerous educational methods described in the literature. These methods include Applied Behavior Analysis (ABA), Treatment and Education of Autistic and Communication handicapped Children (TEACCH), and Picture Communication System (PCS), to name a few. Research in each method has demonstrated success for children with autism and many teachers attend conferences and workshops describing these strategies. However, many teachers struggle to apply them successfully in autistic support classrooms beyond one-to-one instruction.

WHAT CAN ADMINISTRATORS DO TO IMPROVE AUTISTIC SUPPORT PROGRAMS IN THEIR SCHOOLS AND HELP FACULTY SUCCEED? GETTING THE MOST FROM PROFESSIONAL DEVELOPMENT:

The professional development program at The Timothy School provides a good model for other schools. It includes comprehensive training combined with classroom consultation and extensive teacher mentoring. Meetings focus on characteristics of autism specific to each student and how these impact student performance.

Teachers are given the opportunity to practice newly acquired skills with guidance of experienced staff. Teachers are also encouraged to seek new information, try new approaches and share classroom successes with colleagues, promoting a professional learning community around education of children with autism. Multidisciplinary teams meet to

discuss student needs and successes from multiple perspectives. Common preparation time allows for regular communication with the entire IEP team.

ACTION RESEARCH:

We encourage teachers to engage in action research. The Timothy School administrators selected the Brigance Test, which is useful for assessing developmental levels of students with special needs, and began to collect data at the beginning and end of each year. We use the results of these tests to track student progress longitudinally and compare more recent cohorts of students to earlier cohorts. We'd also like to use action research to assess specific components of the instructional model and teacher training model. We're learning from our experiences in this effort in that we have a fairly large set of longitudinal test scores spanning several years. In fact, our analyses showed moderate to large gains in several areas, including self-help, social-emotional and academic skill. However, to truly prove a strong causal inference, we need to consult experts in research methodology so we have a clear research framework to assess internal validity of results.

Although we can't prove what caused students' documented improvements, we believe Timothy school teachers have that extra something special. They do something that's working that other teachers will want to learn.

SHARING KNOWLEDGE AND IMPROVING PRACTICE:

Our training model promotes professional collaboration essential to success in student achievement. Autistic support teachers in public schools need to develop expertise and serve as mentors within their own faculties. Typically, teachers in public schools are sent to conferences and workshops and then return to test out new-found skills in isolated classrooms.

We believe they need the support and mentoring of a seasoned peer in these moments. Sometimes, they're asked to share the conference information without the depth of knowledge needed for success. Without the mentoring aspect, any changes that occur are minimal and short-lived. To sustain positive change in the classroom, administrators need to provide continual support as teachers build skills and understanding of autism. Mentoring provides someone for question and answer opportunities, modeling and classroom coaching in which teachers learn to respond to each child's unique needs and develop classroom strategies geared towards student achievement.

Our policy is to monitor each student's progress to track successes and try to analyze causes of those successes. Teachers and mentors work together to articulate behavioral goals and objectives for each student and the mentoring process then focuses on specific objectives. An important feature of this process is that we write student behavior programs designed to teach

new skills, not just prevent problem behaviors for students who exhibit inappropriate behavior.

We then monitor student progress toward those goals. These are aspects of every good classroom; and yet, we've observed that these steps are often skipped within autistic support classrooms. Our philosophy is to raise expectations of students, teachers and parents with regard to potential of students with autism. Children with autism can learn. They need instructors with a clear understanding of their characteristics and technical know-how to make instruction more meaningful. The characteristics of autism can be a help or hindrance in the educational process. Teachers can exhaust themselves and burn-out if they try to fight certain behaviors or can learn how to turn characteristics such as attention to visual cues or affinity for routine to the mutual advantage of teacher and student. With clearer understanding of specific characteristics of children with autism, teachers learn to work with the student and raise behavioral expectations, just as they would when working with typically developing students.

**AN APPROACH TO PROMOTE
ADULT LEARNING
AND STUDENT SUCCESS:**

The Timothy School has provided training for professionals for many years as part of the school program. The need for effective staff development for educational professionals working with this population has grown tremendously so we established The TIM Academy

to address the need. The TIM Academy's most effective training model includes time working directly with students applying new knowledge and skills immediately. Teachers learn best when provided an understanding of theoretical background, opportunity for implementation and time for reflection. This is accomplished through workshops that include demonstration classrooms or staff development programs followed by direct consultation. Teachers implement new strategies and have access to immediate feedback from a coach.

Students with autism are all so unique that this process needs to include student assessment. Strategies may differ from student to student as their characteristics of autism, communication skills and academic abilities differ.

There's no "cookbook" teaching method that works for all students on this broad spectrum. The mentor must have varied experience educating students diagnosed with autism to assist the teacher to provide a prescriptive program for each student.

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*Life is a field of
unlimited possibilities.
- Deepak Chopra*

*A closed mind is like a closed book;
just a block of wood.
- Chinese Proverb*

***William Stillman,
a self-advocate with Asperger's Syndrome
is a consultant, speaker, and award-winning author
of numerous books about autism.***

***For further information visit:
www.williamstillman.com***



**Acknowledging Resilience
By
William Stillman**

Elizabeth Edwards' new book is titled, simply, *Resilience*, documenting her travails, fallout, and struggle to rise to grace following her politician-husband's infidelity. Resilience is an interesting word when applied to those long-suffering and burdened by the actions (or lack thereof) on the part of others with whom we have relationships. According to my dictionary, resilience, in part, is defined as "capable of returning to original shape after being compromised."

When I reflect upon my work in human services since 1987, I recognize that individuals who endeavor resilience have not been properly acknowledged for their capability to sustain and endure.

Specifically, I'm speaking of adults who have been misinterpreted as possessing intellectual deficiency and have been segregated and virtually ostracized of any sense of authentic personhood. Instead, conformity dictates conjoinment with an archaic service system that creates incongruence in *how* it serves for implementing an antiquated service model instead of a model that respects the needs of the autistic individual. This was most prevalent fifty years ago, when the eugenics movement was in full swing, and persons deemed void, vacant and unaware were warehoused in institutional settings, but still it persists today - twisted in a slightly different form.

Recently, an article in my Sunday paper lauded the local efforts of a well-intentioned group to provide a prom for teens with "special needs." One visionary citizen reacted in an editorial, decrying this type of segregation in contrast with historic efforts to extinguish racial segregation. The special needs prom, they avowed, was not cute or precious but an infringement on the inclusionary rights of the young people involved. I couldn't have agreed more but I also wondered how many of those young people involved understood that their inclusionary rights had been violated.

It is precisely this absence of information - an entitlement of human rights - that has *created* our segregation mindset. We have fostered gullibility and naïveté in many individuals by not informing them in ways akin to the average person. Resilience comes to the fore when such uninformed individuals assert their personhood by refusing to conform to the management of others. Enforced complacency negates resilience and leads to a surrender of spirit. Those who have survived with their will intact deserve an acknowledgment of their resilience to overcome.

Neurodiversity is not a passing fad; it is a legitimate movement whose time is past due. But instead of being capable of returning to an original shape after being compromised, neurodiversity promises a new and dynamic reshaping of old paradigms such that, one day soon, the concept of resilience will lessen in priority in favor of advancing not merely acceptance but equality. And that's a given.

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THE PROM NIGHT THAT NEVER WAS By Christopher John Agro
Written: 1 June, A. D. 2009.

The evening of 6 June, A. D. 1981 was balmy but rather warm for late spring. That evening was also my high school class' Senior Prom, and whilst the vast majority of my classmates attended this elaborate, expensive affair, I remained at home with only some phonograph recordings - sorry for dating myself here! - to console me. Someone was calling my former neighbour's son, whose name is the same as my own, and that had made the pain I felt worse; finally, a limousine appeared and whisked him off to the Prom, and I was unable to partake of the festivities.

Although I have always been a shy, bookish fellow, even back then, I did show some interest in some girls whom I wanted to take to the Prom, but they all turned me down flat. Who had a boyfriend, who was going with someone else, who did not wish to go with me... the usual cruel responses from one's teenage years. What made it worse was the fact that I had no steady girlfriend of whom to speak at the time, so I asked a number of girls whom I wrongfully believed would enjoy going to the Prom with me in order to disprove the fantasy that I am homosexual; I had no girlfriend, and I refused to sleep with every girl in that school, so many of my schoolmates believed me to be gay, despite my claims to the contrary (which is correct, by the way). What really killed any hope of attending my Prom was the fact that my parents "could not afford it" (their *ipsissima verba*), so I did not go.

Ironically, my parents were (somehow) able to cough up enough money for the elder of my two younger sisters to go to her Prom three years later or so, and I really resented that a great deal. How on earth could they "not afford" to send their son to his Prom, but they "could afford" to send my sister to hers? Even now that question bothers me. As far as the younger of my two younger sisters is concerned, she did the bravest thing a teenager could do: she gathered some of her single friends - she had no boyfriend at that time - and tried to get into her Prom, only to be denied entry because they were "unattached". That really riled me up, because I thought they had every right to attend that event, even though they had no boyfriends, so that they could be with their friends for one last time before Commencement; alas, there was nothing anyone could do. The ban stood.

So, every year, on 6 June, I remember this sad event and pray for all those who never attended their senior Prom - my youngest sister included - and hope they have a brighter future at university or in the job market. I call it "The Prom Night That Never Was", because for me it was not a Prom Night, but a sad day in my life. I even cried myself to sleep! I have also been calling for the abolition of the event based on the fact that it has become a modernised version of a Roman orgy, complete with illicit sexual activity, drugs, underage drinking, and other illegal activities. But the tradition has still remained, and the orgy continues in my hometown on a yearly basis.

Autism Hope by Leeann Whiffen
Author of
*A Child's Journey
out of Autism*



I still remember the brown and red flecks in the carpet and stale smell of the room I was sitting in when my son Clay was diagnosed with autism right before his second birthday. The sudden wave of sick that washed through my stomach after hearing he was functioning at the level of a nine month old baby almost swept me out of my chair. My son didn't know who I was. He didn't look at me or have any connection with me. I thought his fate was sealed with that one word - autism. Then I started reading stories from other parents. I attended conferences and researched treatment options. My hope for our son swelled and ultimately manifested itself in a resolve to fight to the end - as many parents experience. It gave me the energy to keep plodding despite the days I yearned for him just to look at me. Upon receiving an autism diagnosis, many emotions and words come to parents' minds. For some it's grief and denial, then depression. For

others, it's the relief of finally having a name that propels them into action. Hope often comes later, a product morphed from those initial feelings. At some point in the process, hope often takes root and becomes deeply intertwined with the soul.

My son ended up being one of the lucky ones. He was re-evaluated before kindergarten and no longer met the criteria for an autism diagnosis or any diagnosis on the autism spectrum. Today he is eight years old and not even his teacher knew he had once been diagnosed with autism.

Hope for autism doesn't necessarily mean hope for recovery. As David Kirby once wrote, "Recovery from autism may not be desirable for everyone. But it is possible for many. And for the thousands of loving parents that I have met all over America, it is the most joyous, desirable thing in the universe."

I posed the following question on Facebook: "What are your hopes and dreams for your child with autism," and I watched the replies come quickly and passionately. Here's one mom's response:

"When my son was first diagnosed, I kind of abandoned a lot of dreams...college, wife, kids, etc. Now, as he evolves over the years, I can see some of these dreams coming true. I

once dreamed, rather selfishly, that ... my son would be an Ivy League student, would play football, have tons of friends, be president of the class, etc. He is now 11 and in the fifth grade. He is a savant in math, science and history. My dreams of him loving learning have come true. I prayed that he would "just" speak and he does. Now I can't shut him up."

Hope is celebrating who our children are - even beyond autism - and who they can become. We'll do everything we can for them, even if it is the small, but significant victories we find ourselves celebrating.

"That he will tell me he loves me."

Opinions in the autism community are about as unique as the individual fabric patterns and strategically placed shapes in a patchwork quilt. But having hope and a deep desire for our children to be happy is something with which we can all agree.

"We just want him to be happy. However he wants it just to be happy. I realize how selfish I was to have all these dreams for him and who knows if those dreams were his. Just to be happy. Isn't that all any of us want?"

Some kept it real. There are days your ears might ache to hear their voice. Other days your ears ache because you're hearing their voice.

"Just one day without screaming would be really nice too."

My fellow author and friend, Chantal Sicile-Kira, has a son with autism in his early twenties who communicates by pointing to letters. She wrote, "This morning my son woke up with a huge grin on his face. At breakfast, I asked him why he was smiling and he spelled out, 'I had a great dream.'"

I asked him if he wanted to elaborate. He spelled out, "In my dream I could talk."

"Really," she replied.

He spelled out, "Yes. In my dream, I wanted to talk, and you told me if I wanted to, I could do it. So I did."

So I did. So I did, Mom, because you told me I could do it. Though hope can be defined in as many different ways as our kids display autism symptoms, we do know this: Hope for autism is a belief in our children, so strong, so unwavering, they feel it, think it, and they do it.

Because we told them they could.

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



Travis Breeding Bio:

Travis Breeding is a 24 year old from Fort Wayne, Indiana. Travis was diagnosed with Asperger's Syndrome at the age of 22. Currently Travis is pursuing a bachelor's of Music Education along with a bachelor's in Trombone Performance from Indiana University.

Travis has just recently really begun to embrace his diagnosis and is starting to see it as more of a gift than anything else. He remembers sitting down and reading Dr. Attwood's book "The Complete Guide to Asperger's Syndrome" and feeling like he was reading a book that someone had written about him.

Today, Travis is in the process of writing his first book, "Living without Knowing Who You Are, Unlocking a Diagnosis of Asperger's Syndrome." He is also working hard to organize and establish a foundation called "Educating the World about Autism with Our Special Interests. Travis is currently actively pursuing speaking engagements across the Midwest as well as the rest of the country. He has a story to tell and he believes that it's crucial everyone hear it and not just people who are on the spectrum. Travis' goals are to create camps that combine special interests along with autism education for individuals both on and off the spectrum to attend to learn more about each other.

Travis also has a goal of one day turning his book into a movie and a Broadway musical. It is his goal that in doing so, more people will be able to be reached and educated. One day soon, Travis hopes that it will become possible to take that Broadway music on tour and perform at Elementary Schools, Middle Schools, High Schools and Universities across the country and the world. If you're curious in learning more about Travis please contact him at: travisbreeding@gmail.com or by visiting his website at www.travisbreeding.webs.com

He would love to hear from you!

“Living Without Knowing Who You Are, Unlocking A Diagnosis of Asperger’s Syndrome” is a book that I decided to write to help give other adults with Autism Spectrum Disorders an inside look at what it can be like to grow up and live with AS. But more importantly, I wanted to write this book for parents of kids who are on the spectrum to help give them some insight as to what they and their child may experience when their children grow up and become young adults.

This book is written by an adult who is living with Asperger’s syndrome and has experienced everything that comes along with having AS for many, many years. It is my goal that one day we will have a lot more resources available for adults and that we will continue to get better at diagnosing Autism Spectrum disorders in early childhood. It is crucial that the diagnosis comes very early in life so that one can spend lots of time learning the basic communication skills necessary for survival.

As we all know, autism spectrum disorders are not something that are taken lightly. Everyone who has an autism spectrum disorder experiences it to our own degree and level. In this book, you will see firsthand how Asperger’s Syndrome has affected me and my life. I was one of those who had a late diagnosis. I got diagnosed in the fall of 2007. I was 22 years old at the time and getting the diagnosis was somewhat of a relief but at the same time it was somewhat frustrating. While it’s great to know that you’re not just some crazy psycho roaming around the world and there’s actually something pretty severe in nature wrong with you, it can also be overwhelming to realize that there’s really not much that can be done as far as a cure or making it go away. You will now realize that you have a lot of work ahead of you.

In this book you will see real life examples from my life. I think that the bad things really stand out and I tend to focus on them quite a lot and therefore it’s made it easy to remember nearly every detail and to pass it along to you today. While I must admit there have been some good things that have happened in life; unfortunately, none of those have ever had anything to do with social relationships.

Just recently, I’ve had the pleasure of meeting a couple of women who have experience in the Autism world. I’ve met Kara Skaggs (Who runs an Asperger’s support group here in town, as well as Sue Christman (who works for an agency that provides assistance to people with disabilities. I would highly recommend that if you are an AS individual that you get hooked up with a support group and also make connections with as many people as you can so that you can get the best available help that’s out there. I’ve found that there are people that care; you just have to do the research and find them. As a person with AS, it’s very important that you have at least one or two people who fully understand what autism is and what you’re going through on your side. I cannot stress how important it is for you to find or have that one or two people that get you and understand you that are willing to listen to you and provide assistance in any way in which they are capable of doing.

Unfortunately for me, I didn’t know of the support that was out there when I was first diagnosed with Asperger’s syndrome. I got diagnosed in October of 2007 and spent about a year or so just saying “Ok, what now? What do I do? I don’t fit in

and I don't know how to." I continued trying to attend school and obtain employment and it just wasn't working out. Finally, in late March or early April of 2009, I got lucky and something turned up. I was able to find out about the Asperger's support group that was meeting at a local hospital here in town and I became very interested in finding out more about it. I called Kara and I learned that the next meeting was only a few days away. I knew I had to attend if I was going to have any chance at succeeding in life.

On Monday, April 12th, 2009 I was able to convince myself to go to the meeting. I will admit that it was extremely difficult to go to the meeting. I kind of figured that I'd probably end up just sitting there and listening to everyone else talk since it was my first time there. Somehow, that's not exactly what happened. They had actually had the meeting set up that evening so that siblings of people with an AS diagnosis were speaking and answering questions on what it was like to be a sibling to someone on the spectrum. It was very insightful to me. As the night went on, to my surprise I was able to contribute to the conversation and had some parents of AS kids asking me questions and wanting to learn about me. I feel that I really put myself out there and provided a lot of valuable information to those parents that night; however, there is still so much more to get out there to them.

Through the meeting on April 12th of 2009 I was also able to make the connection with Sue, who can help people on the spectrum obtain benefits and provide all kinds of valuable resources and information. To my surprise, there are several resources available to all of us on the spectrum and I highly recommend that if you have AS you should take advantage of all of the available resources. If you do not know of any resources available in your area, please Google it and find out.

Today as I write this, I am still very much in the process of figuring out the resources that are available and learning about Asperger's Syndrome. It's kind of like Asperger's in itself has become some sort of a special interest for me. Maybe there's nothing wrong with that at all because in all actuality, I'm learning about myself and I am my special interest. We cannot learn to interact with others until we have learned how to interact with ourselves and be happy with whom we are. What you are about to read in this book are the events which have happened in my life that have gotten me to where I am today. These events are and will always be a part of my life and have made me who I am today. I hope that I can continue to grow and become better aware of communicating with NT's. There is so much to learn. At the same time, I hope that I can help better prepare you, the reader (parent of someone on the spectrum or if you yourself are on the spectrum) become more educated on what it might be like for an adult to live their life with an Autism Spectrum Disorder. Please note that I am telling my story and while a lot of the events that have happened to me seem pretty bad, I tell you this not to discourage you but to provide an education and encourage you to seek help and prevent as much of this from happening to you, your son/daughter, or anyone else you may know who's on the Spectrum.

The Invisibility of Asperger's Syndrome

By Travis Breeding

Recently, I was speaking to a group of people. I thought that I would try a little experiment at the beginning of my presentation. I asked for volunteers to raise the hands and tell me the first word that comes to mind when they look at me. As you might imagine, I received many interesting answers but I didn't hear the word "Autism" or "Asperger's."

I was not surprised by this either. I was simply doing this little experiment to prove a point. Asperger's Syndrome is one of if not the most invisible disabilities that exist. Asperger's doesn't interfere too much with anyone's physical ability or characteristics. You will not be able to meet someone with Asperger's and simply say hi to them and talk to them for 30 seconds and tell that they have Asperger's.

In fact, Asperger's is so invisible that you will most likely not be able to tell if someone has it or not until you've spent some time trying to develop a social interaction with them. This is where you will see the first signs of "awkwardness" appearing in the aspie.

This is something that can be very frustrating for both people with Asperger's and Neurotypical individuals. Sometimes I've often wished that I had something in which people could just look at me and then be able to tell that there's something wrong with me. I have thought that my life would be much easier if someone could look at me and see that I had a broken leg or something.

This isn't the case though, as I have two legs and two arms and am quite capable of taking care of myself. The problem that I have is what we like to call the missing link or that one missing piece to the puzzle. I've gotten to the point in my life in which I'm quite comfortable with having Asperger's - in fact, I often feel that it is a gift and can be a really great quality. Sometimes, though, one of the most frustrating parts is how people just create such negative judgments and form negative opinions about us.

Because Asperger's is often so invisible, especially in someone who is "high functioning", it's nearly impossible to tell that there is something wrong with them. People will quickly form the opinion that you are some sort of a weird psychopath if one isn't capable of conforming to the society's social norms. I've heard names such as psycho, creepy, weirdo, stupid, dumb, and many more.

There have often been times in which I've tried to talk to people and because it's hard for me to read the social cues and know when it's appropriate for me to say something or not I get made fun of or told that I'm an idiot.

I really struggle with knowing when it's my turn to talk in a group. It seems like everyone has this whole group interaction thing all scripted out. Like, sometimes I wonder if NT's don't meet up in a group or something somewhere else before I am with them and script out this conversation in which they will know what to say, exactly when and how to say it, as well as with whom to make eye contact while they are saying it.

I will become so lost and confused about the way in which they are interacting with each other that I won't even be able to take anything away from the conversation. I will quickly become exhausted by it and move on to the next group of people to try and fit in. Sometimes, it's as if I am playing musical chairs, but only with social groups instead of chairs. Eventually in social situations, I'll find that I've tried all of the chairs and there isn't one left for me to sit in so I'll give up and begin to withdraw myself. This means withdrawing myself from society and creating my own little make-believe world with imaginary people in it who I know won't judge me or make fun of me simply because I've created them.

Unfortunately, sometimes when I am in this "make believe" world that feels so comfortable and safe, it can become challenging to even force myself to come back to reality and enter the real world.

I've learned that real peers (people my age) in the real world equal instant pain and stress as well as rejection, which can lead to so many things; and at times in the past for me has led to thoughts of suicide and even a suicide attempt. When you feel as if there's no one to relate to, it's easy to lose hope and become negative and quit trying.

In the past, I've often had thoughts of "No matter how hard I try, I always get rejected, made fun of, ridiculed, or taken advantage of." I've learned to deal with all of those things, though, as they are just something that I have to endure every day. I'm trying to get over this still to this day, but it's like I almost go out expecting bad things to happen to me because of this. In fact, I'm often surprised when someone tells me they want to talk to me without asking me to pay them money first.

What I haven't really come to grips with yet, however, is the bullying. I still remember it quite clearly to this day. I was twenty, so the year would have been 2004. I was trying really hard to develop a friendship with a coworker. He told me that I could hang out with him and his group of friends if I paid him \$100.00 per month and bought all of their food and drinks when we were out. So out of desperation, I said okay. Later on, as we were beginning to hang out, he told me that I had to go through the group initiation. So I said okay, thinking no big deal, right.

I couldn't have been more wrong. The group initiation ended up being me getting tied to a tree. It was supposedly a custom for anyone

who wanted to be friends with him and his group of buds to get tied up to a tree and have a chance to prove how tough they were. He said if I could withstand the pain for a half hour I could be a part of their group.

I would encounter being hit, punched, kicked, and even have a couple of baseball bats swung at me by those guys. Unfortunately by that point it was already too late for me as I was tied to a tree. Eventually, after a half hour was up, they let me go and said "welcome to the group."

I was so desperate for friendships that I would often put up with this type of thing simply because I needed friends and these were the closest things to friends that I had (except for the imaginary world friends).

I just began to expect to have to endure physical pain and emotional pain every day as I thought that this was how it had to be for me. In order for me to have friends, I would have to be hit, punched, kicked, and have bats swung at.

To this day, I am still struggling with some issues. Luckily, the physical abuse part has diminished quite a bit due the fact that I'm a little more aware and bigger now. However, I still have people tell me they will hang out with me if I pay them significant amounts of money; and yes, girls tell me that they will go on a date with me if I give them money or buy them new televisions or something they need. I would love to just be able to ask a girl on a date and have her tell me "yes", without asking or telling me I'd have to buy her something just to get to talk to her.

To this day, I still can't make myself tell someone "no" if they tell me that they will hang out with me if I pay them \$500.00; immediately I start trying to come up with money. I can't say no because I need real social interaction and friends. Having money to pay guys to hang out with me and girls for having coffee with me has become in a sense, a source of survival.

After enduring everything that I have, I've decided that I have an obligation. I have an obligation to tell my story so that other people won't have to go through something like this; but more importantly, so that the little five and six year old boys and girls who have autism or Asperger's now will be better prepared and aware of situations like this that may develop when they become teenagers and young adults. I feel that it's my duty to help protect them.

Therefore, it is my goal to turn Asperger's Syndrome into one of the most visible and recognized things in the world. Notice I didn't say the most recognized "disability" in the world, because disability is something it's not. There are very intelligent people with Asperger's and Autism. It's the problems that we encounter because of people that misunderstand us that cause us to become disabled.

Russell Lehmann

I am 18 years-old and I have high-functioning autism. I was born in Seattle, Washington, and moved to Reno, Nevada in October of 2007. My favorite thing to do is work out and play football/basketball. I live with my parents, and I have a sister who attends The University of Nevada at Reno.



THE STRUGGLES of AN EARLY LIFE

My name is Russell Lehmann and I am 18 years old. My doctor diagnosed me with high-functioning autism when I was 12. The most problematic things in my life are OCD (Obsessive Compulsive Disorder), anxiety and depression.

Living with OCD is extremely tough. A few years ago, it took over my life. Everything I looked at I would have to look at again, in duplicates of four. I believed that if I looked at something an odd number of times, my family and I would be struck with bad luck.

If I did look at something an odd number of times, I would be overwhelmed by what I call “intrusive thoughts,” such as family members dying, our house catching on fire, and so forth. Once these thoughts entered my mind, I would become very depressed. When the depression hit, my OCD would become even worse. All of these things put a ton of stress on me. My whole life seemed like it was fading away.

I have also had a share of panic attacks in my life. Well, actually a ton of panic attacks. In the third grade, I stopped attending school. The only place where I felt comfortable was inside my home. It was very difficult for me to go outside. I never went back to school that year. This event repeated itself for the next two years.

I had isolated myself from the world. I lost friendships with all of my friends because I was afraid they would ask me why I wasn’t at school. I did not like talking about it. Whenever I was in a big crowd of people, my whole body would shut down. I was a victim of sensory overload.

When I finally received some help, it was amazing how fast I recovered. On February 3, 2003, I was admitted to the psychiatric unit in Children’s Hospital. The next five weeks were the toughest weeks of my life. When I was discharged in March, everything I experienced was great, compared to the atmosphere of the hospital.

I have since regained control of my life. I lowered my OCD to the lowest it has been in a very long time, and I have learned many coping methods to deal with my anxiety. Currently, I am enrolled in a virtual school through my computer, and am a starter on my high school varsity football team.

This story was difficult for me to write. It is intended to spread the word about autism and to let others know what it is like living with it. I also hope this will help you understand more about autism.

The Conscience of Man

**Little do know
That inside of us grows
Miniature men
Who fight for our souls**

**Some good, some bad
Some sad, some glad
To most seem transparent
When ones out to gad**

**They look after our species
Though they rarely agree
On the decisions we make
For our blind eyes they foresee**

**The trouble we make
In the events we partake
Are none for their pleasure
They recognize our mistake**

**But who shall guide them?
In their troubles that stem
From the ignorant thoughts
Of their shell that is man**

**For they venture alone
In the dark they condone
They shall fight no more
Their weakness has shown**

**Free from their shell
They no longer dwell
In their shell's hollow heart
For their ship has set sail**

**A soul, unprotected
A soul, now infected
With nerves of pure ice
Is a soul, now neglected**

**The love is no more
The heart is ignored
The mind is a follower
To its master no more**

**So soon said and done
The evil has won
For in hell awaits
The end of their run**

A Day in Darfur

His name was Jabari from the city of the slain
There was no one in sight, as his body lay maimed
For hours and hours, at this spot he laid
His feelings were numb as he continued to pray
His world was now empty with nothing in sight
His body left behind, as his soul saw the light

The yard will be full, it has been full
The red crosses have been struck
Their bodies are salvaged by silk and needle
The rest is up to luck

For years it has ensued, and for years it will not pass
The flames that one encounters, is nothing new alas
All rule appears inept, the dwellers weak and frail
No hope for help to come, for the anguish is to trail

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A Dejected Life

There is nothing, nothing, my thoughts are just nothing
How could I be here, if everything is nothing
For I do not know what was, I know not what will be
My eyes look around, but there is nothing to see

I stand here alone, but how do I know
If everything is nothing, how could I know?
Why keep myself company, when there is nothing to be?
I stand here alone, for I am nothing to me

I know not what is nothing, it means nothing to me
But how do I know it means nothing to me?
All of these thoughts merely mean not a thing
If everything is nothing, then what could nothing mean?

Nothing knows me, it knows me well
How could it be that it knows me so well?
I have nothing to fear, for I know now what it means
The real meaning of nothing, is the real meaning of me

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OAARSN offers information and communication tools to connect adults with Autism, family members, caregivers, friends, support workers, teachers, administrators and policymakers. We can all benefit from the opportunities for mutual support and encouragement and the sharing of knowledge and experience. Our efforts to promote positive approaches and best practices in supporting adults with Autism can help all who live and work on the front lines.

OAARSN's focus on adult issues balances the emphasis on children in most other Internet resources about Autism Spectrum Disorders. OAARSN provides resources and links to share information about ASD, its various symptoms and types, current research, and helpful treatments and therapies-as these may be relevant to adults.

OAARSN was first launched in February-March 2000. Awareness of Autism has increased since then, with the huge growth of Internet information resources. There is still a role for OAARSN as an independent site representing all kinds of people concerned with adult Autism issues. The website has a simple and logical structure, with all features accessible from this homepage.

Autism Information

addresses questions such as:

- "What is Autism?"
- "How many people have Autism?"
- "What causes Autism?"
- "How is Autism diagnosed?"
- "Types of Autism"
- and "Autism in adulthood".

Treatments and Therapies

discusses various helpful interventions for adults.

Autism Resources

outlines the values and approaches that can support each individual with the complex needs to have the greatest quality of life. It also provides some guidance in searching for further Internet resources as well as to organizations that we have found helpful.

Creative Supports for Vulnerable Citizens

outlines the larger context and values in creating a good life for all people with a disability - including supported decision-making, independent planning and facilitation (aka brokerage of personal supports), direct and individualized funding, building community capacity, and inclusion.

Document Centre

presents links to PDF documents on the OAARSN site that may have lasting value - including perspectives on individual and family experiences, statements of helpful approaches and methods, and accounts of special meetings and project plans.

Communications Centre has six sections, to which new materials are continuously added and announced in our OAARSN and Creative Supports news bulletins.

--[Books on the Autism Spectrum](#)

--[OAARSN's Adult Autism News Bulletins](#)

--[Creative Supports Bulletins](#)

--[AROHA-Entities for Personal Empowerment and Support](#)

--[Bridges-Over-Barriers Communication Support Initiative](#)

--[Guelph Services for Adults with Autism](#)

OAARSN was developed by Elizabeth and Gerald Bloomfield, based on a lifetime of support and advocacy with our son Andrew (born 1968). Our experiences convinced us that "there must be a better way!" We have realized the importance of sharing information and strategies that may help others.

This site is dedicated to the idea that adults with autism can continue to develop and learn. They and their primary caregivers deserve all the support, faith, imagination and patience we can give them. We who are directly involved believe in this idea because we know and love our particular adults and respond to their humanity.

But even sceptics should ponder the social and economic benefits of encouraging continued development and increased quality of life.

We honour Andrew for being a brave pioneer, and his friends for their loyalty. We appreciate the dedication and ingenuity of Peter McCaskell in designing the first website in early 2000, and the support of the University of Guelph in hosting OAARSN on its web server. We thank Liana Rowlands of Guelph for working on this revised website. We value the connections made with members of the OAARSN, in Ontario, Canada and all over the world.

Contact us: OAARSN@uoguelph.ca

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Bridges-Over-Barriers Communication Support Initiative:

A creative communication group was started in 2004 by six Ontario men who live with quite severe challenges of Autism. As they do not speak with their voices, other people might assume that they have nothing to say - even that they do not think or feel. But they are very expressive on many topics, supported by AAC technology (alternative and augmentative communication) and the presence of family and friends who believe in them. The idea of meeting regularly began with one of the men, who also proposes agenda topics and acts as host. Family members and friends just facilitate the dream in practical ways - and listen! The men gather in Guelph from all over southern Ontario, and there are corresponding members in faraway places too.

The pioneers have a dream of Bridges-Over-Barriers as "a centre for friends and family who live with the challenges of autism to come together to share support, ideas and community. Bridges is the beginning of an idea for us to build on a small community of adults with autism who have been meeting a few times a year since January 2004.

We have been developing our skills as communicators and sharing technology ideas and friendship. "We want to extend this community of pioneers to include more people.

"We would like there to be more opportunities for others to benefit from our experience, and to encourage and train more people to support those of us with communication and movement disorders."

Members of Bridges share the philosophy of "People First": "Nothing about me without me" and "Though I may not speak with my voice, I have plenty to say." Friends and families of the men like the potential of Bridges-Over-Barriers to help with supported decision-making, and are supporting them to start realizing the vision.

They share a vision of helping more adults who use supported typing and other forms of AAC to express their thoughts and dreams. The newsletter (see link below for more information) contains more information on specific projects, such as a demonstration DVD, a resource manual, and an IT system designed to enhance communication among the group in both real and virtual gatherings.

Some of the men express themselves in poetry, some of which may be found in the Bridges-Over-Barriers newsletters. [In My Mind](#) is a published collection of thoughts and words (often expressed as poetry) by one of the Bridges group.

DISCLAIMER: Please note that OAARSN provides resources for information purposes only. We do not endorse any treatment, program, product or service. The contents of this website are not medical, legal, technical or therapeutic advice. Information should be reviewed with qualified professionals. We will not be held responsible for misuse of information or for any adverse effects of recommendations mentioned on this website or on any other websites linked to it. Views, opinions or announcements posted by subscribers to any area of this site do not necessarily reflect those of OAARSN and we do not assume responsibility for any discrepancies or errors.

For more info, go to:

<http://www.ont-autism.uoguelph.ca/bridges.shtml>

Brandi Roth, Ph.D.
PSYCHOLOGIST psy11855
433 North Camden Drive, Suite 1128
Beverly Hills, Ca 90210
OFFICE (310) 205-0615
* FAX (310) 275-3885
www.associationofideas.com

ESTHER B. HESS, PH.D.
PSYCHOLOGIST PSY16090
540 W. Knoll Drive, #3
Los Angeles, CA 90048
OFFICE (310) 652-7581
* FAX (310) 652-7582
www.drhessautism.com

**CHILD AND PARENT CHALLENGES AND
STRATEGIES ASSOCIATED WITH TOILET
TRAINING A CHILD WITH DEVELOPMENTAL
DELAYS**

Esther Hess, Ph.D. and Brandi Roth, Ph.D. are psychologists in private practice. They help parents develop strategies for successful child rearing including toilet training and the building of confidence in overcoming fears. In addition to treating typically developing children they also assist and have expertise with supporting youngsters with developmental delays.

Parents today have an enormous task in front of them in regard to raising children. They are forced to balance extremely busy professional careers in a fast paced world with little time and little auxiliary support from extended family. It's hard to tolerate children who can't keep up with the demands of the family schedule. If a child's own developmental time table for one of most fundamental milestones of maturation, toilet training, does not match with the timing that his/her parents have delegated for the activity, then it's not uncommon for parents to delegate out this task (Wall Street Journal, 2007). The new experts are

pediatricians, physical and occupational therapists, speech therapist and mental health practitioners. While finding the right resources of support, parents are losing the connection with their child, particularly if the child is neurologically delayed and cannot fit into the tightly woven schedule of the family. Rather than have outside people do the job of parenting, Mom and Dad, with the right tools, can regain and maintain that critical relationship with their child who delays and is struggling with the fundamentals of mastering toileting.

Most children can take in a variety of information that the world presents to them in a systematic fashion. They generally do not become overwhelmed by the amount of environmental information they need to help them understand what is going on around them. Children with developmental delays, however, are unable to take in environmental cues in the same way. They become easily confused and either retreat or pummel through life in an attempt to try to make sense of all the information that in essence is flooding their neurological systems. These children are often classified as having processing difficulties. Processing

distortions mean sensory information is taken in and reorganized chaotically in the brain. It is the inability to make order out of that jumble that brings them to the attention of professionals, and alerts teachers and parents that something is not developing in a systematic way.

If a child presents to a clinician with developmental delays the list of concerns typically includes some or all of the following symptoms:

- Inattention
- Rigidity
- Difficulty with transitions
- Difficulty with bowel or bladder training
- Hyper or hypo-activity and impulsivity
- Hyper-sensitivity to sound, light, touch
- Clumsiness associated with both small and large motor capacities
- Frequently unaware of their body and space
- Need to flee or conversely pummel through environments or situations causing havoc and little awareness of consequences of their actions.
- Physically aggressive (typically the aggression is associated with anxiety or a maladapted response to a situation where they appear to not have the tools to respond rather than with intent to do harm.)
- Difficulty with sequencing and time sense, as well as motor planning and motor follow through.

The developmentally delayed child more commonly has these additional symptoms:

- A social-emotional disconnection from primary people in their lives.

- Difficulty with maintaining direct eye gaze.
- Language delays including both receptive and expressive capacities.
- Difficulty staying on topic.
- Regulatory issues are more extreme. For example: eating (aversion to taste and texture); tactically defensive (to clothing textures); sleep issues (awakening prematurely or difficulty falling asleep.)

A MULTI-SYSTEMS APPROACH TO TOILET TRAINING:

For the task of toileting to be accomplished there must be mutuality between parent and child. This includes the parent's reflective ability to be able to see their own parenting style in realistic terms, the child's physical and developmental capacities to actually accomplish the task of going to the bathroom when a full bowel or bladder signals them and the mutual awareness of the cues between parent and child so that the messages between these two are understood.

In our practices we are aware that children take in information through a variety of neuronal pathways in the brain. Successful toilet training incorporates these different sensorial pathways so that the child can correctly read and understand the messages necessary to complete the task at hand. Parent and child are happiest when the parent presents information to the child in a way that the child can understand. Very few parents realize that developmentally a child's readiness for toileting coincides with the parent's ability to allow their child to move forward in the world. By separating out all the different ways that

children process information we increase the chances for overall understanding of what is expected. This article gives ideas to parents on how to reach the informational pathways using vision, hearing and touch as a way to guarantee toileting success.

TYPICAL BOWEL TRAINING PROGRESSION:

Getting the parent ready to toilet train:

A child's readiness for toileting coincides with a parent's ability to recognize their child's emerging independence. Before a parent can correctly read the signals for toilet readiness they have to be prepared to ask themselves five reflective questions regarding their attitude toward toilet training, discipline and about their own experiences with compliant versus oppositional behavior.

1. What are my feelings about my child's ability or capacity to toilet by himself?
2. Does my parenting ability have anything to do with my child's success or failure in the bathroom?
3. Am I able to tell the difference between my child's inability to understand my cues versus my child being just oppositional or independent?
4. How do I feel about setting limits for my child i.e. can I comfortably say "no" to my two or three old?
5. How much importance do I give to other people's opinions of my parenting ability?

If any of these questions provoke ambivalence by the parent regarding their ability or capacity to parent, then it can potentially present itself into either not

reading correctly their child's signals of readiness or misinterpreting their child's resistance as either oppositional or defiant. What results is a power struggle rather than a mutual co-regulated interchange.

If a power struggle occurs there are several choices. Parents can wait to toilet their child and give him or her the gift of time. During that time period the parent can seek some counsel with other experts to clarify in their own mind the goals and the plan for toileting success. Counseling might also include actively looking at the parent's own childhood and reflecting on unresolved history within their own family of origin. Unresolved conflicts from childhood can get reanimated in the interactions that a parent has with their child in the present. In addition there is societal pressure to complete developmental stages prematurely. Over 50% of homes in the U.S. have dual income workers. Many parents need to see their child more competent than the child truly is, in part to ease their own guilt for having to return to work. It is harder to leave a defenseless toddler at home than it is a child who is competent, toileted and ready for school.

GETTING THE CHILD DEVELOPMENTALLY READY TO TOILET TRAIN:

Parents need to understand that when a child first begins to show interest in toilet training, it may not always indicate that the child is ready. A child may have some awareness of what a full bladder or bowel feels like, but is still unsuccessful in getting him or herself to the toilet and depositing the waste appropriately. At that time we often see parents who get anxious and eager for the

next stage and may be overzealous at that point and push for toileting too fast and too soon. They may not recognize the pacing required at that level. As a consequence of the parent's anxiety the child is rushed beyond their appropriate developmental level and may regress. This is not, however, a permanent regression. Given enough support the child will readily come back to the point where they were ready to use the toilet in the appropriate sequence.

Getting both the parent and child physically and emotionally ready:

The ground is set for both a physical and emotional readiness on the part of the parent and the child when a parent has prepared him/herself for the toilet training process and correctly reads the child's signals of interest and ability. That mutual understanding will allow the parent to be able to appropriately and correctly pick up the signals from their child and not misinterpret difficulties that the child is either oppositional or defiant.

Some of the beginning developmental signs that a child may be ready for toilet training include the child's comments or observations of other children in a school setting or a play setting who are already using or attempting to use the toilet. When a child is between the ages of 24 and 36 months he or she begins to understand certain parts of language. Concepts such as: In and out, clean and dirty, messy and neat, toilet, sit, dry, wet, stop, and go must be in place before a child is able to execute the activity. They need to have the ability to engage in and sustain attention and interest in participating in the process. Physiologically they have to show signs

that their bowel and bladder system has matured enough to progress with training. There needs to be a rhythm to the child's bladder and bowel elimination where the parent can predictably know the child has one or two bowel movements a day and more or less when those are timed.

It is time to encourage self awareness when a child can regulate his liquid intake and there is predictability to the elimination rhythm of his body, when his bladder is full, when his bladder is empty. We can also see this readiness visually as a child begins to enjoy and indulge in increased sand and water play. To help a child understand the concept of full and empty utilize playing with water by letting the child observe liquid dripping out of a water balloon or a bladder like container. The child can see that they can control both the stopping and starting of the fluid and the pace of the fluid leaving the container. Sometimes, children demonstrate they are ready to toilet by being distressed that they are wet or soiled. At those times, that is another entry point of opportunity to introduce a toilet. Some children also begin to demonstrate grimaces and facial expressions around their bowel movements and that body awareness can indicate that they may be ready to begin toilet training.

Games - Activities - Strategies:

Taking into consideration the child's individual differences parents can come up with strategies that are sensitive to the sensorial processes that are necessary for toileting success. Toileting should never become a power struggle. It can become a fun, creative activity between parent and child where the child knows that the

parent is supporting them up the developmental ladder in a playful yet productive manner. The following includes a number of strategies and approaches to toileting.

1. Food:

Introduce foods that promote bowel regularity like bran, plums, prunes, and dried fruit. To get around any resistance parents need to create a game around the food. It might be something like having in each hand a pitted plum or a small piece of dried fruit that would easily fit into a child's mouth. Have the child pick which hand. The parent pops one in their mouth and the child pops one in their mouth. Here are some additional fun and creative ways to introduce food that promotes digestion:

- a. Consider giving juice instead of actual fruit
- b. Sprinkling bran on yogurt or in cereal
- c. Having the child feed themselves as opposed to having a parent feed them.

2. Sensorial ways to experience the body:

Warm weather permitting let the child run nude from the waist down so they can visually take in their body and see exactly how bodily waste exits from its proper spots.

3. Role Play:

If a child is having trouble releasing his/her bowel, have a stuffed animal or toy reenact difficulties in the bathroom. Parent should participate in the session with the child by talking in a high-pitched toy voice. "Ouch, my poop hurts when I go to the bathroom." Have the child help strategize together with the parent.

"What do we do?" Figure out in a safe play environment how to go ahead and come up with some answers to help relieve this toy figure of the difficulty going to the bathroom.

Safety is being created because parent and child are addressing the child's issues through pretend play rather than pressuring the child to look at himself/herself directly. By being patient and playful (the language and pacing of children), the parent will begin to understand what is going on in the child's mind that is making the idea of toileting so difficult.

4. Practicing:

Use a soft squeezable ball or some like object to repeatedly practice squeezing and releasing. Use an anatomically correct doll and clay or play dough to represent the concept of a bowel movement. Parents need to emphasize to the child that actual bowels are not to be touched but that in this exercise we can make pretend poop. Show the child how the doll can squeeze out the play dough. This provides sensorial information to the child and helps them organize at the same time. Another possibility is to take chocolate drops that are used to make chocolate chip cookies. Place them in a doll with the anatomically correct rear opening, squeeze the belly and allow the chocolate drops to drop into the toilet, thereby simulating the visual and auditory experience of the doll pooping. In the absence of an anatomically correct doll this can be done from behind a toy as if bowel were dropping into the toilet.

5. Visual and sequential aids for learning differences.

Some children have temporal sequential delays in the ability to sequence, plan and execute the plan. Toileting requires a specific sequence. There are a variety of ways to create sequencing by using visual charts and auditory supports. A written word list with a check-list where the child could check off the steps is also very helpful. The kinetic action of checking off what they have accomplished also gives a message for organization to the brain.

Children who learn visually will benefit from having a sequence presented to them on a poster board. Place the chart next to the toilet with pictures or photographs next to the words that demonstrate the sequential steps. The idea behind the visual progression of steps is that children often learn differently and we need to connect with their strengths and abilities if we want them to succeed. If a child takes in information auditorially, then the presentation in sequential steps can be given in a verbal manner. One idea that is attractive to many toddlers is presenting the instructions in a sing-song fashion. For example, to the tune of "Hokey Pokey", the sequence of the toileting process is introduced; "first you do this and then you do that"...

A typical set of sequences includes:

- a. Go to the toilet
- b. Pull down your pants
- c. Sit on the toilet
- d. Poop and or pee

- e. Wipe front to back
- f. Pull your pants back up
- g. Flush the toilet
- h. Wash your hands

6. Modeling.

One additional strategy includes the idea of modeling where the child is invited into the bathroom of the same sex parent to watch both bowel and bladder product appropriately deposited into the toilet.

a. Little boys, they can watch and practice simultaneously to daddy peeing in the toilet. If that is uncomfortable, fathers can alternatively practice shooting in the toilet with a squirt gun or water from a water bottle.

b. Target practice can be done either with cheerios, which float in the toilet water or pieces of onionskin typing paper with a red "X" on it. Ask if they can hit the mark with the urine flow. This can work both with girls and boys but it is particularly valuable for boys because it is easier to aim at a target. The idea is to make a fun activity out of a necessary duty without any kind of reference to performance.

The adventure of toileting can progress in a variety of ways. For success, parents need to remain calm and apply sensible practical strategies to assure both toileting mastery and a happy child. Necessary ingredients for this happiness include a parent who is comfortable with their own parenting abilities and the ability to see the child for who he/she is developmentally.

Appropriate perspective includes awareness of the child's readiness and the mutual readiness, respect and love between parent and child.

National Awareness Arts Contest
Help us spread the word....

Posters
Videos
Songs
Graphics

**It's Normal
to be
Different**

Deadline 9/30/09

IALQ International Association for Life Quality
A TERI Initiative www.ialq.org

For more information:

Brian Brokowski

Bartell & Associates

619-246-3810

brian.brokowski@bartellassociates.com

**It's Normal to be Different Creative Arts Contest
Breaks Down Barriers, Dispels Stereotypes
of People with Autism and Other Developmental Disabilities**

OCEANSIDE, CA. (May 19, 2009) –

Exciting prizes and opportunities to be featured as part of a national marketing campaign to break down barriers and dispel stereotypes of individuals with autism and other developmental disabilities are now available through the "It's Normal to Be Different" creative arts contest.

Entries are now being accepted in contest categories including posters, videos, stories and songs by the International Association for Life Quality and TERI. Inc. The contest is open to ages 5-21 and deadline for submissions is September 30, 2009. Winning entries will best demonstrate the "It's Normal to Be Different" theme and be announced in October.

The "It's Normal to be Different" campaign also includes an educational curriculum for schools and community organizations as well as the launch of a new online training and knowledge resource center for caregivers and families.

More information on the contest and campaign is available at www.ialq.org.

**The Autism Fight:
One Mom's Journey to Deliver
a Breakthrough for Educating
Special-Needs Children
by Anne Baker Scroggs**



"Your son is autistic."

When I first heard those words in 1991 autism was not the epidemic that it is today. New children were not diagnosed every 20 minutes and few researchers were searching for a cure. It was a relatively rare diagnosis and little was known about how to care for autistic children, let alone educate them.

There are many different ways that a mom can react to the news that her child is autistic. In my own case, I became obsessed with finding special education schools that offered some hope for my son, Mitchell. As a family, we selected the most well-respected private program in our area and learned everything we could about autism. Then, when Mitchell was ready to move to the public school system, we moved to make sure he was in the best school district and we carefully monitored his progress. Mitchell's teacher provided us frequent reports that indicated Mitchell was doing well in the classroom.

However, after several years he hadn't progressed beyond his 30 word vocabulary and at one point when we would talk about school he would just scream. In my heart, I knew something was wrong. I decided to follow my instincts and visit Mitchell's classroom unexpectedly one day.

I found Mitchell playing by himself in a corner of the room while the other higher functioning students were being taught. I hoped this was an unusual event but as I continued to monitor the situation I soon realized that the educators felt that they didn't have the tools necessary to help Mitchell and they had quit trying. The situation was both heart-breaking and infuriating. If this was happening in one of the best special education programs in our state what was happening in the others? Frustrated and furious, I finally pulled Mitchell out of school.

What had I done? I wasn't a teacher and I never intended to become one. However, I believed in my son. I knew he could show progress. I became intensely focused on finding teaching strategies that were proven to achieve results for autistic children. I didn't want the latest trendy educational program - I wanted education strategies that offered real evidence of progress. Eventually, through a lot of trial and error, I used this research to create a comprehensive suite of special education tools that I could use with Mitchell which was:

- **Research-based** – Combined a number of teaching strategies which universities had proven achieved results.
- **Progressive and Integrated** – Built upon one another to reinforce key concepts and advance learning.
- **Engaging and Easy to Implement** – Made learning fun for Mitchell and straight-forward for me to implement.
- **Measurable** – Allowed me to set expectations, track Mitchell's progress, and see measurable results.

Using this system of learning tools, Mitchell improved from a 30 word vocabulary to a 275 word vocabulary in just 6 months and I was able to place him back into the school system where he could interact with other students. I went back and visited the educators who hadn't been able to make progress with Mitchell earlier and showed them the results. They were shocked and soon special education teachers throughout Washington State began to ask me for copies of my tools. These teachers started seeing results as well. Children who didn't have any sight words started progressing to over 75 words in just 5 months.

One school saw increases in communicative speech between 200-400% for their special-needs students. Success stories like these spread beyond Washington and soon teachers in California, Illinois, Pennsylvania, and even Canada began asking me for the tools. I realized that through my desire to help my own son I had created a system that could help special-needs children everywhere.

Acknowledging this responsibility, I soon made another informal career change from teacher to entrepreneur. I launched my own company, Creative Teaching CAP (<http://www.creativeteachingcap.com>), a special education organization dedicated to creating a comprehensive suite of

measurable learning tools that are proven to help autistic and special-needs students thrive. My hope is that by launching Creative Teaching CAP others parents and teachers will never feel as alone as I did when I started this journey and that, by using these tools, we can join together and revolutionize special education programs across America.

Nearly two decades after first receiving my son's autism diagnosis, Mitchell now can both speak and read over 1200 words. I look back on this entire experience with pride in all that we have accomplished and anticipation for the progress we will make in the future. Ultimately, I have found that in helping my son achieve his full potential I have also come to achieve my own. I now understand the one word in our vocabulary which sums up what it means to fight and persevere in the midst of unimaginable challenges and seemingly insurmountable odds: "mom".

Anne Scroggs is the CEO and Founder of Creative Teaching CAP (<http://www.creativeteachingcap.com>), a special education organization dedicated to creating a comprehensive suite of measurable learning tools that are proven to help autistic and special-needs students thrive. She is a long time student of autistic spectrum disorders and an accomplished advocate for special-needs students. Anne formerly held management positions at a number of Fortune 500 companies, including Seafirst Bank, NCR, and Wang Laboratories, and was recognized for her accomplishments in creating efficiencies in banking systems. Anne resides in Issaquah, WA with her husband and two sons.



Link to a video of children and special ed. teacher using the products:

http://www.creativeteachingcap.com/v/vspfiles/files/video_pages/in_the_classroom.html

From David Willey of Germany:



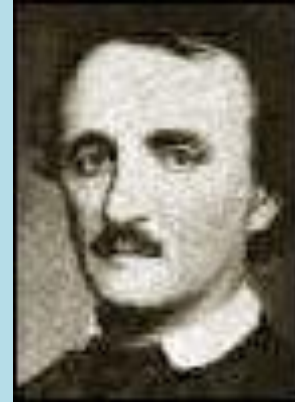
David Willey

Hi Sharisa, I've given this a lot of thought, and rather than babble about what I've been through or my personal ideas about autism I'd like to offer this poem written by Edgar Allan Poe. It's not about autism per se but it reflects what I consider to be the struggles involved in being a person with disabilities. In this case I can offer nothing better to express what I believe an autistic person, their family or direct caregiver would immediately understand. I offer this with a heart full of compassion and empathy:



Sunday afternoon in Holzhausen

Edgar Allen Poe
(1809—1849)



Edgar A. Poe.

Alone

*From childhood's hour I have not been
As others were — I have not seen
As others saw — I could not bring
My passions from a common spring —
From the same source I have not taken
My sorrow — I could not awaken
My heart to joy at the same tone —
And all I lov'd — I lov'd alone —
Then — in my childhood — in the dawn
Of a most stormy life — was drawn
From ev'ry depth of good and ill
The mystery which binds me still —
From the torrent, or the fountain —
From the red cliff of the mountain —
From the sun that 'round me roll'd
In its autumn tint of gold —
From the lightning in the sky
As it pass'd me flying by —
From the thunder, and the storm —
And the cloud that took the form
(When the rest of Heaven was blue)
Of a demon in my view —*

**From Emily Dickinson
(1830-86)**



**My hair is bold like the chestnut burr;
and my eyes,
like the sherry in the glass
that the guest leaves.**

XXVII

**I'm nobody! Who are you?
Are you nobody, too?
Then there's a pair of us — don't tell!
They'd banish us, you know.**

**How dreary to be somebody!
How public, like a frog
To tell your name the livelong day
To an admiring bog!**

**My Reply When I Was 15:
I'm Somebody by Sharisa Joy 4-24-94**

**I'm somebody! You know it's true.
Aren't you - somebody - too?
I hope we can be a pair!
So there! It's less lonely - you know!**

**How dreary - to be - nobody!
How lonesome - like the mist -
To shout your name - in emptiness -
To prove that you exist!**

**My Life as a Zero,
My Life as a Hero
Sharisa Joy
5/7/95
revised 9-15-98**

**In retrospect,
I ask myself
Was I there?
Did I hear?
Did I feel,
Think or care?**

**When I changed
Could I know
Just how far
I might go?**

**From Zero
To Hero
The journey's been strange,
Yet there isn't one thing
I would dare to change.**

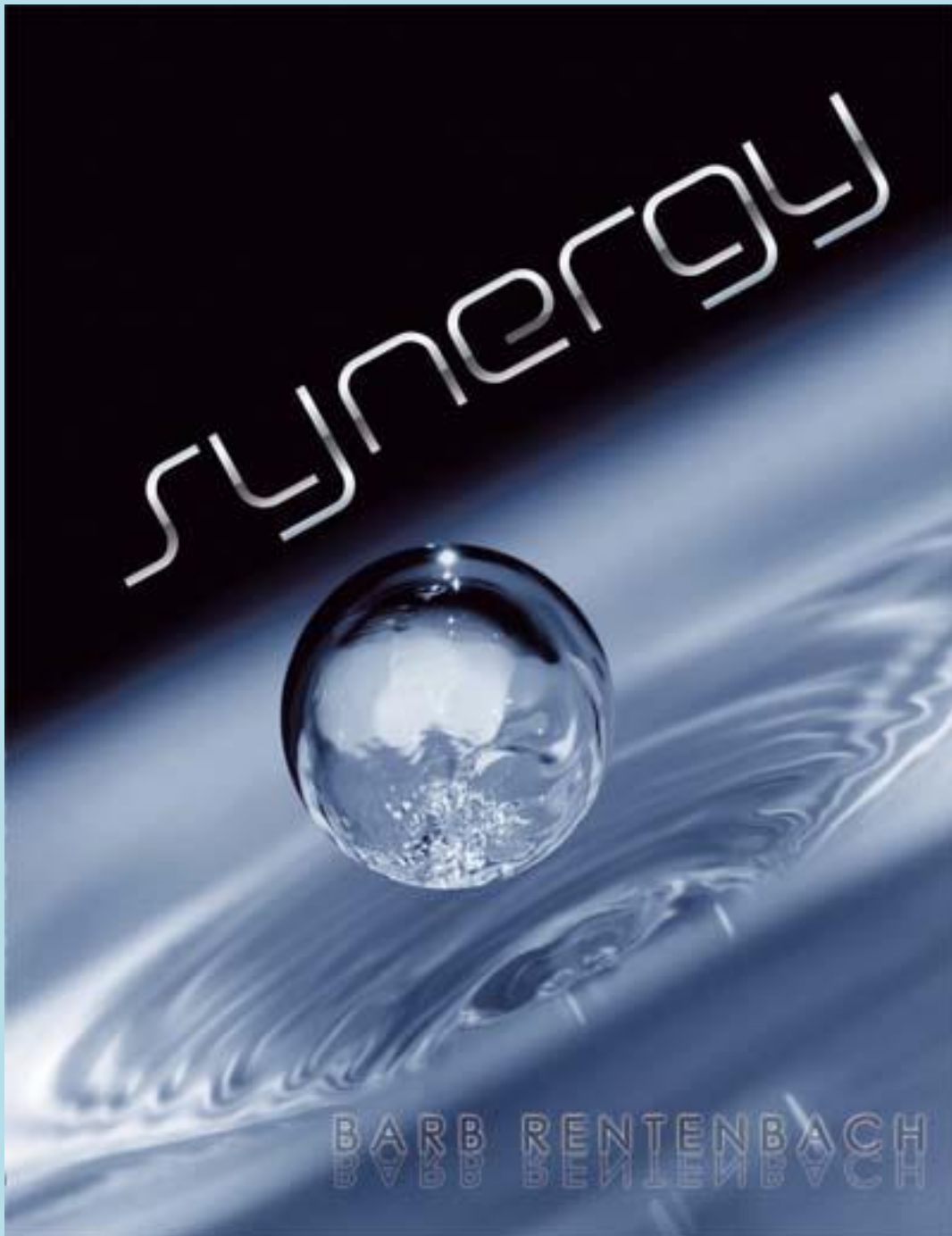
Poetry In Progress

**The journey to light is tough and long,
But it helps if you fill the darkness with song.**

**My heart fills with feelings,
My mind with emotions
That often are
Much deeper than oceans.**

**Poetry is a way for me
To set ideas and emotions free.**

**Give me a new body and brain
When days just feel like endless rain
And take away the tears and pain
That threaten to drive me insane.**



Please allow me to do my part in promoting the beautiful mission of "The Voices and Choices of Autism" magazine. I am Barb Rentenbach, the author of Synergy, which is about this adult learning to live with Autism and everyone else. I am disguised as a poor thinker, but dont judge this book by that cover. I am writing to you while a friend supports my forearm so that my lifeline index finger hovers above an oversized keyboard. This process is called

facilitated communication (FC) and freaks out a lot of people. Critics contend that the normal who supports the hand of the "abnormal" leads the typing and therefore fraudulently takes advantage of the clueless, disabled victim. I can only speak for myself and will continue to do just that. I am neither clueless, disabled, nor a victim. Today, I am rich with true friends, clear purpose, and exciting future. The paths to that state of being were filled with considerable pain, intense anger, frustration, and lots of trial and error. And that is not half of what my parents went through. Synergy contains accounts of my experiences with exclusion, confusion and what helped me find myself, my voice, joy and purpose. Practical implications for folk on the ASD spectrum, their families, support network, and all teachers are highlighted in hopes that others may be assisted in finding their way and giving capacity. All proceeds from the sale of Synergy go to the "Greater Living Institute" (GLI) a 501(c)3 created to serve adults and adolescents with Autism to help them in maximizing their potential. Contributions may be sent to GLI c/o Psychoeducational Network, 2892 Alcoa Hwy, Knoxville, TN 37920. To purchase or learn more, please visit barbrentenbach.com. Synergy is also available through Amazon.com, Barnes & Noble, and Borders...but is cheaper through me or my publisher, Authorhouse.com, so buy several. Enjoy.

Sincerely, Barb



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 awhile to get it.

Shasti McLaughlin

**Everything has its beauty
but not everyone sees it.
- Confucius**

**Whatever you do may seem insignificant,
but it is most important that you do it.
- Gandhi**

**I am not a teacher,
but an awakener.
- Robert Frost**

**Don't find fault,
find a remedy.
- Henry Ford**

**Every aspect of our lives is,
in a sense,
a vote for the kind of world
we want to live in.
- Frances Moore Lappe**

**The only limit to our realization of tomorrow
will be our doubts of today.
Let us move forward with strong and active faith.
- Franklin D. Roosevelt**

**Life is either a daring adventure or nothing.
- Helen Keller**

**Be yourself,
everyone else is already taken.
- Oscar Wilde**

**Nobody realizes
that some people
expend tremendous energy
merely to be normal.
- Albert Camus**

**I want to remake the world;
anything less is not worth the trouble.
- Karen Cushman**

**Words that soak into your ears are whispered, not yelled.
- Unknown**

On a starry night
When the moon shines bright
I remember when I
Couldn't see the light.

- Sharisa Joy 6/9/09

Neutrality helps the oppressor,
never the victim.
Silence encourages the tormentor,
never the tormented.

- Elie Wiesel, writer,
Nobel laureate



If I look in your eyes
will you know my mind,
Or will you still be
mean and unkind?

Sharisa Joy 6/10/09
I am only me,
What more (or less) can I be?

@@

To make the right choices in life,
you have to
get in touch with your soul.
To do this,
you need to experience solitude,
which most people are afraid of,
because in the silence
you hear the truth
and know the solutions.
- Deepak Chopra

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

+++++

A man can fail many times,
but he isn't a failure
until he begins
to blame somebody else for it.
- John Burroughs,
American naturalist, 1873-1921

Closing Touches of Wisdom:

Mystery creates wonder
and wonder is the basis of
man's desire to understand.
- Neil Armstrong

What we must decide
is perhaps how we are valuable,
rather than how valuable we are.
- F. Scott Fitzgerald

America's health care system
is neither healthy, caring,
nor a system. - Walter Cronkite

A drop of help
is better than
an ocean of sympathy.
- Anonymous

I can be changed
by what happens to me.
But I refuse to be reduced by it.
- Dr. Maya Angelou

We live in a world in which
we need to share responsibility.
It's easy to say
"It's not my child, not my community,
not my world, not my problem."
Then there are those
who see the need and respond.
I consider those people my heroes.
- Fred "Mr." Rogers

Little minds
are tamed and subdued
by misfortune,
but great minds rise above them.
- Washington Irving

I think it's important
for everyone to understand
that embracing individuality,
and support for one another,
will result in a more rewarding life
for all of us -
autistic, neurotypical
and everyone in between.
- Kathy Williamson, mom

By labeling people's behavior
we often feel we have the right
to act on how the behavior affects us
rather than on
what the person doing it
might be trying to communicate.
- Herb Lovett, *Learning to Listen*

The natural flights of the human mind
are not from pleasure to pleasure
but from hope to hope.
- Samuel Johnson

Every new opinion, at its starting,
is precisely in a minority of one.
- Thomas Carlyle

New opinions are always suspected,
and usually opposed,
without any other reason
but because
they are not already common.
- John Locke

The difference between
genius and stupidity
is that genius
has its limitations.
- Albert Einstein

Few people are capable
of expressing with equanimity
opinions which differ from
the prejudices of
their social environment.
Most people are even incapable
of forming such opinions.
- Einstein

The door of a bigoted mind opens
outwards so that the only result of
the pressure of facts upon it is to
close it more snugly.
- Ogden Nash, author (1902-71)

Just don't give up trying to do what
you really want to do. Where there's
love and inspiration, I don't think you
can go wrong. - Ella Fitzgerald

The beginning is the most important part of the work. - Plato