



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

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EVERYTHING YOU ALWAYS WANTED TO KNOW ABOUT ADVOCACY BUT WERE AFRAID TO ASK

by Sharisa Joy Kochmeister, Award-Winning Advocate

“Encarta Online Dictionary” defines advocacy as: “*giving aid to cause: active verbal support for a cause or position*”.

“Wikipedia”, which is not always my favorite source to cite goes a bit further in their definition, telling us: “Advocacy is the pursuit of influencing outcomes - including public-policy and resource allocation decisions within political, economic, and social systems and institutions - that directly affect people’s current lives. (Cohen, 2001)”

They go on to explain that: “Therefore, advocacy can be seen as a deliberate process of speaking out on issues of concern in order to exert some influence on behalf of ideas or persons. Based on this definition, Cohen (2001) states that “ideologues of all persuasions advocate” to bring a change in people’s lives. However, advocacy has many interpretations depending on the issue at stake, which can be different from this initial value-neutral definition.”

At this point, I became intrigued with “Wikipedia’s” take on advocacy and will now share the rest of it with you, my fearless readers:

“Forms of advocacy

There are several forms of advocacy, which each represent a different approach in the way change is brought into society. One of the most popular forms is social justice advocacy.

Although it is true, the initial definition does not encompass the notions of power relations, people’s participation and a vision of a just society as promoted by social justice advocates. For them, advocacy represents the series of actions taken and issues highlighted to change the “what is” into a “what should be”, considering that this “what should be” is a more decent and a more just society (ib., 2001.) Those actions, which vary with the political, economical and social environment in which they are conducted, have several points in common (ib., 2001.) They:

- * question the way policy is administered
- * participate in the agenda setting as they raise significant issues
- * target political systems “because those systems are not responding to people’s needs”
- * are inclusive and engaging
- * propose policy solutions
- * open up space for public argumentation.

Some of the other forms of advocacy include:

* **Ideological advocacy:** in this approach, groups fight, sometimes during protests, to advance their ideas in the decision-making circles.

* **Mass advocacy:** is any type of action taken by large groups (petitions, demonstrations, etc.)

* **Interest-group advocacy:** lobbying is the main tool used by interests groups doing mass advocacy. It is a form of action that does not always succeed at influencing political decision-makers as it requires resources and organisation to be effective.

* **Bureaucratic advocacy:** people considered "experts" have more chance to succeed at presenting their issues to decision-makers. They use bureaucratic advocacy to influence the agenda, however at a slower pace.

* **Legislative advocacy:** legislative advocacy is the "reliance on the state or federal legislative process" as part of a strategy to create change. (Loue, Lloyd and O'Shea, 2003)

* **Media advocacy:** is "the strategic use of the mass media as a resource to advance a social or public policy initiative" (Jernigan and Wright, 1996.) In Canada for example, the Manitoba Public Insurance campaigns illustrate how media advocacy was used to fight alcohol and tobacco-related health issues. We can also consider the role of health advocacy and the media in "the enactment of municipal smoking bylaws in Canada between 1970 and 1995." (Asbridge, 2004)

* **Budget advocacy:** Budget advocacy is another aspect of advocacy that ensures proactive engagement of Civil Society Organizations with the government budget to make the government more accountable to the people and promote transparency. Budget advocacy also enables citizens and social action groups to compel the government to be more alert to the needs and aspirations of people in general and the deprived sections of the community.

Different contexts in which advocacy is used:

* **In a legal/law context:** An 'advocate' is the title of a specific person who is authorized/appointed (in some way) to speak on behalf of a person in a legal process. See advocate.

* **In a political context:** An 'advocacy group' is an organized collection of people who seek to influence political decisions and policy, without seeking election to public office. See interest group.

* **In a social care context:** Both terms (and more specific ones such as 'independent advocacy') are used in the UK in the context of a network of interconnected organisations and projects which seek to benefit people who are in difficulty (primarily in the context of disability and mental health).

* **In the context of inclusion:** Citizen Advocacy organisations (citizen advocacy programmes) seek to cause benefit by reconnecting people who have become isolated. Their practice was defined in two key documents: CAPE, and Learning from Citizen Advocacy Programs. See Citizen Advocacy organisations.

Advocacy groups

Advocacy is led by advocates or, when they are organized in groups as is the case most of the time, advocacy groups. Advocacy groups as defined by Young and Everitt (2004, 5) are different from political parties which "seek to influence government policy by governing." They are "any organization that seeks to influence government policy, but not to govern." This definition includes social movements, sometimes network of organizations which are also focused on encouraging social change. Social movements try to either influence governments or, like the environmental movement, to influence people's ideas or actions.

Today, advocacy groups contribute to democracy in many ways (ib., 2004.) They have five key functions:

- * Give a voice to (misrepresented) citizen interests
- * Mobilize citizens to participate in the democratic process
- * Support the development of a culture of democracy
- * Assist in the development of better public policy
- * Ensure governments' accountability to citizens.

In comparison to other countries and other the last thirty years, an increasing number (40 percent) of the Canadian population is member of an organization which has had an advocacy role and has tried to achieve political change. Such a level of participation is a positive indicator of the health of the democracy in Canada (ib., 2004.)

Transnational advocacy

Advocates and advocacy groups represent a wide range of categories and support several issues as listed on World Advocacy. The Advocacy Institute, a US-based global organization, is dedicated to strengthening the capacity of political, social, and economic justice advocates to influence and change public policy (Cohen, de la Vega & Watson, 2001.)

The phenomenon of globalization draws a special attention to advocacy beyond countries' borders. The core existence of networks such as World Advocacy or the Advocacy Institute demonstrates the increasing importance of transnational advocacy and international advocacy. Transnational advocacy networks are more likely to emerge around issues where external influence is necessary to ease the communication between internal groups and their own 1 government. Groups of advocates willing to further their mission also tend to promote networks and to meet with their internal counterparts to exchange ideas (Keck and Sikkink, 1998.)

References

- * Asbridge, M. 2004. Public place restrictions on smoking in Canada: assessing the role of the state, media, science and public health advocacy. *Social science & medicine* 58(1):13-24.
- * Cohen, D., R. de la Vega, G. Watson. 2001. *Advocacy for social justice*. Bloomfield, CT: Kumarian Press Inc.
- * Jerningan, D.H. and P. Wright. 1996. Media advocacy: lessons from community experiences. *Journal of Public Health Policy* Vol.17, No.3: 306-330.
- * Keck, M.E. and K. Sikkink. 1998. *Activists beyond borders: advocacy networks in international politics*. Baltimore, MD: Cornell University Press.
- * Loue, S., L.S. Lloyd, D. J. O'shea. 2003. *Community health advocacy*. New York: Kluwer Academic/Plenum Publishers.
- * Young, L. And J. Everitt. 2004. *Advocacy groups*. Vancouver, BC: UBC Press"

This is where "Wikipedia" ends one truly fine descriptive article and where I now will discuss what advocacy is for me:

"IN - CLUSION" NOW! Sharisa Joy Kochmeister

Everyone should become advocates for full inclusion of all people. What exactly is "inclusion?" Inclusion is what people attempt with "special needs" students and adults in the workforce and community. The legal definition is education and integration of people with "disabilities" in regular schools, classes, jobs and communities instead of "special" ones. According to the U.N., 10% of the world's population has developmental disabilities. This is quite likely a very conservative estimate. As research repeatedly demonstrates, increased contact brings greater tolerance and understanding, and inclusion works! However, inclusion is often difficult merely because there are more interpretations and models than one might imagine. Full inclusion is superior to the selective and institutionalized segregation that still currently exists because no one benefits at all when anyone is excluded. Exclusion causes prejudice, discrimination, and lack of understanding along with suspicion and distrust. It ostracizes people regarded as "different." Apart from this, inclusion is federal law, international policy, and the morally correct thing to do!

The biggest problem is that most people outside the disability community as well as many inside of it have no solid idea what's

really meant by "inclusion." Why should everyone care? After all, inclusion is just a *word* to most people. It probably isn't even a concept they ever consider, at least until they're told to start *doing* it! Imagine how scary that is, given the fact they don't really know how to define it, let alone make it work! People think: "Why should I care about inclusion? It doesn't really apply to me!"

There are several excellent replies. The first is for those who are or will soon be in college and/or the workforce. Changes in laws and practices brought about by the Americans with Disabilities Act (A.D.A.) and Individuals with Disabilities Education Act (I.D.E.A.) make it quite likely that the person sitting next to us in class or working with us has some type of disability. Inclusion can work, but only with proper preparation, training, supports, and true understanding on behalf of all involved.

People are always people first and foremost, and we all deserve fair treatment as a right, not a "gift." All people should be treated as aware and competent, regardless of how they look, what disability they have, whether they speak or are non-verbal, and what devices/assistance they might require to be fully included. *Nobody* would choose exclusion over real interaction with peers. How would you feel if this was done to *you* merely because of a disability? Would you think: "*Wow! It's so great that I never went to regular school, lived in a home of my own, had a real job, married or had children, and even had any real friends! What a rich life it's been!*" No sane human being would choose this scenario. We would, as Dylan Thomas so eloquently said: "*rage against the dying of the light,*" thinking: "*If I could only have all those empty years back! If I could only be sure it never happens to anyone else ever again! How can I do that?*"

Do you dare to think that what I describe isn't still very real not only in other countries but in the bastion of "equality" known as the USA? Well, here's some news for you – the above scenario is the reality that was tolerated for far too long and often still is – a reality I lived with for the first half of MY life! It certainly should not be permitted to remain reality any longer! What can be done right now to help make inclusion reality? Write petitions and get as many signatures as possible. Contact educators, legislators, businesses and government executives. Challenge them to get it right and finally set it right!

Tell them we want inclusion in a loud, clear, unified voice. Let them know we are not only talking about inclusion in schools – we want it everywhere for everyone. No one should ever feel disenfranchised or excluded in a society that prides itself on the provision of

freedom, liberty, equality and "justice for all" citizens! It is way past the time to make it so!

This is advocacy for me!

Major personal accomplishment: I am pleased and proud to announce that NIH and NIMH have appointed me to an advisory panel for the IACC - Inter-agency Autism Coordinating Committee... to help determine federal policy and research targets/spending. Apparently, they think I'm an expert on autism! We will be presenting in Bethesda 9/30-10/1. I am excited about this appointment, honored and humbled.

I Sing My Life by Sharisa Joy

**Where are the years that I was broken,
And left alone to wonder why?
What are the effects of a life unspoken?
What is the sound of a silent cry?**

**I know my life is rich with meaning.
I know my thoughts are rich with song.
I know my life is just beginning.
I know it must be more than just long.**

**There is a world so deep within me
I want the world outside to see.
There is a place where I begin me.
There is a place inside that's free**

**To speak and sing a song of sorrow,
A song of joy, a song of love;
To gather strength for each tomorrow,
To gather strength to soar above**

**A world so full of fear and danger;
A world so full of grief and pain,
A world where I was just a stranger
Living deep inside my brain.**

**I need to sing my songs of being,
Songs of laughter, songs of peace;
My songs that are so spirit-freeing,
My songs that bring me sweet release**

**From pain and anger, woe and sorrow,
The fear that held my life before;
I'll sing today and each tomorrow.
I'll sing till I can breathe no more.**

"Autism and the autistic rights movement"

August 27 Long Island Autism Examiner Marc Rosen

(used by permission from the author)

<http://www.examiner.com/x-21742-Long-Island-Autism-Examiner?showbio>

Some groups claim that autism is a vaccine injury, and have been disproven repeatedly. Others insist that it must be some sort of illness or disease, but their point of view has accomplished little other than to invite prejudice and discrimination against autistic people. Dr. Laurent Mottron, one of the top researchers studying autism, has gone so far as to say "We don't really know what autism actually is." What is known is that it affects the entire person, is not likely to be dietary or a reaction to environment, and is so utterly a part of the autistic brain and mind that the very notion of a "cure" would be absurd.

Aspies For Freedom, the Autistic Self-Advocacy Network, ADAPT, ACT UP, and other autistic rights and disability rights organizations stand by the consensus of the scientific community which currently believes that autism (including the entire spectrum) is mostly genetic, and likely to be a complex interaction involving hundreds or thousands of traits.

Given that, the hope of well-known groups such as Autism Speaks for a "cure" or a means of "preventing autism" (mostly a euphemism for prenatal screening similar to that which is available for trisomy-21, also known as Down Syndrome) is highly unlikely to happen.

There is no way to predict how functional a child will be later on based on initial diagnosis, and a person on the spectrum may be relabeled numerous times before age 13. Even so, there are hundreds of groups that hold this "curebie" perspective, as many autistic rights activists prefer to refer to it. Most of these organizations are infamous for refusing to include any autistic people in their leadership, and often even exclude them from the rank and file memberships as well. Many attempt to narrow the definition of autism and to disregard the presence of a spectrum outside of their message that it's a menace that must be stopped.

To the average autistic person, that comes across as being attacked simply for existing. As a result of this desire to not be "cured", the idea of neurodiversity, which states that all people have the right to be accepted regardless of their neurology, became more prominent in autism-related discussions, much to the ire of some rather venomous individuals who have gone as far as making death threats against autistic rights activists for their views.

Currently, the major concerns of the autistic rights movements are to address inequalities in employment, housing, health care, education, and so on. The primary messages of the autistic rights movement are that autistics have the right to exist as they are, the right to live in their communities in the most appropriate and most integrated setting possible, and the right to equal access to all public facets of life. In time, that message is likely to be heard by many more people...



Meet Eric Chessen

Email: eric@autismfitness.com

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

I was an active kid who began to gain weight in middle school and, through discovering exercise and nutrition in high school, became physically fit and healthier. With the new found appreciation of how I looked and felt, I began to develop a greater sense of self-esteem and was more confident. I became more sociable and wanted to provide others with both the motivation and practical knowledge to succeed in creating a fitness lifestyle. I became certified as a fitness trainer and worked with general population clients for several years.

I began working with the autism population about a decade ago as a summer camp counselor. Even then, prior to foreseeing my career, I was fascinated with the few children I met with Autism. While taking graduate courses towards a degree in general psychology, a classmate asked if I would be interested in applying my fitness background to a program for teenagers on the Autism Spectrum. At that time, I was unsure of what I wanted in a career. I was hired to develop and implement fitness programs for several students who, in addition to having autism, exhibited some gross motor challenges.

While developing fitness programs for my students, I underwent intensive training in Applied Behavior Analysis (ABA). I integrated the teaching strategies from ABA with my working knowledge of exercise, and steadily began developing my own model and methods for implementing successful fitness programs for children with Autism.

Around the same time, I was researching, or attempting to research the most effective fitness programs for young people on the autism spectrum. I found virtually nothing on the subject. It was at this point I realized what I wanted to do with my career; to be an advocate and resource for bringing fitness to the autism community.

My career as the "autism fitness guy" grew slowly. I began working with new clients who made great progress in their physical, emotional, and cognitive health. I started writing for autism publications, speaking at various functions and workshops, and filmed my first DVD. In 2008 I changed from my company name from Theraplay-ny to Beyond Boundaries Fitness, as my goal became to bring fitness to as many children and families as possible.

Now (finally in this name change bonanza) as Autism Fitness, I am dedicated to not only providing fitness services to young individuals on the

spectrum, but to educating their families, teachers, and other professionals on how to optimize development through exercise. With fitness as a cornerstone, optimal development is enabled.

Autism Fitness FAQ's by Eric Chessen WHAT IS FITNESS?

Much confusion surrounds the term "fitness." Is fitness about being better at sports? Is fitness about being big and strong? Is fitness only for particular children or adults? My philosophy is that fitness is the ability to successfully navigate through everyday challenges, from getting dressed to taking out the garbage to playing on the monkey bars. At the foundation of all human performance is fitness. One of the first challenges we face in life is movement against gravity. This involves becoming aware of our bodies and our surroundings. Children on the autism spectrum, as well as those with related disorders and other special needs often have movement deficits that are clearly evident, and many that are less-than-obvious. Fitness, and well-designed exercise programs, are gateways towards some of the most crucial developmental objectives for young individuals including Self-Esteem, Self-Efficacy, and Socialization. Fitness should ultimately result in a developing a joy of movement and a lifetime of healthy activity.

Isn't Fitness taught in school through sports and Physical Education?

It was, at one time. For the past several decades, general fitness has fallen out of most P.E. curriculums in favor of sports-focused activities. Without general fitness, two major problems occur:

- 1) Children do not develop the basic skills necessary to be successful, or even enjoy, sports and
- 2) Children who do not naturally gravitate towards a particular sport eventually cease all physical activity.

For individuals on the autism spectrum, fitness and exercise are often overlooked as life skills, however there is an abundance of research and clinical evidence supporting the dramatic benefits of implementing fitness programs for special needs populations.

What do children need to be doing?

Jumping, climbing, skipping, pushing, pulling, throwing, catching. Essentially, playing. As a result of the deficits in socialization that individuals with ASD typically exhibit, creative and active play may be a rare, if non-existent activity. Beyond Boundaries develops individualized fitness programs that incorporate a wide array of activities all based in the five essential movement patterns:

- Pushing
- Pulling
- Level Change
- Rotation
- Locomotion

What does an Autism Fitness Session Look Like?

At Autism Fitness, methods of Applied Behavior Analysis (ABA) are used as constructs for teaching integrative exercises and movement patterns. Essentially, complex movements are broken down into smaller components so that they are learned incrementally, safely, and independently. Depending on the skill level of the athlete, numerous exercises are introduced to develop and optimize movement, stability, strength, balance, and coordination. Some of our favorite movements include medicine ball throws, stepping over cones and hurdles, bear walks, and skipping.

One-to-one fitness instruction with individuals and small groups

My goal is to educate those involved with the autism population on the many benefits of fitness for young individuals with autism. Self-efficacy, self-esteem, and socialization. I do not, however, make outrageous or unsubstantiated claims about what Autism Fitness Athletes will achieve. The one claim I do stand by is that Autism Fitness participants will, over time, learn to move better and have exposure to a therapeutic fitness experience.

Eric Chessen, M.S., YCS offers individual client sessions as well as group sessions in the Long Island and Queens, NY area. Availability is extremely limited. Please contact Eric@autismfitness.com to inquire about rates and scheduling.

Individual consultation sessions include:

- Mobility, flexibility, and focus activities developed specifically for each athlete
- Goal-oriented programming for sports or other extracurricular activities
- Inclusive programs for general targets (speech, tolerance of new/novel activities, social skills, etc.)
- Continued parent education for maintaining/progressing the program at home

Single consultation with full movement evaluation and home-based program is available in the NY metro area. Please contact for availability.

Eric Chessen, M.S., YCS, offers parent and educator training sessions both in person and via phone/email. Within the Long Island and Queens, NY area, in-home evaluation/consultation sessions can be scheduled for individuals ages 5-21. Distance consultations are also available.

Autism Fitness now in Technicolor! (New Videos)

Technicolor technology is the new wave of the Future!

Okay, perhaps I am a bit behind tech-wise here, but I wanted to share with you some of the AWESOME new videos we have up at www.AUTISMFITNESS.com. For a while I have wanted to provide more video content, answers to the question "what do these exercises actually look like?"

We all have different learning styles. Some are primarily auditory learners, some visual, some kinesthetic, and most of us are a varying pie chart of the three. Rather than describe exercise, I find it much more helpful to demonstrate, don't you agree? In the near future, we will be posting more video content to both the main site and the blog (www.ERICCHESSEN.com)

More Fun to come!

Live Inspired,

-EC

www.autismfitness.com

www.ericchessen.com

90 Sherman Ave, Williston Park, NY 11596, USA

Nothing is so contagious as example, and our every really good or bad action inspires a similar one. - La Rochefoucauld

Individual faults and frailties are no excuse to give in - and no exemption from the common obligation to give of ourselves.

- Edward M. Kennedy

There is a wonderful mythical law of nature that the three things we crave most in life - happiness, freedom, and peace of mind - are always attained by giving them to someone else.

- Peyton Conway March, American general, 1864-1955

The future is something, which everyone reaches at the rate of sixty minutes an hour, whatever he does, whoever he is. - C. S. Lewis

There is nothing as certain as silence, stillness, and solitude to introduce you to the secrets of yourself. - Guy Finley

Humans think they are smarter than dolphins because we build cars and buildings and start wars etc., and all that dolphins do is swim in the water, eat fish and play around. Dolphins believe that they are smarter for exactly the same reasons.

- Douglas Adams, writer, dramatist & musician

National Autism Center Releases Groundbreaking Report on Autism Treatments

**National Autism Center
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Randolph, Mass. – The National Autism Center, a nonprofit organization dedicated to serving individuals with Autism Spectrum Disorders (ASD), today released its National Standards Report, the most comprehensive analysis of treatments for children and adolescents with ASD ever published.

“This report cuts through the confusing and often conflicting information about the myriad treatments available for ASD,” said Susan M. Wilczynski, Ph.D., BCBA, Executive Director of the National Autism Center. “It is designed to serve as a single, authoritative source of guidance for parents, caregivers, educators, and service providers as they make informed treatment decisions.”

The report is the culmination of the National Standards Project, a multi-year project that began with more than 6,400 research abstracts about autism treatments and concluded with a comprehensive National Standards Report. Forty-five nationally recognized scholars, researchers, experts in autism, and other leaders representing diverse fields of study were involved in the project. The report includes, among other findings, 11 “established” treatments that produce beneficial outcomes and are known to be effective for individuals (under 22) on the autism spectrum.

“The National Standards Report covers a broad range of applied treatments and identifies the levels of scientific evidence available for each one,” continued Dr. Wilczynski. “These treatments target the core symptoms of autism, as well as many other challenges that individuals on the autism spectrum face.”

In addition to 11 established treatments, the report identifies 22 “emerging” treatments that have some evidence of effectiveness, but still require more research, and five “unestablished” treatments

that have little or no evidence of effectiveness. Nearly 90% of the established treatments came from behavioral literature (i.e. applied behavior analysis, behavioral psychology, and positive behavior support). The report also identifies limitations of the existing autism treatment research and encourages the scientific community to more aggressively pursue targeted treatment research.

“The National Standards Project will provide guidance, encourage families and service providers to make informed decisions, and promote the use of evidence-based treatments,” said Patricia Wright, Ph.D., MPH, National Director of Autism Services for Easter Seals, Inc., and one of dozens of individuals and organizations from around the country who are expressing support for national standards. “With the implementation of these standards, our outcome will be citizens with autism who move into adulthood with increased skills and the ability to contribute their talents to our diverse communities.”

The National Autism Center is disseminating the results of the National Standards Project in order to provide families and professionals with better tools to make treatment decisions to meet the needs of individuals with ASD in their care.

“Families have waited a long time for something like the National Standards Project, which will provide direction for parents and educators so they can be confident in their decisions and not waste valuable time and money on unproven treatments,” said Lisa Borges, Executive Director of The Doug Flutie, Jr. Foundation for Autism, Inc.

The National Standards Report is available for download on www.nationalautismcenter.org.

More about it on the pages following the below quotes!

The actions of men are the best interpreters of their thoughts.
- John Locke

Live truth instead of professing it.
- Elbert Green Hubbard, American philosopher, 1856-1915

Some humans would do anything to see if it was possible to do it. If you put a large switch in some cave somewhere, with a sign on it saying “End-of-the-World Switch. PLEASE DO NOT TOUCH”, the paint wouldn't even have time to dry. - Terry Pratchett, novelist (b. 1948)



National Standards Project

ADDRESSING THE NEED FOR EVIDENCE-BASED PRACTICE GUIDELINES FOR AUTISM SPECTRUM DISORDERS



The National Autism Center announces the completion of the National Standards Project and the publication of the National Standards Report.

The National Standards Project answers one of the most pressing public health questions of our time—how do we effectively treat individuals with Autism Spectrum Disorders (ASD)?

The National Autism Center launched the project in 2005 with the support and guidance of an expert panel composed of nationally recognized scholars, researchers, and other leaders representing diverse fields of study. The culmination of this rigorous multi-year project is the National Standards Report, the most comprehensive analysis available to date about treatments for children and adolescents with ASD.

Families, educators, and service providers are constantly bombarded by a massive amount of confusing and often conflicting information about the myriad treatments available. The National Standards Report will help reduce the resulting turmoil and uncertainty by addressing the need for evidence-based practice standards and providing guidelines for how to make treatment choices.

The primary goal of the National Standards Project is to provide critical information about which

treatments have been shown to be effective for individuals with ASD. The project examined and quantified the level of research supporting interventions that target the core characteristics of ASD in children, adolescents, and young adults (below 22 years of age) on the autism spectrum.

This groundbreaking report covers a broad range of applied treatments and identifies the level of scientific evidence available for each. It includes 775 research studies—the largest number of studies ever reviewed. For the first time, families can find specific information about the age groups, treatment targets, and diagnostic populations to which these treatments have been applied.

The National Standards Report will serve as a single, authoritative source of guidance for parents, caregivers, educators, and service providers as they make informed treatment decisions. We are confident that these findings and recommendations will change lives and give hope and direction to people whose lives are touched by autism.

over...

The National Standards Report

The National Standards Report is the most comprehensive analysis available about treatments for children and adolescents with ASD.

Significant Findings

The findings include the identification of:

- **11 “Established” Treatments:** treatments that produce beneficial outcomes and are known to be effective for individuals on the autism spectrum. The overwhelming majority of these interventions were developed in the behavioral literature (e.g., applied behavior analysis, behavioral psychology, and positive behavior support).
The 11 Established Treatments are: Antecedent Package; Behavioral Package; Comprehensive Behavioral Treatment for Young Children; Joint Attention Intervention; Modeling; Naturalistic Teaching Strategies; Peer Training Package; Pivotal Response Treatment; Schedules; Self-management; and Story-based Intervention Package.
- **22 “Emerging” Treatments:** treatments that have some evidence of effectiveness, but not enough for us to be confident that they are truly effective.
- **5 “Unestablished” Treatments:** treatments for which there is no sound evidence of effectiveness.

There is no way to rule out the possibility these treatments are ineffective or harmful.

The report encourages parents, educators, and service providers to use this information about treatment effectiveness as they make decisions about which treatments to select. It also strongly advises decision-makers to consider other factors in addition to treatment effectiveness, including the judgment and data-based clinical recommendations of qualified professional(s), the values and preferences of the individual with ASD and those who care for him/her, and the capacity of their local schools and/or treatment programs to deliver the treatment correctly.

The project identified significant limitations of current autism treatment research. The National Autism Center is hopeful that the results of the project will encourage the research community to concentrate its efforts and conduct more research in areas that have not been studied adequately. In addition, research on all treatments should be extended to appropriate age groups, treatment targets, and diagnostic populations.

About the National Autism Center

The National Center is a nonprofit organization dedicated to supporting effective, evidence-based treatment approaches for Autism Spectrum Disorders (ASD) and to providing direction to families, practitioners, organizations, policy-makers, and funders. The Center's goal is to serve individuals with ASD by responding to the rising demand for reliable information and by providing comprehensive resources for families and communities.

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**Susan M. Wilczynski, Ph.D., BCBA
Executive Director, National Autism Center
Chair, National Standards Project**

Dr. Wilczynski is the Executive Director of the National Autism Center. In her role as Chair of the National Standards Project, she has worked in collaboration with experts from around the country in order to establish national standards for the treatment of individuals on the autism spectrum. Under Dr. Wilczynski's leadership, the National Autism Center has recently published Evidence-based Practice and Autism in the Schools. This resource manual for educators is being distributed to school systems across the country. It is the first in a series of manuals to support families, educators, physicians, and service providers.

Before joining the National Autism Center as Executive Director, Dr. Wilczynski developed and directed an intensive early intervention program for children with Autism Spectrum Disorders (ASD) at Munroe-Meyer Institute for Genetics and Rehabilitation. She has authored multiple articles and book chapters on the treatment of ASD and has co-edited the book, *Effective Practices for Children with Autism*.

A licensed psychologist and a board certified behavior analyst, Dr. Wilczynski has held academic appointments at the University of Southern Mississippi, the University of Nebraska Medical Center, and UMASS-Boston.

She is a frequent keynote speaker on the national conference circuit for issues related to early identification of and intervention for children with ASD, treatment selection, and parent education, as well as building and sustaining system-wide capacity to deliver effective, evidence-based treatment for individuals with ASD.

Character is like a tree and reputation like its shadow. The shadow is what we think of it; the tree is the real thing. - Lincoln

Anyone can hold the helm when the sea is calm. - Unknown

**A man is rich in proportion to the number of things he can let alone.
- Thoreau**

Every problem has in it the seeds of its own solution. If you don't have any problems, you don't get any seeds. - Norman Vincent Peale

**Discovery of a solution consists of looking at the same thing as everyone else and thinking something different.
- Albert Szent-Gyorgyi**

There is no security in life, only opportunity. - Denis Waitley

If opportunity doesn't knock, build a door. - Milton Berle

When you make a mistake, don't look back at it long. Take the reason of the thing into your mind, and then look forward. Mistakes are lessons of wisdom. The past cannot be changed. The future is yet in your power. - Mary Pickford

You only have to solve two problems when going to the moon: first, how to get there; and second, how to get back. The key is don't leave until you have solved both problems. - Neil Armstrong

**Isn't it enough to see that a garden is beautiful without having to believe that there are fairies at the bottom of it too?
- Douglas Adams**

**You can preach a better sermon with your life than with your lips.
- Oliver Goldsmith (1728-74)**

Problems are good, not bad. Welcome them and become the solution. When you have solved enough problems, people will thank you. - Mark Victor Hansen

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

**Just think of the tragedy of teaching children not to doubt.
- Clarence Darrow**

**A Career In Advocacy by Mark F. Romoser
"Systems Change Advocate,
Silicon Valley Independent Living Center, San Jose, CA".**

Believe it or not, it all started with dolphins. The chance to interact with dolphins off the island of O'ahu was what first brought me to Hawai'i back around 1998. A couple of years later, I moved there to stay (or so I thought). At first, I was with a small technology startup. How small? I used to joke that "it was a two-man operation: one of us has a social disability that prevents him from forming meaningful business relationships – and the other one has autism!" Well, needless to say, it didn't take long for him to run the company into the ground.

What was I to do? 5,000 miles from home, in a place with very few jobs that don't require placing a lei around a stranger's neck and saying "Aloha!", and with terrible interview skills to boot. Then I saw a newspaper ad for a self-advocacy coordinator. Bachelor's degree? Check. Experience with disability? Check. Only one thing: I had no idea what a "self-advocacy coordinator" was. Turns out, neither did anyone else in Hawai'i. So after a few sessions with the Internet, I knew enough about it to get hired.

Hawai'i's Developmental Disabilities Council, in cooperation with Hawaii Centers for Independent Living, had created something called Hawaii SAND (Self-Advocacy Network on Disability). They selected ten people, most of them with disabilities, from around the state: two from each island, with the two halves of the Big Island counted separately. There are no ferry services between the main islands. The only way to get there is to fly on one of a few regional airlines. This gets expensive in a hurry. The first order of business was for me to figure out who would pay for the air tickets so the new self-advocates could get to statewide meetings. At one point the DD Council's planner accused me (jokingly, I think) of extortion! Then a new director came to HCIL. Pat was much more interested in political advocacy than the old director, Mark, had been. Soon she had me working the halls of the Hawai'i State Legislature (it's right across from "Iolani Palace", the building used as Hawaii Five-O's headquarters on TV). I spent much of my time attending hearings on bills that affected people with disabilities, including autism. I got to meet key representatives and senators, as well as some of the heads of state departments. This may sound scary and intimidating to some of you, but it really isn't. Remember, these people depend on your votes in order to keep their jobs in the legislature or Congress. The last thing they want to do is make you mad at them in any way.

Hawai'i's definition of "developmental disability" contains a quirk: unlike most other states, it has no IQ cutoff. Thus, a person with an IQ somewhere around 160, a cum laude degree from Yale, and autism can be considered a person with DD, and be on the DD Council. After a few years on the Council I was elected chair. This meant I got to go to nationwide conferences of DD Councils (alas, it was before our esteemed editor-in-chief was on the Colorado council!). The first year, the conference was in Alexandria, Va., right outside Washington, D.C. So we all went to Washington to visit our Senators and Representatives on Capitol Hill. After I and other council members explained our positions on issues like "Money Follows The Person", I even got my picture taken with Sen. Daniel Akaka! The next year, I went back to Washington with NCIL, the National Council on Independent Living, and went to Capitol Hill again. This time I met Sen. Daniel Inouye on the way out of his office! Now I'm enough of a Washington insider that I know where to get the best food on the Hill: the Regional American dishes at the House food court.

Back at home, I kept busy helping to start SAAC, the Self-Advocates' Advisory Council. This is the closest thing Hawai'i has to People First. It may even join the national group SABE (Self-Advocates Becoming Empowered) someday. If you're ever out there, be sure to say Aloha to SAAC and their best self-advocate, Sarah Ahina. Something else they do in Hawai'i is the annual DD Council Family Day at the Capitol. Over 400 people with disabilities, parents and caregivers come to the Capitol for a day of meetings with their legislators. Many fly over for the day from their home island. It's the largest event of its kind during the whole legislative session. The "Neighbor Islands" (Maui, Kaua'i, and the island of Hawai'i, the "Big Island") usually each get a room where they can meet with their legislators. I used to spend the day going back and forth from room to room to see where the action was, rather than just making appointments with one or two legislators.

Alas, some people in Hawai'i were resistant to the kind of change Pat was bringing to the islands. They managed to get the Legislature involved, and before long, Pat went back to the mainland. After Pat left, it got harder and harder to get any advocacy done in Hawai'i. There was hardly anyone from other agencies, except maybe the DD Council and the Autism Society, that I could work with. Finally I decided it was too much to take, and started looking around for jobs on the mainland.

After a while I saw one at the similar center here in San Jose, Calif. We're about fifty miles southeast of San Francisco, and actually the largest city in Northern California, larger than S.F. itself. Our new

director, Sarah, is kind of like "Pat Jr." (she's only in her mid-30s). She has a national reputation for being a strong advocate for people with disabilities. So I applied, got the job, and am now working as the Systems Change Advocate here. I've only been here a couple of weeks, but already I've been to Sacramento, our state capital, to meet with other advocates from around the state, and by the time you read this, I'll have met with my first assemblymember (same as "state representative" in most other states).

So now you know how a person with autism got his start as a professional advocate. There's really no reason any of you can't do it, too!

A weed is a plant that has mastered every survival skill except for learning how to grow in rows. - Doug Larson

**In the right light, at the right time, everything is extraordinary.
- Aaron Rose**

**If you carry your childhood with you, you never become older.
- Tom Stoppard**

There is a difference between the waiting of the prophet and the standing still of the fool. - Emerson

The worth of a book is to be measured by what you can carry away from it. - James Bryce

To think is to differ. - Clarence Darrow

All words are pegs to hang ideas on. - Henry Ward Beecher

Lost time is never found again. - Benjamin Franklin

Human nature will not flourish, any more than a potato, if it be planted and replanted, for too long a series of generations, in the same worn-out soil. My children have had other birthplaces, and, so far as their fortunes may be within my control, shall strike their roots into unaccustomed earth. - Nathaniel Hawthorne

Don't bother just to be better than your contemporaries or predecessors. Try to be better than yourself. - William Faulkner

Success comes in cans, failure in can'ts. - Unknown



**The Power of Words:
How We Talk About People with Autism Spectrum Disorders Matters!
By Judy Endow, MSW**

Excerpted from "The Power of Words" DVD enclosed pamphlet:

"Autism is on the rise. The latest statistics from the Centers for Disease Control and Prevention (2008; http://www.cdc.gov/ncbddd/autism/faq_prevalence.htm) tell us that 1 in 150 children in the United States has autism. A proper and early diagnosis is critical, as early intervention has shown to be successful.

An unfortunate effect of receiving a diagnosis is that it can separate you from the rest of the population. As an adult with an autism diagnosis, I have experienced this first-hand. It is one of the necessary evils embedded in diagnosing and treating an autism spectrum disorder as well as many other disorders and conditions.

To mitigate the negative effects of what can otherwise be a useful "label," it is important to be continually mindful of the separation that language can cause between people – in this case, between the group of the 149 with typical neurology and the 1 with autism neurology. How the 149 talk about the 1 with autism is powerful. Even the nice and kind words you speak can set the tone for acceptance or rejection, for inclusion or exclusion.

For example, although I am an experienced speaker and presenter, in situations requiring extensive travel, I need a support person. I do not need any support in speaking, but I need support to navigate the logistics required to negotiate strange airports and conference centers for several days in a row. I

easily get lost in unfamiliar places, I do not recognize faces and, in addition, I need to receive sensory input daily when in unfamiliar environments.

The way others talk about my need for support in situations like this on my behalf can be the determining factor in whether or not I am issued an invitation to speak at a conference. After all, no conference organizer is eager to sign on an incompetent speaker, and his or her perception of my competence often depends on how my need for a support person is communicated.

In this production, We/They statement pairs are used to show the language differential often unwittingly employed by those who are defined as our “helpers,” whether our families, our teachers, or the professionals who work with us. Interspersed throughout the DVD are short poems reflecting my personal thoughts and experiences as this sort of language has been used to describe me and my behavior at different times throughout my life.

The We/They word pairs are based on Mayer Shevin’s poem “The Language of Us and Them” (1987: www.shevin.org), which is very meaningful to me. In their hectic lives, most people do not take the time to read poems. My hope is that by translating the meaning of Shevin’s words into visual images, I have made them accessible to many more people and that, therefore, they will have a greater impact. My son Daniel, a talented musician (not merely a mother’s bragging, but a fact – among other things, he has performed three times in Carnegie Hall!), composed the background music specifically to go with the DVD.

It is my hope that after viewing this production, you will be inspired to use language more wisely... Your words have the power to add inches, and even feet, to my stature. What you say and how you say it matters. It sets the stage for my acceptance or rejection. It paves the way for possibilities, opening or closing doors.

Now that I am diagnosed with an autism spectrum disorder, how will you speak about me? How will you choose to use your power?”

If you wish to watch this DVD it can be ordered from Autism Asperger Publishing Company www.asperger.net.

What others have said about *The Power of Words* by Judy Endow:

“This DVD perfectly captures the significance of the words we choose and more importantly, the intentions behind our word choices when discussing people with autism. *The Power of Words* is a powerful tool that will help us set the tone for acceptance and inclusion rather than rejection and exclusion.”

- Marguerite Kirst Colston, vice president, Constituent Relations, Autism Society of America

“Too few people in this country understand that negative campaigns and messages about autism put people on the spectrum at a great psychological disadvantage. I would love if everyone saw *The Power of Words* at least once in their lives.”

- Michael John Carley, executive director, GRASP, and author of *Asperger’s From the Inside-Out: A Supportive and Practical Guide for Anyone with Asperger’s Syndrome*

“Judy Endow has done it again. As with her other thought-provoking writings, Endow is sure to change both hearts and minds with *The Power of Words*. I have always been moved by Mayer Shevin’s poem ‘The Language of Us and Them.’ It is stirring to see this landmark work integrated with Judy’s own stark and beautiful prose. Every teacher and teacher-to-be needs to see this unique and stunning video.”

- Paula Kluth, Ph.D., author of *You're Going to Love This Kid: Teaching Students with Autism in the Inclusive Classroom*

"Words can change thoughts, knowledge, and attitudes. Watching this DVD will give you a new and valid perspective on autism."

- Tony Attwood, Ph.D., international writer and speaker on autism spectrum disorders

Judy Endow, MSW, maintains a private practice in Madison, Wisconsin, providing consultation for families, school districts and other agencies. Besides having autism herself, she is the parent of three now grown sons, one of whom is on the autism spectrum.

Daniel Endow attends the University of Wisconsin-Madison. He has performed in Carnegie Hall on three occasions, the most recent in 2006 as pianist for the National Wind Ensemble.

A Brief Review of this DVD by Sharisa and Jay Kochmeister:

We were fortunate to have the opportunity to pre-view and review this wonderful DVD Package for AutCom's Conference at Judy Endow's request and recommended its use there. We are also fortunate to know Judy Endow and Mayer Shevin, whose words inspired this remarkable video.

We were extremely moved by Daniel's music, the images and the words and highly recommend this video to any and all who want to understand disabilities and how words wound as well as heal.

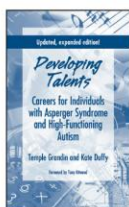
The following are Mayer Shevin's words and that is followed by a very special offer for our readers from the publishing company:

"The Language of Us and Them" (Poem by Mayer Shevin)

We like things.
They fixate on objects.
We try to make friends.
They display attention-seeking behavior.
We take breaks
They display off task behavior
We stand up for ourselves
They are non-compliant
We have hobbies
They self-stim
We choose our friends wisely
They display poor peer socialization
We persevere
They perseverate
We like people
They have dependencies on people
We go for a walk
They run away
We insist
They tantrum
We change our minds
They are disoriented and have short attention spans
We have talents
They have splinter skills
We are human
They are???

Meet Our Authors on the Spectrum

AAPC is proud to showcase a variety of works by authors on the autism spectrum. These works include everything from first person accounts to educational curriculum. We hope that the breadth and depth of materials available will foster an increased awareness and understanding of autism along with practical information on how we can all – whether neurotypical or autistic – live and learn together successfully in a world that is not always “autism-friendly.”



Developing Talents: Careers for Individuals with Asperger Syndrome and High-Functioning Autism – Updated and Expanded Edition

Temple Grandin and
Kate Duffy

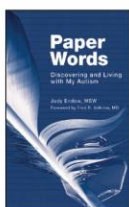
Code: 9027
Price: \$21.95



Asperger Download: A Guide to Help Teenage Males with Asperger Syndrome Trouble-Shoot Life's Challenges

Josie and Damian
Santomauro

Code: 9990
Price: \$19.95



Paper Words: Discovering and Living with My Autism

Judy Endow, MSW

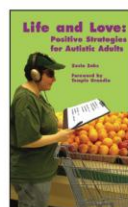
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Price: \$18.95



The Power of Words: How We Talk About People with Autism Spectrum Disorders Matters! (DVD)

Judy Endow, MSW

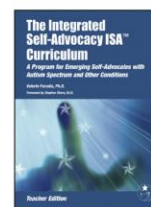
Code: 9730
Price: \$9.95



Life and Love: Positive Strategies for Autistic Adults

Zosia Zaks; Foreword
by Temple Grandin

Code: 9965
Price \$21.95



The Integrated Self-Advocacy ISA™ Curriculum – A Program for Emerging Self-Advocates with Autism Spectrum and Other Conditions

Valerie Paradiz, Ph.D.;
Foreword by Stephen
Shore, Ed.D.

Code: 9028
Price: \$21.95

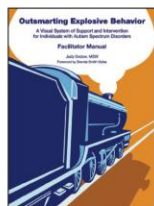
Code: 9048
Price: \$18.95



Ask and Tell: Self-Advocacy and Disclosure for People on the Autism Spectrum

Edited by Stephen M.
Shore; Foreword by
Temple Grandin;
contributing authors:
Ruth Elaine Hane,
Kassiane Sibley,
Stephen M. Shore,
Roger N. Meyer, Phil
Schwarz, Liane Holliday
Willey

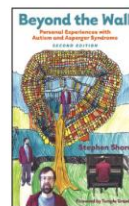
Code: 9940
Price: \$21.95



Outsmarting Explosive Behavior – A Visual System of Support and Intervention for Individuals with Autism Spectrum Disorders

Judy Endow, MSW;
Foreword by Brenda
Smith Myles, Ph.D.

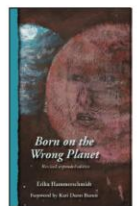
Code: 9035
Price \$49.95



Beyond the Wall: Personal Experiences with Autism and Asperger Syndrome; Second Edition

Stephen M. Shore;
Foreword by Temple
Grandin

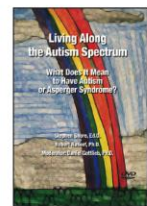
Code: 9922
Price: \$21.95



Born on the Wrong Planet

Erika Hammerschmidt;
Foreword by Kari Dunn
Buron

Code: 9014
Price: \$16.95



Living Along the Autism Spectrum – What Does It Mean to Have Autism or Asperger Syndrome? (DVD)

Daniel Gottlieb, Ph.D.,
Robert Naseef, Ph.D.
and Stephen Shore,
Ed.D.

Code: 9729
Price: \$29.95



Autism Asperger Publishing Company

www.asperger.net • 877-277-8254 (phone) • 913-681-9473 (fax)

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Internet orders: Enter AUTHOR at checkout in the Coupon/Promotional Code box.
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ADVOCACY - THE PERSONAL TOUCH by Xenia Grant

In Webster's dictionary, advocacy is a noun and the definition is the act or process of advocating or supporting a cause or proposal. The same dictionary defines an advocate as a noun where one pleads the cause of another, specifically one that pleads for the cause of another before a tribunal or judicial court. The second part of the definition says that an advocate is one that defends or maintains a cause or proposal and one that supports or promotes the interests of another. In addition, when the word advocate is a transitive verb, the definition is to plead in favor of.

How do I bring a personal touch to advocacy?

Let me tell you how I do it when the word "advocacy" is used as noun. First, as a person with autism, just by living independently, working, and just plain living, I am advocating for myself. How? By helping people when they come to ask for information on what support groups are in the Denver area or wanting information on who to contact when it comes to employment or seeking professional help. Many times, I talk to that person, professional or parent on the phone or I send an email with the information that he/she wants or websites and email addresses of various people and/or organizations that help them in the area where that person wants assistance. Also part of being an advocate is listening to a person talk. Many times, be it a parent, professional or person with autism, he/she will tell me about the struggles and difficulties that the person with autism is living with. Just by being there, whether by phone or in person, listening is valuable. Many times autistic people feel misunderstood and sometimes trust in people is at a minimum or not there at all. Not only is listening important, but also taking interest in what that autistic person likes and what he/she is interested in is major. Many times people on the spectrum, including me, have interests that few people share or understand. So by showing interest and talking about subjects that range from steam engines to antique refrigerators to superheroes to quantum physics is a way not only to advocate for that person but it is a way to build the bonds of trust. Without trust, communication and advocacy are not possible.

When the word advocate is used as a noun, I prefer the third use of the definition. When it comes to autism, all of us on the spectrum need support and people promoting their interests. After all, many people on the spectrum don't feel understood by the non-autistic world. And to have someone with autism come and help in some small way or just simply listen to his/her story about what ever trial or tribulation that person is experiencing makes a huge difference.

Mainly, I think of advocacy as a verb because I am active and not passive in helping that person or family member. Many times, that person wants information on the services that are available in Denver, Boulder and adjacent areas. Or that person

wants to know more about support groups and ask questions on what is available and I lead him/her to the support groups that are free because in this tough economic climate, people don't have lots of money to spend on a group that last 6-8 weeks, when the free ones runs continuously through out the year.

Advocacy also takes form in that I am on two boards, two Governor appointed positions and am co-facilitator of a local chapter of an organization whose headquarters is in New York City. By being on these more formal and/or political entities, it shows that I am out in the public eye and being part of the official system. Because of that, I get calls from places as far as Grand Junction and emails from various people. In addition, earlier this year, I have called various state senators and representatives to encourage them to vote yes on Senate Bill 244. The bill passed and Governor Ritter signed it on June 2. Learning about the political process and being involved is part of what advocacy is about, but only a small part. Being involved in the cultural aspect is also what advocacy is about. Promoting awareness of autism as a culture, unique and worthy of respect and preservation is part of being an advocate. I believe that the world at large can learn much from people with autism. We have traits that are critical to the success and well-being of humanity as a whole. Traits such as honesty, hard work, loyalty, a different way of looking at the world and creativity are so needed in the 21st Century. After all, the arts and sciences wouldn't be where they are today if it weren't for people on the spectrum. Think of Donna Williams, Albert Einstein, Glenn Gould, Vernon Smith, Temple Grandin, plus countless others who have contributed mightily to the well being of our civilization. Being an advocate means highlighting autistic culture and what we offer to the world at large.

Everyone has a purpose in life... a unique gift or special talent to give to others. And when we blend this unique talent with service to others, we experience the ecstasy and exultation of our own spirit, which is the ultimate goal of all goals.
- Deepak Chopra

Advice is like snow - the softer it falls, the longer it dwells, and the deeper it sinks into the mind. - Samuel Taylor Coleridge

Nearly every man who develops an idea works at it up to the point where it looks impossible and then gets discouraged. That's not the place to become discouraged. - Thomas A. Edison

Some people procrastinate so much that all they can do is run around like firefighters all day - putting out fires that should not have gotten started in the first place. - Nido Qubein

Just begin. It's like striking a match. It forces you to do something with it or get burned. - Bob Perks

Advocacy by Chantelle Jary - Autism Mum

This month I turned to wikipedia for clues on how Advocacy is defined. Not because I do not understand the word but because I was curious as to whether my understanding of my own role in the advocacy for my child on the Autism Spectrum fits neatly into an official definition. As you would know if you read my submission last month, I am not a fan of strict and unchangeable definitions, labels and neat explanations; so was thrilled to see the definition of the word advocacy "has many interpretations" as wikipedia definition explains below:

"Advocacy is the pursuit of influencing outcomes – including public-policy and resource allocation decisions within political, economic, and social systems and institutions – that directly affect people's current lives. (Cohen, 2001)

Therefore, advocacy can be seen as a deliberate process of speaking out on issues of concern in order to exert some influence on behalf of ideas or persons. Based on this definition, Cohen (2001) states that "ideologues of all persuasions advocate" to bring a change in people's lives. However, advocacy has many interpretations depending on the issue at stake, which can be different from this initial value-neutral definition."

Every parent is an advocate for their child whether they are conscious of their role or not. On the diagnosis day or "D day" as we call it around here at home, which at one time stood for desperation, developmental assessment, diagnosis, devastation and dreams lost, I walked out of that little room in Hornsby, NSW, Australia devoid of feeling. I had nodded along and listened silently to the developmental "expert" deliver the most dreadful news I'd ever thought I would hear. I was totally devoid of any feeling... devoid and numb.

I did not have my Jackson with me that day when the results of his developmental assessment were delivered to me. I was told to come in without him as it would be a long appointment and they preferred the child in question was not present for the discussion about how they "performed" in the assessment and the conversation about their diagnosis and future outcomes. Not only did I not have Jackson with me, I did not have my husband either. He was on a plane somewhere overhead returning from a conference for his work so I was in that little room with the expert and my younger son, Hunter who was around 5 months old, breastfed at the time and was pretty much a permanent accessory on my person during that period of our lives.

There we were. Hunter, on the breast as usual, the developmental assessor with kind eyes and bad news... and me... numb and nodding.

Helen. That was her name. I'll never forget it as long as I live. Helen opened the appointment matter of factly and pulled no punches about what the developmental assessment my Jackson

had undergone the previous week revealed about my son's future. The paperwork with all the diagnostic terms was full of separate explanations and diagnoses including global developmental delay, speech and language delay, hyperactivity disorder and the big one... Autistic Spectrum Disorder. I was told Jackson would have high ongoing needs for the rest of his life, would require ongoing speech therapy throughout his schooling years, would more than likely need specialist schooling in an Autism-specific class and would possibly require a group home setting as an adult with this type of lifelong disability. Nodding, nodding, nodding. Numb, numb, numb.

Helen gave me a copy of all the results and some paperwork for the social benefits office here in Australia, Centrelink, to process so I could receive my carer's allowance now that I was officially the mother of a child with a perceived disability. She helped me put a tired, crying and grumpy baby, Hunter, in the pram so I could walk back to the car and return home to my newly deemed Autistic son and carry on with my new life.

One thousand things went through my mind on that drive home and at the same time nothing went through my mind. As I said... devoid.

The word Advocate certainly never entered my psyche during that drive and I doubt I have officially or consciously recognised it as part of my actual "job description" in my role as a mother until recently.

Unconsciously, though, is another story. As I look back on that lonely trip home with a baby in the back who was surely crying but also surely not heard by me in my devoid and numb world, inhabiting an alternate and certainly not present space on autopilot to get us home, I do remember thinking about Helen's words and predictions about Jackson's future.

"He's only two years old!" "He is only two years old!" I could not comprehend that at two years old how anyone, "expert" or not could predict what on earth my child's life would be like at twenty five years old and whether he would be living in a group home or whether he would be the director of his own multinational company regardless of a diagnosis made in August 2008. "He's only two years old."

I now realise this mantra, this silent outcry running on repeat in my head was the beginning of advocating for a little boy who might otherwise be written off into a predestined future with a predetermined outcome. This was the beginning of my pursuit to change the outcome of his then current life as the wikipedia definition of advocacy suggests.

My husband returned home that night and as we read through the results of that assessment together we sobbed and grieved and mourned for Jackson's predicted outcome. Then, I started to get

really angry. The rage I felt at my son's future or at the societal perception that he was now disabled and would live a predetermined life with limited choices available because of his label was tangible. The rage was overwhelming and all-encompassing. I still feel that rage even today but I'm learning to curb it, control it and channel it into picking the important battles to fight for this child's future and to make changes in how the world will perceive my son and his Autism.

So now I know that when we wear an Autism awareness ribbon on our lapels or when we explain to a stranger who has offered unsolicited advice on parenting our "naughty" child whilst out and about that we are all advocates and practising advocacy. The simple act of talking about Autism and educating a previously ignorant community member about why our child is overwhelmed in a bright, busy shopping centre is advocating for them. Does this mean I am ten foot tall and bulletproof and march out with my Autism Advocacy armour on every day? No way. Some days I am so exhausted and so overwhelmed at the task at hand in my "pursuit to change my son's outcome" I can barely muster the strength to say hello to the checkout operator at the supermarket or answer my phone to an old friend wanting to chat and catch up on where I've been and what I've been doing this last year.

I do have my own version of Autism Armour though. Every day I wear a necklace. On the chain hangs two special pieces of my armour. My boys gave me a pendant of their fingerprints this year with their initials inscribed on the reverse side. Everywhere I go and every single day I wear my boys' fingerprints and an Autism awareness ribbon charm around my neck. I find myself fingering it and feeling the ridges of my little boys little fingerprints unconsciously throughout the day. I've noticed when I am talking about my boys or when I am talking about Autism my hand automatically goes to the pendant and I run the fingerprints and the ribbon charm up and down the chain and around my neck. It's my safety blanket. My comfort item. My armour.



In the early days following diagnosis, I thought advocacy or raising awareness meant chastising the onlookers who felt it necessary to criticise my parenting when Jackson was being difficult or oppositional whilst he was distracted by

fluorescent lights in the supermarket or in sensory overload in the line to get a treat at McDonalds. I felt like I needed a t-shirt or a sign to hold above my head saying, "My son has AUTISM! What's your excuse?" I was so angry, so defiant and so aggressive in my bid to advocate for this little boy. I scolded family members, shunned friends and lamented that they "just did not get it" all the while thinking they need to learn! I found myself yelling at an old lady who told me Jackson needed a good smack on the bottom because he was such a naughty little boy. Not only did I yell at her, I called the local newspaper and asked them to write a feature story about Autism. The local paper was extremely supportive and did a story about our encounter with the old lady at the shop and highlighted the local services for children with Autism and I think I felt like I could change the world one local newspaper at a time. I'm still pleased we did the article but I look back and think how much more effective it would have been to politely explain the situation and to recognise that the little old lady in the shop was coming from a place of ignorance through no fault of her own. I do not think anymore that she was coming from a place of nastiness.

I felt I had to "explain" my son wherever we went and would announce that he has Autism which is why he was not answering the friendly passer' by who said hello or tell the other parent in the park that he has Autism when he would get into another kid's space not realising they were not interested in playing with him. I felt advocacy was about "rescuing" him from any situation where he might look or feel different or be perceived as such. Not ever because I was ashamed. Far from it. But, because I was so so fearful of him ever feeling the pain of rejection or ridicule as I outlined in last month's submission.

I still get angry at rude and/or ignorant people and still find myself "explaining" him but not nearly as much anymore. I choose to do the explaining when at doctor's appointments or in situations that will be a definite cause of anxiety for him and where he will be most likely to need a little bit of extra understanding. I'm conserving my rage and advocacy energy for the battle that lies ahead with the education options or lack thereof in this country for children with Autism. At this point in time, we are sitting pretty in a comfortable preschool setting and are settled into our own unique early intervention programs but we are in for some big time advocacy struggles to find the right school setting that will continue to nurture my child's difference and not try to constantly change it and therefore change him. For now things are going smoothly with fewer opportunities presenting themselves where we need to pull out the big guns and the serious armour in the advocacy war but we realise there will be many battles to come to conserve our energy for. I've come to understand it's too tiring to be in that heightened battle mode 24/7.

Some days I can only concentrate on the basic daily routine and driving Jackson to preschool but even putting one foot in front of the other on those days is advocating. By sending Jackson to preschool, speaking to the teachers, the other parents and watching Jackson play happily with the other kids is advocating for Autism, for my son. Some days I would choose to miss out on an activity because I think it will all be too hard to manage as a family or secretly hope Jackson does not get invited to the party all the other kids are going to because I am frightened about how he will be perceived or how he will "behave" in relation to the other parents standards. Every single time I have those doubts, every single time, Jackson has proven them unfounded. He's managed. He 'behaves" just fine. He displays and more importantly feels happiness at the events with the other kids, at the zoo, at the picnic, wherever we've been brave enough to go of late. I'm usually frantically caressing my pendants to calm my own stress levels but every single time Jackson copes well (not completely without the odd hitch or stressful moment but overall, copes remarkably well).

Every time.

I will continue to fight the battles when they arise and stand behind him every single step of the way ready to don the armour, raise awareness and advocate for my son and my family as a whole.

However...

You know...

I think Jackson is becoming his own best advocate.

This makes me want to stand up and cheer!

Bravo little man. Bravo.

Pics of Chantelle and Her Boys:



Channeling Dan by Jennifer A. Peterson

In the wake of Patrick Swayze's death from pancreatic cancer, it serves as a bittersweet reminder of someone else I lost from the same disease: my former boss. His name was Dan Bebble. He was a loving husband, father of four, formidable attorney, community leader, and all-around solid guy. Dan died of pancreatic cancer at the age of 37.

The approach I take in life is that everything happens for a reason. There is no doubt whatsoever the work that I did for Dan paved my future as an advocate for my children. He helped me to realize and apply my potential. In college, I started working for a degree in Nursing and I managed to learn a vast amount of medical terminology and anatomy. In the end, I changed majors to Justice Studies and the rest is history.

Before working with Dan, I knew how to format a letter but did not know how to write one. In time, I learned his style of stating the facts, maintaining neutral tone, and playing to the preferences of the reader. I learned how to be a pussycat: purring to cozy up to the reader and returning favors in kind, yet agile and swift when action is demanded of the recipient. My bite is in the facts. There needn't be malice or an overbearing attitude to get things done.

Dan was my favorite of the attorneys I have worked for. It most likely has something to do with our proximity in age. He was of the mindset that I was his "assistant" and not just his "secretary". He is part of the next generation of lawyers who respect the women in their employ and what they can be capable of doing to get the job done. He preferred to do a lot of the administrative tasks that other attorneys (or bosses, in general) usually delegate to the support staff.

He was a fair person to work with and took any mistakes I made in stride. One time after having to admit a very serious mistake that other people would not have shown up to work the next day for, Dan proceeded to ask me if I would be interested in doing the medical record summaries for the plaintiffs in our cases. I was elated at his capacity for forgiveness and the opportunity he offered. It was truly a defining moment in my life. One of the more fulfilling aspects of my career was leafing through the records in search of pertinent information for other casework. Another privilege I had on one occasion was to attend a set of depositions with him. I took notes on the testimony before the witness transcripts came back. It was fascinating to observe the dynamics of people testifying under oath in a given dispute.

Fast-forward to right now and with Dan's assistance, I have been able to sift through my childrens' records and do my little "secretary thing". Drafting correspondence in support of my childrens' needs has been a breeze. I have produced a ton of work related to coordinating their education supports and medical issues in the classroom. In the years since Dan passed on, I've found myself asking: "What would Dan do?"



Ondrea Marisa Robinson

Testimony

**As I look back over my life,
I think a lot of things over.
I am a blessed young woman
Sharing my testimony
With those who need to hear it.**

**God has truly blessed me
Even though I have autism.
I will rise to the occasion
And let God guide me
To do what's right.**

People who consider themselves victims of their circumstances will always remain victims unless they develop a greater vision for their lives. - Stedman Graham

Don't be disquieted in time of adversity. Be firm with dignity and self-reliant with vigor. - Chiang Kai-Shek

The one resolution, which was in my mind long before it took the form of a resolution, is the keynote of my life. It is this, always to regard as mere impertinences of fate the handicaps which were placed upon my life almost at the beginning. I resolved that they should not crush or dwarf my soul, but rather be made to blossom, like Aaron's rod, with flowers. - Helen Keller

You may delay, but time will not. - Benjamin Franklin

What to do Before the IEP Meeting by Jane Strauss

Here it is; the beginning of the school year again! Perhaps your child has made a significant change - for better or worse or just different - over the summer. Maybe they are transitioning to a new school, district or program. Perhaps an annual review is coming up, or even the three year review. Whatever the situation, you can be sure that at some point an IEP meeting will be coming up.

I've been advocating for my family and others since 1988. As an advocate, my strategy is to provide clients with some hints, tips, and tools, and then stand back to let them run with their new knowledge. Since this month's topic is advocacy, this piece will be about the background of my advocacy model and some tips and tools for good outcomes.

The background of this model is a dollop of old-fashioned open market bargaining, with a bit of formal negotiation thrown in. In order to pull it off, you basically have to realize and fully own two things:

- You are the expert on your child, and
- Nothing ventured, nothing gained.

The first is obvious. Unless you are working 90 hours a week and someone else is raising your child, you probably see more of him or her than anyone else, and certainly than any school staff member. You know the kid's manipulations, their little foibles, likes, and dislikes. Jimmy may be able to convince his DAPE instructor that he can't balance on one foot, but you see him do it regularly at Martial Arts or on the playground. Susy may convince her OT she can't button one inch buttons, but you see her closing half inch ones on doll clothing.

The second is common sense, which is not common and often ignored. School staff members are accustomed to following a set pattern for all students with a given label. You can't expect them to consider deviating from it, even when appropriate, unless you ask.

A standard model of negotiation involves

- You ask for what you really want, the "best," even an "extreme" in some folks' opinion
- The other side tries to push the "usual" service or level of service.
- You respectfully decline and bolster your request with evidence.
- They move a little.
- You stand firm, perhaps modifying your request a tiny bit.
- You negotiate until either they cave or an "in between" is agreed upon.

I give three major pieces of advice to parents entering the IEP situation. They are:

1. **Be sure you are not alone in the meeting.** If possible bring at least two other people with you, at least for moral support. It's even better if you have a PCA, a tutor, an outside therapist, or a respite provider along. Schools are accustomed to having large numbers of their personnel overwhelming a single parent or at most two, and it keeps them off guard. In one meeting with a preschool Special Ed team, we had five participants to their five, and I rarely had issues with the school again.
2. **Be sure you know where you are, what has worked before, what has not worked before, and what goals you (and your child, if they are over 14 and capable of formulating goals) have.** If you don't know where you have been and where you want to go, you are likely to end up somewhere else!
3. **Be sure you do your homework.** Bring with you any relevant testing, physician notes, or other materials you have. Ask for paperwork in advance (though don't be surprised if the school declines to provide it - they are busy and often finish paperwork right before meetings) and don't be afraid to ask that the meeting be postponed or rescheduled if you feel you are being pressured to make a decision and need more time to review the paperwork. How to do the homework? First, prepare by reading the most recent IEP. Think about what seems to be working, what is not, and how your child has changed since it was written. Have any goals been accomplished? Have any needs changed? Do you know of any new applicable resources? Make lists of these, and try to keep related material and information together. Even if the resources are simple, such as ergonomic tools, list them.

Don't assume that the professionals know everything. I read on one of my Listservs a note from another parent about ergonomic, "Twist n Write" pencils. They worked really well for my son, increasing his control in writing immensely. So far, I have shown ours to at least 2 Special Educators and 3 OTs (who you'd think would already be aware of the things) and none of them had seen this tool before. All the OTs announced an intention to go right out after school and buy some. Kind of makes you wonder what kind of

The Marketplace script for this is:

- *How much is that lettuce?*
- *Three dollars*
- *Nope, it's limp, brown and looks like it was picked last week.*
- *Three dollars.*
- *Okay, then I'll buy from Jones across the market, he is charging \$1.50.*
- *It will kill me to do this, but \$2.*
- *Sold.....You get the idea!*

marketing the pencil's manufacturer is (or isn't) doing, doesn't it? Some people find it easiest to have a format for thinking about issues before the meeting. Something as simple as a pair of charts can be a valuable tool. The first chart gives a starting point, by looking at the student in the context of past experience.

Pre-planner

Strengths	Challenges	What has Worked?
Sense of Humor	Staff don't understand his sense of humor Gets silly in classroom	Explain his kind of joking to staff Setting times for joking
Persistence	Perseverates Doesn't finish work	

This gives an opportunity to think of strengths first, bringing a more positive view to the entire enterprise. For space considerations, I usually print the chart in landscape format which gives a bit more room for jotting notes. To remember what has been effective, it may help to look at a number of old IEPs and similar documents.

The second chart looks ahead, modifies existing goals, and puts them in the context of the current team, its strategies, and responsibilities. It provides detail to be included in the IEP, and background for its construction. It also provides tools for implementation that need not be included but can be valuable for keeping the program on track.

Interim Planner

Goal <u>1</u>	Tell time to the quarter hour by the end of 2nd trimester and to 5 minutes by end of school year, using both analog and digital clocks, with 75% accuracy
Rationale	Will not always have access to digital timepiece and through life needs to take responsibility for being on time for class and in future work
Strategies	Use model timepieces and then build in timetelling during the day Develop VABA script and share with family for consistency
Measurement	Document accuracy at least 6 time during school day over course of a week
Responsibility	Classroom instructor, EA, OT, Family members

After you have gone through the existing IEP document, and your list of changes, the second step is to rank order goals in order of importance. Realize that several people may have some responsibility for monitoring any goal, and that several strategies may contribute to its success. Schools are sometimes of the opinion that only a small number of Goals can be achieved, and will leave them out, rather than "look bad" on paper. Your first line of defense against this strategy to limit their responsibility is to have a clear rationale for your hierarchy of your child's needs.

For example, the school might not rank telling time in analog and digital as a high priority, but you may see it as a significant part of both Math and survival skills. Their ranking is fifteen, and yours is five. You have a conflict, and may need to stand firm, if you wish the school and you to be on the same page. Be certain that you can articulate the rationale for its high priority in the scheme of things.

If you believe a Goal is in your child's best interest, push to have it left in. If the Goal isn't there it is easier for the District or School to avoid any responsibility for it. The excuse of "too many goals can never be achieved" can best be met with: "Too few goals result in inadequate and unbalanced progress, and lack of accountability, and partial achievement is better than none."

Third, look at any programming your child is participating in outside of the school day. It can be useful to get information from teachers or helpers who know your child well. For example, in one situation I obtained documentation from a piano teacher, the Sensei at a Dojo, and several PCAs. This documented that the child was able to do many more things than school personnel thought she could, and that higher goals were appropriate.

Remember that you do not have to sign the IEP for it to go into effect - you DO have to object to it in writing for it not to go into effect. Especially if there is a possibility you may have a protracted period of either renegotiation or appeals and formal hearings, as the parent, first and best advocate for your child, it is best to stay organized. It helps to get an Accordion File in which to keep the previous IEP, these planning documents, testing reports, any drafts, and the final document. Bring it to all meetings and file new information as soon as you get it in order to avoid its going astray. Use the information in the file to write out your concerns and read them at meetings if that is helpful.

Don't be afraid to call in an advocate if you find yourself beyond your comfort level or in over your head; www.pacer.org has listings of Parent Centers where you may be able to get help. Other sources are private advocates, Legal Aid, and associations such as the local Autism Association, ARC, or Learning Disabilities Association.

This Shell of Mine by Jeffrey M. Kellen - continued from last issue

But enough whining. I told you that at the beginning that I was determined to break free of this shell, and I remain undaunted to this day. I'm thirty-five now and am still living with Mom and Dad. Brian and Steve have gone on with their own lives, moved out, went to college, married the women of their dreams, and are raising their own little rugrats. I still see them from time to time, mostly at family gatherings and the like, but pretty much now it's just me and the folks. I still have my part-time job at the local cookie factory where I box cookies for some untold amount (I've heard all my monies are placed in some sort of fiduciary account controlled by my parents, but money really doesn't have any meaning to me). It seems that shortly after I started working there that the company was so impressed with my work that they started to hire other mentally and physically disabled individuals. There are a few other autistics like myself who work with me, but we pretty much keep to ourselves. Again, my mind is only limited by what my grey matter can come up with, and so far it's kept me pretty busy. Sometimes when I leave the factory at night, it darn near feels like I just walked in, like I've gone through some strange time portal.

Do you want to know something else? Another pathetic irony? I don't know why it didn't happen earlier or why I didn't pick up on it in all of my years in school surrounded with fairly like-minded individuals, but after about my third week of work, I began to sense something that had never happened before, and only with my fellow co-workers.

I told you before how, unbeknownst to my parents, that I would often peruse the family library. Well, Dad, I suppose, when he was much younger, was one heck of a sci-fi fan and, besides the Joyce and Faulkner, those books were often some of my favorites. I mean, talk about catapulting your brains into the stratosphere! Alien life forms, telekinesis, time travel, inter-dimensional travel, contemplating the Fermi paradox, and on and on and on. The only reason I bring this up is that shortly after my work began, I felt like I was having one of those moments where I was in novel by Asimov or Heinlein.

I don't want to necessarily limit my experience with words like "telepathy" or "Vulcan mind meld" or some petty crap like that. But, every so often, I would get this feeling, the kind that most people would describe as a sensation of being watched from behind or a chill that goes down your back and my mom would always tell my brother that someone just walked over their grave (I always wish I had the capacity to ask her, "But Mom, what if you're cremated?")

Anyway, I got that same feeling, as I said, fairly soon after I started working at the cookie factory. There I was, boxing cookies away like the world's future depended on it, zipping through some other galaxy all within the confines of my twenty-three year-old cranium, when I got that same feeling that someone *else* was actually attempting to communicate with *me*. The feeling was so new, like being splashed with a bucket of cold water, that I really didn't know what to think of it. I looked up, and just for the slightest of moments, so quick that I think anyone other than myself would have missed it, I spotted a very subtle smile from George Stanton, one of my co-workers that had come in shortly before I did.

At first I dismissed the whole thing, thinking that ol' George was probably like me, sailing some cerebral sloop through the Milky Way and amusing himself as I had for aeons previously. But when the very same feeling came about maybe three days later from a woman who had been on the line for just the last three weeks, I began to wonder if there was much credence to this whole telepathy business. It didn't take me long to determine that I was only having these sensations when I was at work and nowhere else. Once or twice I thought I had a very slight vibe when my parents took me to our local mall and I passed within maybe twenty feet of another autistic individual, but the feeling was fleeting and the thought quickly left my consciousness and I returned to counting the tiles along the floor as we made our way around the various shops.

After several months of these mental twinges, the communication level jumped up a notch and before I knew it, whole words and phrases were being exchanged between my fellow coworkers. After a whole year, entire conversations were being exchanged as freely as money at a county fair. What I would have given to see the look on our supervisors' faces if they could have been given the slightest clue about what was taking place right under their own subconscious noses. I'm sure they thought they had it good with a floor full of (for the most part) mute workers that never gave them any real trouble or belly-aching. It seems like the *labor force* was the one that really had it nice! Exchanging work tips, gossiping, flirting, catching up on the latest family news, and all from our very own work stations. You could chat with people three feet across from you or you could trade recipes with someone two floors up and in a different department altogether.

Now, I have to be honest with you here. This discovery at work and its resultant implications ended up being the proverbial two-edged sword for me.

Yes, I was ecstatic after years of living in virtual isolation from most of the outside world from a communicative standpoint, and I

was thrilled at the idea of having something my brothers always took for granted growing up—friends. The ability, much less the capacity, to form, strengthen, and maintain social relationships was simply unheard of for me for my entire life.

Until now.

Now, at work, I had nurtured relationships that rivaled those of my own parents. I mean, when you have the ability to communicate, how can someone be expected to compete with that? It was a gift that I would never take for granted, but in the end, it still spurred me on to my long-term goal.

When I said that my discovery was a two-edged sword, I wasn't kidding. In fact, in some ways, it made my existence outside of the factory that much more miserable and frustrating. Imagine the daily, painful juxtaposition I would make each day when I left work, a place where I was surrounded by those who could truly understand and relate to me, to getting on a bus to take me home where I was now surrounded by those who didn't know the first thing about me or my soul or my yearnings to share my life with anyone willing to listen. Or, at least, those who could.

In the end, it was this chasm that seemed to perpetually exist between my parents and me that fueled my ongoing motivation to establish some sort of tangible connectedness with them. Their love for me and my love for them never waned, but it would still be painful during holidays and such when Mike and Jacob would return home with their own children and how Mom and Dad would fawn over them like a kid does when he gets his first puppy. I could have sworn that when my nieces and nephews, up until about the age of three or so, would every now and then show that same kind of spark that showed up going on several years ago now at my place of employ. But, by the time they were four or five, whenever I would see them again, they would simply look at me as if I had a third eye placed somewhere unceremoniously and move to their Nana and Poppa.

I'm still looking for or attempting to come up with that missing Rosetta Stone that will bridge the gap of language with me and the world. I haven't lost all my faith yet, but even reality's shadow seems a little too dark to bear sometimes. Until then, I keep thinking. And trying.

And hoping.

Sharisa's Note: Thank you, Jeffrey... looking forward to hearing more from you in coming issues!

OUTCAST HORSE - Part 3 of Serialization
by my friend Jessie, 13, who has Asperger's and lives in New Zealand

For a horse that cannot stand a bad home, bad rider, bad life any longer what do they do?

Nothing-they carry on with life hoping for it to end soon, but not Sealistic he has a spirit.

He is a horse that knows what he deserves so it begins, the story of a free-spirited horse called Sealistic.

Racing Start Experience

"Now now, steady there girl!" cried Belinda as Seal let out a ear-blasting whinny and half reared. "Calm down girl, steady there, it'll all be over soon," Belinda soothed, patting her neck. Seal stopped pawing the ground and rushed towards a small chestnut mare next to them and took a chunk of fur out. "Hey! Steady there girl!" said Belinda, pulling her into the coner away from any other horses. "Keep that crazy mare of yours under control!" yelled the angry rider on the chestnut mare. "Riders, please walk your horses to the boxes" said the loud-speaker. One by one, the horses were pulled into the starting box. "Number one-Smooth Surf, please enter the box, Number two-Sunrise, Number three-Baby Blue." Belinda and Seal were listening very closely, waiting for their name to be called. "Number four-Black Satin, Number five-BrokeMyHeart, Number six-ShrinkMeDown, Number seven-SealSlime." Belinda literally jumped when she heard Seal's name being said and egged her on into the box. When Seal heard the doors close behind her, she half reared and her front hoof narrowly missed the starting bar. "Now girl, now is your chance to show everyone how great you are for your age, do your best but don't overdo it," Belinda said soothingly to Seal as the gates flew open....

The Race

The gates flew open and Seal jumped out, eager to be out of her small prison, but what really confused her is no other horses were in front! "C'mon girl we are in the lead already! You needa slow it down or you'll have nothing left for the home-strech!" Seal felt a small tug on the reins and slowed to a canter but was urged into a slow gallop again. "Don't stop the pace, just slow it down girl!" Belinda cried over the wind. "You're doing good, try to keep fifth place for now." Seal heard Belinda talking but had no idea what she was saying, there was so much noise! She just wanted to run! She was aware other horses were around as she could feel the ground moving like a stampede and could see horses in front of her so was sure some were behind. She saw a horse's head, then a neck, and felt a tiny poke in her ribs and jumped in front and passed the horse beside and in front of her so was now in fourth place. "C'mon girl get up!" she heard Belinda's voice clearly now and knew exactly what she was asking and sprang forwards. "That's it girl - c'mon ya! ya!" She felt heels digging into her skinny sides and she felt her legs aching, she heard cries and shouting everywhere, she saw horses in front and people all around her. She startd to spook and let out a small buck throwing Belinda off balance and they had to slow down so she could regain balance. "It's ok girl, keep running!" She felt heels dig into her again and took off, they were fifth again and she passed 3 horses before the finish and came out second. "That was great girl! Good girl! C'mon

slow now, its all over and done calm down." Seal felt a hand on her neck and started slowing her pace and she remembered her leg was hurting.

Second Place Mockery

She felt her saddle get lighter, then Belinda appeared in front of her and clipped the rope on. "C'mon gal, that was your best, it's ok, I'm so proud of you!" Seal knew she must've done something right but didn't know what and she was still thinking about it when she was led into a ring with 3 other horses. The loud-speaker was heard everywhere once again. "First place goes to BrokeMyHeart with an amazing second by first time racer SealSlime and last but certainly not least was Baby Blue!" There were people closing in, making lots of noise, and the horses were letting out whinnies of panic. Seal was scared and confused. She knew Belinda was there so she would be fine, but she forgot all about that when a camera flashed. Seal forgot everything and reached her full height pawing the air and her eyes rolled right back, she screamed a warning to anyone who came too close and landed with a thud but was up quick as a flash again. "Steady girl! Its ok! Calm down girl! Come down from there c'mon, it's all gonna be fine now." Seal heard Belinda and her eyes went normal and she felt a small tug on the rope and came down. She charged at anyone who came too close. "That mare has gone Loco!" cried a spectator. Belinda grinned widely. "No no, that's her son's name" she replied with a chuckle. "You named her son crazy?!" shouted another spectator. Belinda's face was blank for a while, then she turned completely white. "Loco means crazy?" she could only barely whisper the words. "Hey kid! Mabey you should swap their names! She is more Loco than any horse I've seen!" There was mocking laughter among the crowd as she walked off with the second place trophy held tightly to her chest. "Just you wait!" she shouted back nearly in tears. "I'll bring Loco to race next time and you'll see his mother is nowhere near as bad as him!" The crowd just laughed again and told her to keep off the tracks it was no place for kids.

Broken Spirit, Broken Leg

A few days later, and everything was back to normal - well nearly normal, anyway. Belinda was hurt emotionally. She knew nothing they had said was true but it still didn't help the feeling inside that kept growing the more she doubted her beliefs and trusted theirs. She went outside for the first time to see the three horses since the race and saw Seal lying down and went and lay next to her. "I'm sorry girl. I hope they haven't gotten to you too." Seal just shook her head. "well c'mon, after all that racing and then no riding I bet you're full of energy! After all you *are* a Thoroughbred." She stood up and gave Seal's halter a little tug and watched her stand up. When she looked at her legs she couldn't believe what she saw! "Oh, my poor baby! I pushed you too hard, didn't I?" She ran inside and got Greg, then pulled him by the arm outside to see Seal. "She did great! You both did great! what on earth is wro..." He broke off, his jaw dropped and his eyes bulged. "Her... her... her hoof! It's missing!" he cried in alarm. "And look at her leg! It's most properly broken the way it's hanging like that!" Belinda sat with tears streaming down her face. "I don't wanna have her put down, Greg!" she said on her knees, pulling at his shirt - her eyes welling with tears. Greg put his hand on her shoulder and squeezed it reassuringly. "Although I hate to say it... what other chocie do we have?" Belinda looked down and sobbed. "Loco needs her! Didn't you see how he acted when we first

put her on the float to bring them here! And she is always the one to calm him down! You can't do it Greg, you just can't!" Greg looked down and he knew his daughter was already hurting from the comments from the spectators at the races but this would just break her heart! "Get the bandages and some ointment and bring me the phone, she will live as long as she wants to be here and since she is still eating we have a chance!" Belinda stared up at him with disbelief in her eyes. "You mean that, Greg? You really mean that?" She jumped up without waiting for her reply and got all the things Greg asked for, then rang the number Greg told her and ended up on the line with the vet. "Good, now hand me the phone," Greg said without looking up and put one hand out which he wasn't using to rub ointment in. "Doctor, we are in need of urgent help! Our mare lost a hoof during a race and has a broken leg and we are not going to put her down. We need your help to make her as comfortable as possible until she heals and need to know if her hoof will grow back." Belinda was listening the whole time to her dad, but when he stopped she just couldn't hear the vet! "What's he saying, Greg?!" she urged him to tell her, but he just put his hand up and listened. "Yea ok, that'll be fine, as long as you are sure she can live like that... yup okies see you soon." Greg hung up and looked at Belinda, then looked down and stopped putting ointment on Seal's leg. "The doc says the hoof won't grow back and the easiest thing to do is cut off her leg." Belinda's eyes widened. "No! no we can't! Greg we can't do that! They need 4 legs for racing!" Greg stared at her with his 'Don't-Give-Me-That' look and said, "She won't be racing again-ever. It's just too dangerous with only three legs!"

Three Legged Horse

Belinda stared in horror as the vet shot a tranquilizer into Seal and rolled her gently onto the stretcher then lifted her into the HUGE back of his van. He added some attachable pieces to the table so he could rest her leg up on it. Belinda stood at the door watching her poor Seal but she could do nothing to stop it! She turned away as the vet shot another few injections into her leg to numb it completely, then took out a chainsaw-looking thing except a little bigger. "We have to wait at least five minutes to be sure she doesn't feel anything and panic while she is down or it could mess up everything." Belinda could watch and listen no more, she couldn't watch her poor baby get her leg cut off. She turned and walked towards the field with a lead and clipped it onto Loco's halter. "C'mon boy, we gotta get you outta here while your mother has her... operation." That was the nicest way Belinda could think of putting it and she walked Loco out to the pole but tied him so he wasn't facing the van then went and got the tack. When Belinda got back, Loco had turned his head and was staring at the man who was now cutting his mother's leg off! He let out a long shrill whistle and reared, twisting and turning in every direction. Belinda could only stand back and watch - she thought the ropes she had made could hold anything after the 7 years she had been doing business with her father and the men, but this one horse with the twisting like a snake broke it and headed straight for the van! Belinda caught hold of the rope and tied it quickly to a boulder and Loco was jerked to a stop. Belinda went up and put the tack on him and he calmed a little, but still threw a buck every now and then and reared almost every thirty seconds.

TO BE CONTINUED NEXT MONTH

A Life of Stages by Sharisa Joy

In the opening act
of a life so long,
a baby's cry
is a plaintive song,
a child's laugh
is music sweet
and feelings of love
make the song complete.

In the second act
as we learn and grow,
there's so many things
we need to know
and so many lessons
that we must learn;
and feelings of love
make our wheels turn.

In the third great act
we start to mature
and try to find
a way to be sure
that we are the people
we're meant to be
so that feelings of love
help us learn to be free.

And the fourth act,
adulthood
is long indeed,
as we seek the wisdom
we deeply need
in order to live
the lives we should
in a way we will feel
is loving and good

Till the closing act
when the curtain falls
and stills our laughter,
cries, and calls
us on to whatever
may lie in wait -
however small
or however great.



Hi my name is Monique and my son, Oliver is 7 years old. He loves to dance and his favourite movie is "Singing in the Rain" with Gene Kelly, which he has watched for years (even the documentary disc keeps him riveted), and he knows all the steps of the famous song! Oli also loves the alphabet and numbers and playing with their structure... his latest is counting to 20 alternating in Italian and English... uno, two, tre, four, etc....

I am a social worker and artist and have studied and worked in the fields of travel, psychology, politics, research, human rights, storytelling and philosophy. I love drawing, writing poetry, doing cryptic crosswords, meditating, community theatre, going to the beach and being with friends. I am really passionate about social justice, resilience, what gives people optimism and hope and how to live by one's true inner nature today's world. I have worked for 15 years counseling and supporting families facing challenging life situations, both in Australia and Italy; mostly with families facing cancer as I lost part of my leg to cancer 15 years ago and did chemotherapy and wanted to help others.

I am now working as an autism consultant doing case management for families, needs assessment, visual systems for communicating with children, advocacy and funding submissions and helping families know the choices they have for living with autism and navigating social systems that are sensoryist (is this a word?)

Monique

AUTISM IS FOR 'A'
By
Monique Nazzari

When my son, Oliver, was diagnosed with autism I threw myself into research and my son into therapy. What is autism? How could we cure him? How much is enough therapy? What services are available and how do we access them? What are the rights of children with disabilities? What community education was available and what support was available for carers? I was overwhelmed with options, definitions, studies and statistics.

Much later I realised that, though these processes and systems were essential, they weren't enough to accommodate the extraordinary and dynamic phenomenon of autism. Social and political processes take time and are up for debate (over and over and over!) while autism requires early and immediate intervention.

Every hour a child is diagnosed.

There is no official cause or treatment for autism, and the incidence has risen rapidly and cannot be accounted for. Autism has spawned a whole new industry of assessment, therapies and treatments worth millions.

The definition of autism embraces a "triad of impairment" in social interaction, communication and imagination that seems to originate in a break down in sensory/neurological processing. Repetition, ritual, routine govern behaviour. These "skills" allow people with autism to "fit in" even though their inner struggles and isolation are lifelong.

Autism can be described but the true nature of the connection between Oli and me does not conform to social and linguistic rules. I believe that living with autism requires a quantum leap of the heart and mind.

When I was younger I loved Nonsense poetry with its non-conforming patterns and rhythms that somehow gave birth to truth. I loved the surprises and the absurdity - that all is not as it seems and seems what not it is all. Being with Oli is surrealism in motion. At 7 years old his toddler like curiosity has not abated and his sense of conformity has hardly begun...and so it goes.

When Oli was first diagnosed 3 years ago I wanted to change him and "bring him back" from planet autism. I travelled the dark forest of fear and loss and guilt. We have done regular speech therapy, kinesiology, homeopathy, sensory integration, floortime, PECS and social stories, nutritional improvements, continuing education (both early intervention and now special school), medications for epilepsy and insomnia. We have tried a gluten free diet, NAET, physiotherapy, cranio-sacral therapy and researched many others.

In addition to Oli's "treatment", his father and I have done many courses and research on how to understand and teach him and we have changed our lives to make sure we both get lots of respite and support for our own minds, bodies and spirits. I have been blessed to meet many people over the last 3 years who have offered me wisdom, warmth and friendship to bring home.

In the last 12 months I have begun to let go. Oli started full-time special schooling this year and he has been steadily, if slowly, improving. It was time to let the seeds planted the

last 3 years do their own growing and take their own shape - time for me to let go of the illusions of what Oli could be and embrace who he is. In this expression of faith (born also from hours of counselling and reflection on myself) I have found a deeper meaning, freedom and growth.

I now spend more time being with Oli rather than constantly doing around him. Our connection and love have strengthened though our communication is often in silence rather than words. I laugh with him more and enter his world with pleasure and anticipation rather than an agenda to change him. Our world is still largely surreal but it has its own form and purpose that brings us joy and for that I am truly grateful.

Oli now wakes at 6am rather than 4am, he can respond "Yes" and "No" and have a basic conversation, he toilets mostly without prompts and his capacity and willingness to be affectionate have grown immensely. He will now cuddle for up to half an hour - not long ago he would recoil from any touch. He even makes his own social stories to process an event (over and over and over and over and over and over again!). People say he seems happier and more peaceful.

If I break Oli's routine too much then aggression, seizures and self harm return immediately. I still depend on visual aides and puppets to try and soothe out difficult situations that arise frequently. There are some things that may never change about Oli but I now know that accommodation and appreciation of his differences are part of the journey.

One day, recently, while Oli was having a bath he said "I want a fish, water oesophagus!" (when asked he translated, "I want to drink the bath water!") and we both broke down laughing hysterically for a good few minutes. I didn't see any point in correcting him as the twinkle in his eye told me he was playing with me and knew exactly how to say it "properly" the first time.

The beauty of the soul shines out when a man bears with composure one heavy mischance after another, not because he does not feel them, but because he is a man of high and heroic temper. - Aristotle

All adverse and depressing influences can be overcome, not by fighting, but by rising above them. - Charles Caleb Colton

If you wish to travel far and fast, travel light. Take off all your envies, jealousies, unforgiveness, selfishness and fears.
- Glenn Clark

If you want to get out of the pit, stop digging.
- Ernesto Santos-DeJesus

If you want to read poetry of a great variety with exceptional meaning go to www.erikestabrook.com

I'll have my 50 pg book of Christian poetry called "Attesting to His Glory" out this Fall.

Just to give you an idea every poem is a Christian praise to my savior. Poetry helps me get rid of negative feelings and moods in my life, it also drew me closer in faith without me realizing it at first. My poetry is simply about creating beauty and allowing the reader to feel me through the journey.



The Best Parts of Me by Erik Estabrook

Into the darkness I think I'll go,
to a place where even the sun won't show

where I can mutter, hang, and pretend to know the words
to a song I sung to you long ago

You can have these weary bones,
everyone knows you sold my soul,
I've already been a picture, already been a frame,
already been a musing, already bit your chain,
you've taken the best parts of me

watching you go out, it appears you've stole her glow
took my love and drowned me with it
I thought I knew you but I wasn't even close,

Have we sunk this very low?
enough to suck the devils toes,
and mirror an expression, steal a glance
baby we we're nothing just let this pass,

You can have these weary bones,
everyone knows you sold my soul,
I've already been a picture, already been a frame,
already been a musing, already bit your chain,
you've taken the best parts of me.

Markings on Concrete

Right where they skip double-dutch
I wrote my simple poem
It got trampled by the children,
my poem was only read by one

he told me it stirred his soul
and it should be on colleseums
I replied my poetry has no meaning
its written from a beast within,
when I scribble on concrete it places me in sin

Concrete imagery a phrase that seems so strong,
maybe I'll give up writing about giving up,
and sing a brighter song

I'll see the beauty in everything
go on a mission of love,
make a bunch of cohorts
and fulfill what should be done

Concrete is a beautiful canvas
because of the joy it can create
the markings can be holy and admonish words of hate

I'll mark up everywhere with words of beauty, unique
until they find some viewers in the city of Crete.

by Erik Estabrook

A man would do nothing if he waited until he could do it so well
that no one could find fault. - Cardinal Newman

who dares nothing, need hope for nothing. - Friedrich von
Schiller

Most people spend their entire lives on a fantasy island called
"Someday I'll." - Denis Waitley

The technologies which have had the most profound effects on
human life are usually simple. - Freeman Dyson

You begin saving the world by saving one person at a time; all
else is grandiose romanticism or politics. - Charles Bukowski

There is always one moment in childhood when the door opens and
lets the future in. - Deepak Chopra

In every person who comes near you, look for what is good and
strong. - John Ruskin, English author, 1819-1900

Insights of an Autistic Child
(How I dealt with this as a parent and advocate)
By Jocelyn Plowey of Texas

When she was younger, Siobhan was locked within herself in her own little world with seemingly no association/awareness of the outside world. This would lead to a life of silence, frustration and emptiness and no apparent knowledge of the existence of reality. Something seems to be "hidden" beneath the mind and soul of such a person unable to express the inner feelings and thoughts of a "complex brain disorder" known to the world as "Autism", which inhibits a person's ability to communicate and develop social relationships, and is often accompanied by extreme behavioral challenges.

As an infant full of smiles and laughter, Siobhan was developing into a lovely baby at age two. Suddenly, behavioral changes occurred, such as withdrawal from words and in interactions and seemingly not relating to things around her. Her movements were silent, yet her actions expressed something was wrong. Her words were unheard, for she was unable to express her thoughts. Her anger showed no understanding as her anxiety built up in a rage of tantrums. Her eyes stared and crossed, as she looked over her shoulders and immersed herself in her television shows. She twirled in a corner most of the time, frightened and confused by noises, especially among people she encountered. She escaped to her room or hid behind me as a comfort zone. Her only connection to the world was her attachment to me... a mom who comforted her, slowly guiding her movements in a way "fitted" to ease her, as she slowly "settled down".

Music also comforted her as she opened towards her siblings, showing smiles and love - this was an entrance to some connections but she would drift to her own world again. Much time was spent trying to stop behaviors, causing some frustration. As a team, we had to work with patience (remain calm) and understanding, showing our love and attention, as we guided her in the right path and direction (as in using reinforcement to reward good behavior). Likewise, as with disciplining other children, a "stern look" as well as a direct approach such as saying "NO" (several times) can do the trick! She then senses she is doing something wrong, or that what she is doing is not acceptable to us. Reinforcing "I am Sorry" (with a hug) is a big part for us in gaining her understanding. Timeout, to some degree, does work! It was a struggle we all had, and we still are pushing forward to bring her back to our world of existence... a world with which she had been out of contact, but to which she is now open.

With early intervention and school therapists assisting her, she has regained her lost speech and knowledge. She is now moving towards being mainstreamed in society, interacting with others and associating with things around her. Our life has been lifted up as we support her with every task she tries, guiding

her and appreciating her every day as a lovable, gifted, energetic child willing to excel. She amazes us all the time, bringing us laughter and joy. Some of her “typical autistic ways” and “obsessive compulsory habits” due to reacting abnormally to over-stimulation are part of her, which she can change on her own, or she can remain as acceptable to us for who she is... a “typical” seven-year-old child enjoying life in her own autistic way. She is exploring the beauty within the world now unlocked for her and (to a certain degree) accepting her own identity as being “autistic” in a beautiful way, (not having fear of judgment from others). We hope that in the years to come she will reach a greater understanding about herself and be able to face life’s challenges and changes on her own (many autistic people don’t like change), have people accept her as her own “unique and somewhat different individual”, yet pleasant to be around.

Our journey is not over, and as parents and advocates to our child we take it one step at a time. Dealing with each situation before our eyes is a learning experience for all of us. Having a child on the spectrum is an “awakening” for all of us, bringing us closer as we examine our “true identities”, thus making us better people in our acceptance and appreciation of things we might have otherwise taken for granted. We are fortunate to have a child on the “mild spectrum of Autism”, doing so well and coping to the best of her ability in such a short time without the help of medication and special treatments. She is “God’s gift” to us, to treasure and help others on the spectrum and to educate others to learn to appreciate those on the spectrum, not bully or judge them for acting out in public. They, too, can make a difference with their unique talent and intelligence beyond ours. They, too, can cope with life in different ways, as today we see many successful and famous autistic people contributing to society on their own. We learn to appreciate and embrace them for who they are.



Jocelyn and Siobhan

A teacher is a compass that activates the magnets of curiosity, knowledge, and wisdom in the pupils. - Ever Garrison

The moment of victory is much too short to live for that and nothing else. - Martina Navratilova

But the life that no longer trusts another human being and no longer forms ties to the political community is not a human life any longer. - Martha Nussbaum, "O" Magazine, November 2003

One must desire something to be alive.
- Margaret Deland, "O" Magazine, September 2002

The inner fire is the most important thing mankind possesses.
- Edith Sodergran

Talk sense to a fool and he calls you foolish.
- Euripides (484-406 BC)

Real education should educate us out of self into something far finer; into a selflessness which links us with all humanity.
- Nancy Astor (1879-1964)

Without trust, words become the hollow sound of a wooden gong.
With trust, words become life itself. - John Harold

Perhaps we are wiser, less foolish and more far-seeing than we were two hundred years ago. But we are still imperfect in all these things, and since the turn of the century it has been remarked that neither wisdom nor virtue have increased as rapidly as the need for both. - Joseph Wood Krutch (1893-1970)

Why do you try to understand art? Do you try to understand the song of a bird? - Picasso

Words form the thread on which we string our experiences.
- Aldous Huxley, novelist (1894-1963)

In a time of universal deceit, telling the truth becomes a revolutionary act. - George Orwell

You measure the size of the accomplishment by the obstacles you had to overcome to reach your goals. - Booker T. Washington

It takes no effort to love. - Deepak Chopra

Thousands of candles can be lit from a single candle, and the life of the candle will not be shortened. Happiness never decreases by being shared. - Buddha

Life isn't about finding yourself. Life is about creating yourself. - G.B. Shaw

Eyes can speak and eyes can understand. - George Chapman



My name is Gemma Goode and I am the Admin of Asperger's Awareness on Facebook: a community of 16,000 people where we have nightly discussions, and where Aspies, parents and carers alike support each other and share advice, concerns and personal experiences. I am 26 years old, and I first found out about Asperger's Syndrome when my son was diagnosed 5 years ago. I created the community after years of searching for more information on A.S.

<http://www.facebook.com/home.php#/aspergersawarenesspage?ref=nf>

It has been a long journey...

My son's diagnosis of Asperger's Syndrome left me empty, with nowhere to turn, and nowhere to hide. It was mentally exhausting to say the least, and I craved knowledge of the label that was put upon him. We left the hospital that day with no more than a leaflet and a "Well Done for Being Brave" sticker, bewildered and unsatisfied. "See you in three years", said the Doctor, and that was the last time we ever saw him.

The emphasis at the time was his diagnosis of Attention Deficit Hyper-activity Disorder (A.D.H.D). Having to medicate my son seemed far more important than the way he lined up his cars. Support for this was much easier to find. He attended check-up appointments four times a year, and with a little "Trial and Error" we soon found the right medication to help him.

It was not until three years later that my search for answers really began. By this time, my son was eight years old. His A.D.H.D was under control, but he still was not settling at school. The school headmistress made it very clear that, down to the teachers not being able to cope, they assumed that I could not parent him properly. They were very wrong. My son and I have a very close bond. We have faced many obstacles over the years, and we communicate very well; yet, with the pressure put upon both my son and myself by the teachers at the school, I began to wonder if I was parenting him correctly.

At this time, I began searching frantically for reassurance. I scoured the world wide web for a decent explanation, yet all I discovered were pages of words that I could not understand. Abbreviations, opinions, and statistics flew around my head night after night. My son urgently needed my support, and I was failing due to lack of wisdom. Then, one night, while I was aimlessly flicking through the pages of Myspace, I come across an "Autism Awareness Page". It was as full of useless data as the million other websites I had read, but it inspired me.

I immediately created a new group on the social networking site Bebo. I gathered all the information that I had previously found, and copied it into the Blog module. I made the group, originally, as a "last resort". I was lost, confused, in over my head with hope that will never be fulfilled. As a young mother learning how to find her own way in life, bringing up a child is epic, feeling you are doing it wrong is shattering, but then finding out that he has a "term" that you know nothing about and have nobody to help you find out... it is heartbreaking!

Many people joined the group and told their stories of their struggle for support. Their stories were almost identical to the lives my son and I were living.

I felt I could help so much more.

I decided to create a similar group on Facebook. I invited my friends, and the numbers grew. Within no more than two months, the group had circled the globe. Comments started building up, all from parents as troubled, lost and confused as myself. All had common problems, yet none of the problems were those that I had learned from the Doctor, the leaflets or the websites I had read.

Had I translated the information incorrectly? No. These websites had all been doing the same as me! Passing on textbook information. "Chinese Whispers". That is when I realised... the only people who truly know what Asperger's is are people who have Asperger's. So, who better to ask?

Months rolled on and the numbers grew. I extended the group to a page, just to dig deeper.

with the new page, I was able to send out a question nightly via status, and was already amazed at the 20+ responses per night. These parents and loved ones of people with Aspergers were all very unsure of what Aspergers is. They also found that the information available was misleading.

---Discussions---

with the new page, I was able to send out a question nightly via status, and was already amazed at the 20+ responses per night. These parents and loved ones of people with Aspergers were all very unsure of what Aspergers is. They also found that the information available was misleading. I made an appeal for people with Asperger's Syndrome to come forward and educate us.

Suddenly, people with Asperger's Syndrome were speaking out. They appreciated the welcome to the page and were very happy to share their personal experiences. They taught us that they can be very clever, often very successful, passionate, considerate, independent and wise. They are now becoming role models for other members and when some were once lonely, they now have support and friendship available 24 hours a day, worldwide.

---Talented Aspies---

I became interested in the "genius" side of Asperger's that I was beginning to notice in some of our members and so decided to write an email to John Elder Robison, author of *Look Me In The Eye*, whom I was reading a lot about from our members. I knew that John has Asperger's Syndrome and had written *Look Me in the Eye* about how it guided his life from birth. I asked John if I could feature him on our page as a "Talented Aspie", which I hoped would inspire others to use their gifts and help parents to guide their children to be creative. The possibilities are endless if not held back with "facts" such as "People with Asperger's Syndrome have no imagination", which I was tired of reading about. John replied and agreed quickly and offered to answer members' questions. I was thrilled. A famous author was ready and willing to support our members. Our second "Talented Aspie" was Valery Milovic, an artist from New Mexico. I learned how to "interview" and she very kindly answered the questions that all us worried parents had burning inside, unanswered and unsettled. It was a raw insight to the things that matter most to people with Asperger's Syndrome, such as love, loss, emotions and creativity. The interview shone with truth, not facts.

Our community is now a year old and we have almost 16,000 members. The nightly discussions have built the bond between our friendships. People willingly pour their hearts out for others to learn.

Our community has sparked a lot of interest. The community is now featured on a website in Brazil and aspiring author Sarah Murry has asked if she can write an article for a newspaper in UK.

In July of this year, I sent a message to Sharon da Vanport of AWA (Asperger Women's Association U.S) asking if she would be our featured "Talented Aspie". She was very pleased, and kindly answered questions to my interview. She also asked if I would be a guest on the AWA radio show in U.S in October. I am very excited about this, but also very nervous.

And the rest, as they say, is history...

Life for my Little Soldier is so much easier lately. Now, at ten years old, I cannot stress the improvement he has made with just that little independence and understanding. I still do not have the answers I was hoping for, but what I do know is that he is who he is, and my job is not to parent him based on one doctor's opinion, but to guide him and be there for him as a loving mother and friend, and to help him set his own ambitions in life.

"The sky is the limit"

If our community has taught me anything, it is that no two people are ever the same, and a world full of people cannot be defined in a leaflet.

My inclination was right - the information I had dug up was stereotyping. The Aspies that came forward and offered their input were a complete contrast to the dreary misleading print that had hurt my brain. These people are not emotionless, black and white robots. These people are AMAZING. They teach, they help, they care! The colours of the rainbow suddenly shone!

It is not about spotting the difference... It is about cherishing individuality =]

Always remember that you are bigger than the moment, you are more than anything that could ever happen to you.

- Anthony Robbins

A man needs self-acceptance or he can't live with himself. He needs self-criticism or others can't live with him.

- James Albert Pike, American Episcopal bishop

Only the educated are free. - Epictetus, philosopher (c. 60-120)

Foster independence among your children. Encourage them to cook, clean and contribute. - Brian Tracy

Listen to the desires of your children. Encourage them and then give them the autonomy to make their own decisions.
- Denis Waitley

If you talk to your children, you can help them to keep their lives together. If you talk to them skillfully, you can help them to build future dreams. - Jim Rohn

The cave you most fear to enter contains the greatest treasure.
- Joseph Campbell

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

You must live in the present, launch yourself on every wave, find your eternity in each moment. - Thoreau

Your profession is not what brings home your paycheck. Your profession is what you were put on earth to do with such passion and such intensity that it becomes spiritual in calling.
- Van Gogh

There is no end. There is no beginning. There is only the infinite passion of life. - Federico Fellini

Before you can inspire with emotion, you must be swamped with it yourself. Before you can move their tears, your own must flow. To convince them, you must yourself believe. - Winston Churchill

The single common denominator of men and women who achieve great things is a sense of destiny. - Brian Tracy

How different our lives are when we really know what is deeply important to us, and keeping that picture in mind, we manage ourselves each day to be and to do what really matters most.
- Stephen Covey

You can do anything in life you set your mind to, provided it is powered by your heart. - Doug Firebaugh

To begin to think with purpose is to enter the ranks of those strong ones who only recognize failure as one of the pathways to attainment. - James Allen

wise men talk because they have something to say; fools, because they have to say something. - Plato

The main dangers in this life are the people who want to change everything - or nothing. - Nancy Astor

The only way most people recognize their limits is by trespassing on them. - Tom Morris

To err is human; to forgive, infrequent. - Franklin P. Adams

Will You Be My Friend?
by Jessica Lester

I'm nervous
I'm not supposed to be
Apparently I'm "certified" to teach autistics¹

Yet here I sit in my car
wondering if Rosanne² will like me

what do I do?
Act like a teacher?
"Therapize" her?
Befriend her?
Ask if she wants to "talk"?

what is wrong with me?
I want Rosanne to like me
I want her to let me into her world

what if I "talk" too much?
what if she detests the color I'm wearing?
what if I move too fast?
what if I overload her sensory system?
will she kick me out?

I Promise!
I really just want to
Partner with her
Learn from her
Be with her
Know her

why am I here?
I believe she and others with autistic labels are misunderstood
I am one of those who has misunderstood

For here I am with power
To label
To name
To dismiss her way of being

I am a privileged intellectual named "gifted."
Nothing ever really impedes my way of being.
Nothing ever really impedes my way of doing.
I "be" and "do" whatever I so desire.

Yet here I sit at Rosanne's door
waiting, hoping to
Partner with her
Learn from her
Be with her
Know her

There she sits
Behind stairwell bars
will she let me past?
Oh who built those bars?
Did I participate?

Before an answer comes
Our spirits connect
Hands touch
Friendship sparked
Stereotypes crushed

When she says, "will you be my friend?"

Tears

Flow

Down

My

Face

with each teardrop
Bars shatter
worlds meet
we partner
we learn
we be
we know

References

Sinclair, J. (1993). "why I dislike person first language."
Accessed November 8, 2008
http://web.syr.edu/%7Ejisincla/person_first.htm

Footnotes

1Autism is used to refer to autism spectrum disorders, with "autistic" being used to refer to individuals diagnosed with autism (Sinclair, 1999).

2Rosanne is a composite of many of the children and adults with autism who have been my students and greatest teachers over the years. All of the words within this poetic representation were drawn from the personal journals I have maintained during my time working with and learning from children and adults with autism.

Author's Biography: Jessica Lester has worked as a classroom teacher, special educator, and most recently teacher educator. She currently works in home-based settings and facilitates social groups for children with autism, working to honor and build upon their strengths. During her free time, she is working on her dissertation, focused on the life worlds of individuals diagnosed with autism.

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Remember that nobody will ever get ahead of you as long as he is kicking you in the seat of the pants. - Walter Winchell

Education is what survives when what has been learned has been forgotten. - B.F. Skinner

The only way most people recognize their limits is by trespassing on them. - Tom Morris

To err is human; to forgive, infrequent. - Franklin P. Adams

Do not fear to be eccentric in opinion, for every opinion now accepted was once eccentric. - Bertrand Russell

The soul, like the body, lives by what it feeds on.
- Josiah Gilbert Holland

We do not live to think, but, on the contrary, we think in order that we may succeed in surviving. - Jose Ortega Gasset

There are many paths to enlightenment. Be sure to take one with a heart. - Lao Tzu

From the standpoint of daily life there is one thing we do know: that man is here for the sake of other men. - Einstein

Mere color, unspoiled by meaning, and unallied with definite form, can speak to the soul in a thousand ways. - Oscar Wilde

In a dark time, the eye begins to see. - Theodore Roethke

without challenge, adventure is impossible. - The Universe

Learn the wisdom of compromise, for it is better to bend a little than to break. - H.G. Wells

When people go to work, they shouldn't have to leave their hearts at home. - Betty Bender

Words, like nature, half reveal and half conceal the soul within. - Alfred, Lord Tennyson

Living at risk is jumping off the cliff and building your wings on the way down. - Ray Bradbury

Common sense is the knack of seeing things as they are, and doing things as they ought to be done. - Harriet Beecher Stowe

See the potential but work like it is a reality. - Bob Perks

Neglect starts out as an infection then becomes a disease.
- Jim Rohn

The creation of a thousand forests is in one acorn. - Emerson

POETIC BEGINNINGS - Sharisa Joy

My education program is making sure that "NO CHILD LEFT WITH A MIND" is a thing of the past!

It's a sunny Saturday morning
Filled with laughter and song -
Somehow days like this
Never seem too long.

Every now and then
When people stop to reason
They find that love and logic
Both might be in season.

The sweetness of life,
The transcendence of love
Light every star
That shines above.

When rainbows glow in cloudy skies,
The prisms of color delight my eyes.

About 9-11:
Today is a date we will never forget,
Filled with grieving and regret...
And yet we must get past the sorrow
To focus on a peaceful tomorrow.

Do You Ever 9-26-09
New Poem by Sharisa Joy

Do you ever stop to wonder
Why the world is so unkind?
Did you ever think the human race
Is fully deaf and blind
To the suffering of people
Who are not at all like "us";
So why should we ever help them
When it takes far too much fuss?

Do you ever take the time to breathe
And love the life you're given
Or do you spend all of your days
As someone who is driven
To be better than "the others"
And make them feel "inferior"
Because you think if you do this
It means you are "superior"?



Hello,

This newsletter is my way of providing you with free or low-cost information in regards to autism that you can use in these economically uncertain times.

(If you do not need these little pearls of wisdom, please forward this newsletter to someone who does. They will be grateful).

Parents, caretakers, educators, or community members - we all want more information on how to best help the child, teen or adult on the spectrum that we love. Yet, at times we feel bombarded by too much information and too little time to go through it all.

That is how I can help you. Every month, with this e-newsletter, I will provide you with one practical tip, and three picks of low-cost resources you can use that I have found helpful, insightful, and inspiring. **My goal is to empower you with the knowledge to make a difference in someone's life.**

September's tip is "Teaching the concept of privacy" (see below) and September's picks are two books and a series of monthly webinars.

Episodes: My Life As I See It - Debut writer, Blaze Ginsberg, offers a unique perspective on his life as a highly-functioning autistic 21 year old in **Episodes**. Inspired by the format of the Internet Movie Database, Blaze organizes his life events as a collection of episodes. Some episodes are still running, some are in syndication, and some have sadly come to an end. Some readers may already be familiar with Blaze's earlier years, which where the subject of the book **Raising Blaze**, written by his mother, bestselling author Debra Ginsberg. Blaze's memoir offers a unique insight into what life and school is like for a teen on the spectrum. Blaze's life is still in syndication, with no predictable end; we can only wish him the best and hope to see more episodes in the coming years. Read more about **Episodes** and Blaze [here](#). To order the book, go [here](#).

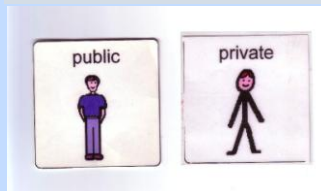
Autism Life Skills. This is my most recent book. When my son was in his

teens, I wondered what adults on the spectrum would say was important to them growing up; what helped them to become the individuals they are today. I interviewed many people on all parts of the spectrum, and the result is this book, which covers ten essential life skills: Making Sense of the World, Communication, Self-esteem, Self-regulation, Self-advocacy, Self-reliance, Safety, Earning a Living, Maintaining Relationships, and Having Fun. Read more about **Autism Life Skills**, go [here](#). To order the book, click [here](#).

momsfightingautism.com Webinars Each month

MomsFightingAutism.com provides free webinars for moms of children on the autism spectrum. These webinars are a great resource for parents and educators who may be unable to go to conferences, or live in areas with limited resources. Listeners can submit questions before and during the webinar. As the moderator, I love doing these webinars because the people listening are able to ask specific questions. The feedback has been great from the listeners. Topics that have been covered include OT, IEP's, insurance coverage, diets, ABA, Floortime, and social skills. You may sign up every month for a free webinar, or you may join and receive transcripts and download. To find out more, go [here](#).

Chantal's Tip: Teaching the concept of privacy



It is extremely important that teenagers understand the different behaviors and conversations that are appropriate in public, and the kind that are meant to be private. For example, touching certain parts of your body in public is inappropriate, and can even get the eighteen and over adolescents in trouble with the law. Having conversations at school that are appropriate to have at the family breakfast table but are inappropriate in a peer lunchroom setting, can get a teen labeled weird at school and prevent friendships from developing.

One way of teaching the concept of "private" and "public" that can be used with different ability levels is to use two picture icons, one of a fully-clothed figure labeled with the word "public," and one of a figure clothed only with underwear labeled "private." to read the rest of this, go to my [Autism & Adolescence column on Examiner.com](#).

Please feel free to share this newsletter with others. If you wish to reprint or share "Chantal's Tip" in your own newsletter and/or on your website, please feel free to do so, as long as you credit the writer (me!).

Let me know how you enjoyed this e-newsletter by emailing me at sicilekira@mac.com. I love hearing from readers.

Sincerely,

Chantal Sicile-Kira

www.chantalsicile-kira.com

Autism Making A Difference, Inc.

Nobody trips over mountains. It is the small pebble that causes you to stumble. Pass all the pebbles in your path and you will find you have crossed the mountain. - Unknown

It takes a great deal of bravery to stand up to our enemies, but just as much to stand up to our friends. - J.K. Rowling

I speak to everyone in the same way, whether he is the garbage man or the president of the university. - Einstein

The only conviction a coward has is that someone or something else is responsible for what he refuses to face in himself. - Guy Finley

Listening is not merely not talking, though even that is beyond most of our powers; it means taking a vigorous, human interest in what is being told us. - Alice Deur Miller

**Imagine for a moment your own version of a perfect future. See yourself in that future with everything you could wish for at this very moment fulfilled. Now take the memory of that future and bring it here into the present. Let it influence how you will behave from this moment on.
- Deepak Chopra**

Perfection is achieved, not when there is nothing more to add, but when there is nothing left to take away. - Antoine de Saint-Exupery

**Stop the habit of wishful thinking and start the habit of thoughtful wishes.
- Mary Martin**

**Anything that is of value in life only multiplies when it is given.
- Deepak Chopra**

I have always grown from my problems and challenges, from the things that didn't work out. That's when I've really learned. - Carol Burnett

I love the man that can smile in trouble, that can gather strength from distress, and grow brave by reflections. - Thomas Paine

The strokes of the pen need deliberation as much as the sword needs swiftness. - Julia Ward Howe

Do not seek to follow in the footsteps of the men of old; seek what they sought. - Matsuo Basho, Japanese poet, 1644-1694)

Don't judge me for what you see. Love me for who I am. - Bob Perks

**Violence of the tongue is very real - sharper than any knife.
- Mother Teresa**

**THE MEANING OF LOVE
SHARISA JOY 6-6-93 REVISED 12-28-95 & 2-23-08**

LOVE has many meanings.

**For tiny babies,
LOVE is found
In bottles and breasts
To satisfy hunger,
Soft voices and touches
To soothe worried cries,
Smiling faces, adoring eyes,
Being held, caressed,
And gently rocked to sleep.**

**For children,
LOVE is as simple
As being read to
Or sung to,
Hurts kissed and hugged away,
And cool, caring hands
On florid, feverish foreheads.**

**As we grow,
LOVE must grow too.
It's a basic human need.
Deprived of it,
Lives are empty,
Hearts and minds wither,
Spirits fail to thrive.**

**We must have LOVE,
So we seek it
Like plants seek sunshine;
We need it
Like fish need water;
We crave it
More than food, water, or air.
It is truly sustenance to us!**

**Define LOVE?
I would much rather try
To define
HEAVEN!**

In A Flash by Sharisa Joy 5/1/97

In a flash
A blink
A nanosecond
The message
Leaps
Across
The synaptic
Connection
Delivering
Valuable
Information
To a mind
So hungry
And thirsty
For KNOWLEDGE

Snapping
Sizzling
Crackling
With power
My mind
Roars
Soars
Explores
Its limits
Its borders
Its boundaries
And
Suddenly
Bursts FREE

Floating
Gliding
Speeding
Faster
Than light
It crosses
Space
Time
The universe
And the barriers
That separate
Us all
From LIGHT

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High Functioning Autism
Asperger's Syndrome and
other Pervasive Developmental Disorders*

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www.aha-as-pdd.org

**HELPING YOUR CHILD TO HELP HIM/HER SELF:
Beginning Self-Advocacy
by Stephen Shore**

Self-advocacy is realizing what one needs in order to maximize functioning in life and knowing how to arrange the environment or obtain accommodations to do so. Or put another way, it is being literate about one's own needs. The road to self-advocacy includes discussions of disclosure, special interests, learning styles, learning accommodations, and even relationships. One place to teach these skills is through involving students in the development of their own Individualized Education Plan (IEP) the moment it is known that a person is on the autism spectrum.

Advocacy in Education as Training for Advocacy in Life

Given that the public schools are charged with enabling the nation's youth to lead fulfilling and productive lives, it only makes sense to include self-advocacy as part of that education for all students with disabilities. Including the student in the development of the IEP is a great way to accomplish this goal.

As much as possible, students should be involved in developing and leading their own IEP process as soon as possible. As mentioned in *Student-Led IEPs* (McGahee, Mason, Wallace, & Jones, 2001), given the great variance of student ability, there is a wide range of options. Some students may just be able to state or read part of their plan for the future to the IEP team, others may go on to explain their disability, describe the need for accommodations, share their strengths and challenges (present levels of performance), and talk about plans for the future.

The eventual goal is a student-led IEP meeting (under the watchful eyes of the IEP team). Dealing with the paradigm shift from being advocated for through the IEP to having to advocate for oneself after high school requires much long-term work. Starting the process of teaching self-advocacy ideally could begin before age 14 when transition planning for life after high school is mandated into the Individual Education Plan (IEP).

Providing students with a well-developed sense of self-advocacy through the process should be an integral part of education. Doing so is vital for gaining a greater understanding of how to obtain the required accommodations upon entering the community, in higher education, employment, and relationships during the late adolescence and adulthood years.

Ramifications of not Learning Self-Advocacy Skills

The ramifications from failing to acquire sufficient self-advocacy skills can be very debilitating. For example, at the higher education level, young adults in this unfortunate position may feel that special education is “all done” and want to “be just like everyone else.” They enter college unaware of their needs and/or refuse to meet with the student support office. However, since variances in learning styles remain with the person, soon difficulties in coursework mount, and then the student may be at a loss on how to obtain the needed assistance. After high school, the onus of obtaining needed accommodations lies with the person themselves. For example, in higher education the student must initiate the process of acquiring accommodations by finding the appropriate office, making the disclosure, preparing the documentation, working with instructors, etc.

Conclusion

Many young adults on the spectrum are forced to learn the realities of self-advocacy after high school and entering the community, workforce, or higher education. Proper preparation through the use of active involvement in the IEP process can help smooth the way for those on the autism spectrum to lead fulfilling and productive lives to greater potential.

Student resources for learning about their own IEPs

- *A Student's Guide to the IEP* (McGahee-Kovac, 2002), and the accompanying
 - Technical Assistance Guide *Helping Students Develop Their Own IEP* (NICHCY, 2002).
- Both are available at www.nichcy.org/pubs/stuguide/st1.htm

Teacher resources on developing self-initiated IEPs

- *Student-Led IEPs* (McGahee, Mason, Wallace, & Jones, 2001) Available at <http://www.cec.sped.org/bk/catalog2/iep.html>

Teacher resources on developing self-initiated IEPs

- Teacher resource for transition planning self-assessment Available at <http://www.vesid.nysed.gov/special/d/transition/t4trans.htm>

Self-Advocacy and Disclosure by Stephen Shore
Reprinted from Autism Spectrum Quarterly • Fall 2004

To understand the quandary that people on the autism spectrum often find themselves in, consider the following scenarios:

1. You have just been shown your new office, which consists of a cubicle lit with fluorescent lights. As a person on the autism spectrum, exposure to this type of lighting is like being in a room with a strobe light—fun on Halloween perhaps, but what about all day, during work?

2. You're in high school. It's time for a math test where each page has ten questions. The scratching sound made by the other students' writing implements drives you, quite literally, to distraction. Not only that, but all those math questions on the test seem to jumble together.

3. You have recently met a special person with whom you think you'd like to have a long-term relationship. Until now, you have put on a good act at "pretending to be normal" (Willey, 1999), and she hasn't noticed a thing - yet - or has she?

These three cases bear directly on the subject of self-advocacy and disclosure, since each scenario is characterized by a need to modify the situation and provide an explanation of your reason for doing so to one or more people. Let's take a look at what self-advocacy and disclosure is, and what it entails.

Two Sides of the Same Coin

It is important to recognize that self-advocacy and disclosure are interrelated. Self-advocacy involves knowing when and how to approach others in order to negotiate desired accommodations, so as to achieve mutual understanding, fulfillment, and productivity. In the process, some degree of disclosure about oneself is usually necessary, particularly if the accommodation(s) requested requires further explanation. In other words, being a successful self-advocate requires one to be not only literate about one's needs, but also knowledgeable about how to get them met in an appropriate manner. In the first scenario noted above, the person who understands how successful self-advocacy and disclosure work will know to make a mental note to talk to her supervisor about modifying the lighting as soon as possible. She will also know that an explanation for her request for different lighting will likely be needed. An important part of this process involves understanding how much disclosure is necessary and/or appropriate. In this particular case, the woman will most likely limit disclosure to merely stating that she has sensitive eyes, as no further explanation is needed. When requesting accommodations it is important to be reasonable. For example, if while watching an action movie in a public theater, a person with aural sensitivities feels pain due to the volume level, is it fair for him to ask the theater manager to lower the volume at the expense of the other patrons? Might there be another way to accommodate his needs? Examples for accommodating oneself include wearing earplugs -

or for those who experience tactile defensiveness - a set of headphones.

Most people in the neurotypical world learn how to advocate for and what to disclose about themselves through a combination of observation, practice, and self-reflection. They quickly learn not only what is appropriate to ask for, but also what to tell others about their personal lives. However, because of their difficulties reading nonverbal cues and comprehending other pragmatic aspects of the "hidden curriculum," (Myles, Trautman, & Schelvan, 2004), most people on the autism spectrum need direct instruction in order to learn the important skills of self-advocacy and disclosure. Sibley (2004) gives excellent examples of how to mentor self-advocacy and disclosure skills in graduated steps. In the early stages, the advocacy partner works with the advocate-in-training and models good advocacy skills by taking advantage of numerous real life situations to familiarize the child with good self-advocacy practice. By the end of the process, the advocacy partner merely serves as a resource to be tapped if and when needed.

Applying Self-Advocacy and Disclosure Skills in Higher Education

Imagine the following: In considering different colleges, a student with Asperger syndrome does research into their disability offices. By perusing college websites, making phone calls, and interviewing appropriate personnel, she learns about the type and level of assistance available, as well as the documentation required to access accommodations and services. Upon acceptance to the college of her choice, she immediately makes an appointment with the college disability counselor to disclose her condition, and to discuss how Asperger syndrome is likely to affect her schoolwork. She then supplies the required documentation, such as a copy of her neuropsychological examination. Additionally, she mentions the academic accommodations that were helpful to her in high school, and inquires if the same or similar assistance may be offered at the college. The student who can lay this groundwork is well on her way towards receiving needed accommodations.

Now let's consider how the high school student in the math example cited earlier might successfully advocate for himself when he enters college. If he has learned that certain accommodations are required for achieving success in math, he is likely to be able to request the same types of accommodations that have worked in the past. For example, perhaps he can discuss with the disabilities counselor the success he experienced when one of his public school teachers reformatted the test so that there was only one question per page. The disabilities counselor may also be able to provide information on the availability of alternate testing sites at the college for students who are easily distracted. As this example demonstrates, there are important benefits that come with learning about one's strengths and challenges in order to successfully adjust the environment to accommodate one's needs.

The Downside Risks of Not Learning Self-Advocacy and Disclosure Skills

The public schools are charged with preparing the nation's youth to lead fulfilling and productive lives according to the customs of a child's society. While this involves the mastery of reading, writing, arithmetic, civic awareness and other academic areas, it also includes instilling a sense of responsibility and addressing moral development. Teaching self-advocacy and disclosure skills to individuals on the spectrum should be undertaken by the schools, as it is a necessary part of their education if they are to become more effective citizens. Here in the United States, the Individuals with Disabilities Education Act (IDEA) provides support for this, since it requires that the public schools identify, assess, and provide needed services for students with disabilities. Unfortunately, upon graduation, obtaining needed accommodations becomes a self-initiated process under the Americans with Disabilities Act (ADA). Sadly, a large majority of students with autism and other disabilities graduate from public schools lacking education in self-advocacy, rendering them unable to successfully advocate for themselves. Likewise, they often lack an understanding of how to handle disclosure. This lack of knowledge can cause people on the spectrum to have significant difficulty in the adult domains of higher education, employment, relationships, and other areas of life.

In a college situation, variances in learning style, combined with the pace of the curriculum, may cause the person with ASD to experience difficulties in meeting course requirements. To make matters worse, the student may be at a loss regarding how to obtain needed assistance. It is important to remember that after high school, the onus of obtaining needed accommodations is on the person with the disability. For example, in higher education the student must initiate the process of acquiring accommodations by contacting the appropriate office, making the appropriate disclosure, preparing the documentation required, working with instructors, etc. Likewise, in the workforce it is incumbent upon the person with the disability to seek out the individual(s) responsible for handling affairs related to the ADA.

The Role of the Individualized Education Plan in Self-Advocacy and Disclosure

The Individualized Education Plan (IEP) is an excellent way to fill the current educational gap in the development of self-advocacy and disclosure skills. Just as the IEP is used to level the academic playing field by allowing those with disabilities to have the same chances as everyone else for success in school, so too must the same be done for teaching self-advocacy. The beauty of using the Individualized Education Plan for teaching school-aged children these skills is that it already exists, and it is an excellent vehicle for this purpose.

Set the Stage by Starting Early

Generally, the best time to start teaching the concepts of self-advocacy and disclosure is when it is first learned that the child has a disability and is deemed in need of special education services. One of the prerequisites for success in this critical subject area is to establish a sense of self-determination within the child; that is, an understanding of one's preferences in the context of one's strengths and challenges. One way to instill a sense of self-determination is to help the child make a list of her likes and dislikes, while at the same time encouraging her to examine how closely her preferences line up with her strong points. With the nonverbal child it's important to recognize that receptive language may be better than expressive, leading the child to understand more than he can tell you. Therefore, narrating or talking through activities that the child likes (e.g., "Boy, you are really good at building houses with those blocks!"), or even ones that he doesn't like (e.g., "I know that waiting is very hard for you, but it is something we have to do.") can help demonstrate to the child that he can and does have preferences, as well as varying abilities depending upon the particular activity. Indeed, helping children to develop a sense of self-determination sets the stage for involving them in the development of their own IEPs.

Reframing the Student's Role in the IEP

Even though IDEA encourages student involvement in the initiation of special education services, and specifically mandates student involvement at age fourteen, as part of the transition out of public school, the reality is that student involvement is downplayed in the early years. In my opinion, it is always appropriate to involve students in designing their educational plans to the extent their disability allows. The challenge is to find ways to involve children of all abilities in their own individualized education plans.

Techniques for Involving Children at all Levels In Designing Their Own IEPs

Just as autism exists on a spectrum with great diversity, there is also a spectrum of ways to involve children in their own IEPs. Some very competent students may eventually be able to spearhead the entire IEP process from discussions with teachers about learning styles and determining appropriate accommodations, to "leading" the IEP meeting under the watchful eyes of the IEP team leader. Other students - for example, a four-year-old hyperactive, nonverbal child - may be able to do little more than attend an IEP meeting, interact with a few of the team members, and then leave. The benefit here is that you are demonstrating to the child that there is a group of people who have assembled to create a customized education for her benefit. An added plus is that you have reminded some of the IEP team members who may have little contact with the child, exactly who that child is, and what some of her needs are.

Most children will fit somewhere between these two extremes. Some children may only be able to read a prepared two- or three-sentence statement to the IEP team.

Other modalities of communication may also be used, especially for children who are unable to be physically present during the IEP meeting. One possibility is to have a student submit his input in writing. Other methods of participating in an IEP meeting include submitting a tape recording, talking on speaker-phone, or using a computerized system to select graphics in order to communicate via synthesized voice. These are excellent ways to fulfill the requirement under IDEA to "take other steps to ensure the student's preferences and interests are considered" (34 C.F.R. §300.344(b)(2)).

Benefits of Learning Self-Advocacy and Disclosure Skills

A major challenge faced by the autism community today, and one that has received little attention over the years, is how to teach those with autism to successfully self-advocate, and how to address the question of how much information to disclose. Clearly, the student who has learned appropriate skills in the areas of self-advocacy and disclosure will have much greater success in life after graduation. On a final note, the time to begin the learning process is now.

References

A guide to the individual education plan program. Office of Special Education Programs. Retrieved March 20, 2003, from http://www.ed.gov/offices/OSERS/OSEP/Products/IEP_Guide/.

Myles, B., Trautman, M., & Schelvan, R. (2004). The hidden curriculum: Practical solutions for understanding unstated rules in social situations. Shawnee Mission, KS: Autism Asperger Publishing.

Shore, S. (2004). Using the IEP to build skills in self-advocacy and disclosure. In S.M. Shore (Ed.), Ask and tell: Self-advocacy and disclosure for people on the autism spectrum (pp. 65-105). Shawnee Mission, KS: Autism Asperger Publishing.

Sibley, K. (2004). Help me help myself: Teaching and learning self-advocacy. In S.M. Shore (Ed.), Ask and tell: Self-advocacy and disclosure for people on the autism spectrum (pp. 33-63). Shawnee Mission, KS: Autism Asperger Publishing.

Willy, L. H. (1999). Pretending to be normal: Living with Asperger's syndrome. London: Jessica Kingsley Publishers.

Silence is one of the great arts of conversation. - Hannah Moore

The ache for home lives in all of us, the safe place where we can go as we are and not be questioned. - Maya Angelou

See You In October: Themes are Creativity and Autism Awareness