

Testimony State House
Joint Commission on Education
Education Committee
BillH1123

To Whom It May Concern:

My name is Jean Stern and I am the Director of Children's Services for the Asperger's Association of New England. I am here on behalf of the Asperger Syndrome community, to strongly support Bill H1123. Schools understand and address academic needs of children such as reading and math, through the IEP but research has shown that despite high intelligence and/or academic success, if students are unable to navigate their social world, they will not succeed in life. In addition, there are children who are so hypersensitive that they will be overwhelmed in a typical school environment. I want to state again that the most important thing that correlates with successful employment in later life is one's social ability not one's academic success. This bill will ensure that non-academic challenges faced by people with Asperger Syndrome will be discussed in the IEP process and addressed by the school. Let me give you examples. *I know a High School student who had a melt down when she was told that her teacher was "all tied up". She took it literally.* This is an example of a student's misunderstanding of a communication.

We know a middle school student who was so confused and scared by the social interactions expected in a school cafeteria that he refused to eat lunch. Unlike typically developing children, students with Asperger Syndrome will not learn the meaning of your facial expressions, your stance, your tone of voice or expressions you might use unless they are specifically taught within a social skills curriculum. Without specific teaching they misread interactions and wind up being seen as antisocial (using withdrawing to cope) or behavior problems (if they respond incorrectly). These are not students with willful attitude problems. Negotiating the unstructured time in the school day like the hallway time, lunch or recess is a minefield they don't understand and may navigate only with social disasters and great exhaustion

In addition, there are children who find sound and touch so overwhelming in a typical school environment that their reactions are perceived as willful misbehavior.

In one high school, classical music plays when classes change instead of the usual bell system. This simple change which cost nothing came about because the staff wanted to help a spectrum student who felt so assaulted by the loud bells that she could not come to school. We have seen kindergarten children standing in line and when one is slightly touched by a neighbor's backpack, they perceive that they are being purposefully hit. Many other spectrum children can misunderstand a casual touch for intentional assault.

We know individuals with multiple college degrees but cannot hold a job.

If the IEP team does not specifically address the areas noted in Bill H1123, the children are at high risk for failure not only in school but in the work place. The number one problem reported by Asperger Adults is unemployment or under employment because of social, communication or sensory issues in the work place. If these issues are addressed early in school children can learn skills to compensate, improve and lessen these difficulties.

It is essential for schools to know that we see adults who may have a master's degree in library science but cannot talk on the phone. As Federal law states, the services provided under an IEP should prepare the student for employment and independent living. This amended sentence would help schools to ensure that the non-academic needs of these children are met.

Thank you,
Jean Stern
Director of Children's Services
AANE



ASPERGER'S ASSOCIATION OF NEW ENGLAND

85 Main Street, Suite 101 • Watertown, MA 02472 • P: (617) 393-3824 • F: (617) 393-3827 • info@aane.org • www.aane.org

Dear Friend:

Welcome to the Asperger's Association of New England (AANE for short). Our mission is to provide awareness, respect, acceptance and support for individuals with Asperger's Syndrome and their families. I am very glad you found us, and hope that you will find a supportive community here, and a source of helpful information.

Let me introduce myself. I am an adult with Asperger's Syndrome (AS for short), and also the past-President of the AANE Board of Directors. A former music student, I am currently a doctoral candidate in Special Education at Boston University. My wife is a fellow musician whom I met in graduate school. You can read more about me in my book *Beyond the Wall: Personal Experiences with Autism and Asperger Syndrome*. You might also want to take a look at my contributions to a second book, *Ask and Tell: Self-Advocacy and Disclosure for People on the Autism Spectrum*. AANE Board V.P. Phil Schwarz also wrote a piece for this book.

At AANE, adults with AS are integral to the organization and its success. We serve (along with the parents of children with AS and professionals in the field) as board members, advisory committee members, volunteers, and public speakers at **Massachusetts Autism Spectrum Awareness Day**, AANE's annual conference (**Asperger Connections**), our annual gala dinner and auction, and as keynote speakers at AANE's first conference just for adults in July 2007. Adults with AS have lobbied at the State House in support of employment programs to benefit our underserved community. Adult speakers educate our whole community—other adults, staff, parents, educators, vocational counselors, other professionals and the general public—by speaking at conferences and trainings or by writing for our newsletter. Our current webmaster, office assistant, and the artist and the poet who have created the mailer for our annual appeals, are all adults with AS. AANE adult members lead our book and movie groups. At our 2007 annual conference, AANE sponsored an art show displaying only the work of adults with AS. The photographs, paintings, metal work, handmade instruments and poetry showcased the incredible talent within the AS community.

We are also very fortunate to have social workers and educators on staff to assist this growing population. Dania Jekel is AANE's Executive Director, Jamie Freed is Director of Adult Services, Gail Kastorf is Director of Vocational Support and Max Sederer is Adult Services Coordinator. The staff members are smart, well-informed about AS, and deeply committed to carrying out AANE's mission. We also have a board with some of the best professionals in the field of AS, and many great volunteers, most of whom are adults with AS or the parents of kids with AS. We are trying hard to expand the services we offer to adults with AS, and your support and participation can make a big difference.

I hope you will choose to become a member of AANE. Membership will entitle you to discounts at AANE conferences, workshops and adult social events. You will receive our informative journal (two issues per year), and notice of upcoming lectures, workshops, trainings, social events, and conferences. When you become a member, you will also receive a substantial packet including our adult book: *Living Loving and Working: Life Issues, Solutions and Resources for Adults with Asperger Syndrome* and a networking list which will provide you with names and contact information for other adults or families of adults with AS. If you cannot afford the \$35 annual membership dues at this time, please fill out the membership application anyway, and check off the box saying that you request a scholarship.

Keep the AANE phone number handy, in case you decide to call for more information, support, resources, or referrals. Periodically, remember to check out our website, www.aane.org, where you can get the latest news about AANE, including information about upcoming events, new groups, or new books. I look forward to meeting you at our annual fall conference and other AANE events.

Sincerely,

Stephen Shore

Stephen Shore, President Emeritus

AANE Board of Directors

Please contact AANE's Adult Services Department at: 617-393-3824

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ADULT/FAMILY MEMBERSHIP FORM

Section One: Adult/Family information

Please check if you are a:

- Parent or other family member of child with AS
- Adult with AS
- Parent of adult
- Other _____

Title _____ Name _____

Address _____

City _____ State _____ Zip _____

Phone _____ E-mail _____

People in your family:

First name (optional)	Gender Male/Female	Date of birth	Asperger's (or suspected AS) diagnosis: Yes/No	Father, mother, son, daughter, other
1.				
2.				
3.				
4.				
5.				

Please notify me of events for: parents teens with AS adults with AS siblings of persons with AS

- I give AANE permission to list my name, phone number, DOB of child/adult with AS, e-mail address, and town on the **Family Networking List**. AANE makes this list available to parents so that they can contact each other.
- I give AANE permission to list my name, phone number, DOB of adult with AS, e-mail address, and town on the **Adult Networking List**. AANE makes this list available to other adults and parents of adults so that they can contact each other.
- I give AANE permission to list my name, phone number, DOB of adult with AS, e-mail address, and town on the **Parent of Adult Networking List**. AANE makes this list available to other parents of adults so that they can contact each other.
- No, please do *not* include my contact information on a networking list.

I may want to volunteer some time to the organization. Please call me. I have the following special skill(s) or interest(s):

I am connected to or know about a foundation, corporation, business, friend or relative who might donate money to AANE

When making a request, I give permission to use my name: yes no

Name of foundation or corporation _____

Contact person: Title _____ Name: _____

Address _____

City _____ State _____ Zip _____

Phone _____ E-mail _____

Section Two: Membership & Donation Payment Information

If you can afford to do so, please help us keep our doors and phone lines open! Thank you!
Donations and dues are fully tax deductible.

I am a new member. I am renewing my membership. adults with AS siblings of persons with AS

Please give me a one-year, need-based scholarship for dues. I can afford to pay \$ _____

Please give me a one-year, need-based full scholarship for dues.

Enclosed please find my annual dues for individual or family (check one) \$35 for 1 year \$65 for 2 years \$95 for 3 years

Dues \$ _____

Donation* (see below) \$ _____

Total Enclosed

\$ _____

I have enclosed a check made out to AANE. OR I prefer to pay by: Mastercard Visa American Express

Credit Card number _____ Expiration Date ____/____/____

Exact name as it appears on credit card: _____

Card billing Address _____

City _____ State _____ Zip _____

Phone _____ E-mail _____

*Would you like us to list your donation in our next newsletter? yes no

If yes, how would you like the donation to be acknowledged?

Please do not list my name.

Please list my name exactly like this: _____

Please acknowledge that the gift is:

In memory of _____

In honor of _____

AANE Staff: Please sign your initials when you complete a task:

Packet sent on ___/___/___ ()

Added to mailing list on ___/___/___ ()

Thanked for donation on ___/___/___ ()

Copy given to Finance Manager for credit card processing ()



Asperger Syndrome Fact Sheet

- It is a neurological disorder that affects the way information is processed in the brain.
- AS is a hidden disability. Many people appear very competent, but have difficulties in the areas of communication and social interaction.
- AS has a genetic and hereditary component and may have additional or interactive environmental causes as yet unknown.
- AS is a developmental disability, all individuals have social/emotional delays but continued growth seems to be life-long
- The incidence of AS is thought to be 1 in 250. As many as 50% of people with AS may be undiagnosed.
- There are currently four males with AS to every one female with AS diagnosed with AS but the true ratio may be as high as one female for every two males.

AS affects each person differently, although there are a core set of features that most people with AS have, to different extents:

- People with AS have normal to very high intelligence and have good verbal skills.
- Challenges with the use and understanding of language in a social context
- Trouble understanding what someone else is thinking and feeling (called theory of mind or perspective taking)
- Needing to be taught social behavior that is learned intuitively by others
- Difficulty understanding non-verbal cues such as hand movements, facial expressions, and tone of voice.
- Challenges with organization, initiation, prioritizing, all called executive functioning tasks.
- Focusing on small details rather than the bigger picture
- Most people with AS have intense interest areas such as movies, geography, history, math, physics, cars, horses, dogs or reptiles. These interest areas change every 3 months to several years
- Friendships are usually formed through mutual interest areas or activities
- Most people with AS view the world in black and white with difficulty compromising or seeing the gray areas
- Most individuals with AS describe themselves as feeling different, like aliens in our world
- Anxiety and/or depression are major components for many people with AS and may affect their ability to function

- Some individuals with AS have extreme and debilitating hyper or hypo sensitivity to light, noise, touch or taste. The environment can have a profound impact on their ability to function.

Other elements and traits some individuals with AS have

- Eye contact is difficult, sometimes painful, usually distracting (or if taught poorly, some individuals may stare)
- Some people with AS are clumsy, most have poor fine motor skills although some excel in individual sports
- Some individuals with AS have additional diagnoses, such as ADD, bi-polar, OCD.
- Some have superior skill in a particular area such as painting, writing, math, music, history, electronics or composing.
- People with AS may have difficulties working in a group
- Children with AS may have meltdowns that last between 10 minutes and several hours, when the child is not in control of his/her behavior
- Self-esteem can be an issue for individuals with AS, especially during middle school
- Many are extremely good at memorizing facts and information
- Some like to systematize the world as a way of understanding it

A Summary of some Basic Interventions that may be helpful for people with AS

- Accepting the diagnosis and learning how it impacts who you are
- Learn how and when to talk about it to others
- Provide support-for adults in the area of budgeting and housekeeping
- Look very carefully at the social and physical environment to ensure it is tolerable for the person
- Learning social and communication skills
- Learning social behavior
- Working with skills and interest areas
- Use of medication
- Setting up routines in the person's life and prepare for transition for all changes
- Minimize transitions and social events with many unknown people
- Provide organizational supports, visual may be better for some people



Asperger Syndrome in Adults: Let's Look through a Broader Lens

by Jamie Freed, MSW

AANE staff have learned about the talents and struggles of adults with AS—and some successful strategies for addressing their challenges—through over a decade of working closely and talking extensively with over 400 adults with AS, ranging in age from 18-79, and with their parents, relatives, and spouses. We have developed a comprehensive array of services and programs to meet adults' needs, including an Asperger's information packet with our own 50 page guide book, telephone and face to face interviews with adults and/or family members, monthly social activities in three locations, a parents of adults support group, adult discussion/support groups, book readings, and internships in the AANE office.

Increasingly, adults with AS have become active partners in educating our community, growing our organization, and setting AANE's agenda. Adults with AS have served in many roles: as the President and Vice President of our Board of Directors, as members of our Adult Advisory Committee, as powerful self-advocates at Massachusetts Autism Spectrum Awareness Day, as part of our legislative advocacy committee, as speakers at our annual conference (Asperger Connections), and our annual gala dinner. They also recommend and serve as keynote speakers and workshop leaders for our conferences and speak to the press. They staff our events, write for our newsletter, volunteer in our office, fix our computers, maintain our web site, and provide artwork and clever text for our annual appeal card.

Since 2002, first as a parent-volunteer and then in my capacity as AANE's Director of Adult Services, I have had the privilege of meeting several hundred adults seeking answers to the question, "Why have I always felt so different from other people, and so distant from them?" The answer is not always, "Because you have Asperger Syndrome," but often it is. I have heard how these adults have survived years of being misunderstood and misdiagnosed. Their stories provide a unique window into the world of Asperger Syndrome. If the rest of us listen we will come to recognize a varied group of bright, funny, articulate, caring, logical, honest, persistent and hard-working individuals, who think differently because their brains happen to be "wired" differently.

People with Asperger Syndrome can look markedly different from one another. Some would prefer to be called "ASPIES" since they do not think Asperger's is something that they "have" but something that is encoded in their very brains and nerves. Throughout this article I may refer to adults as ASPIES which some people will appreciate and to which others might object. And for those ASPIES or people with AS out there, forgive the generalizations. What is written here is a conglomeration of what I have learned from the many hours spent with adult ASPIES, those who wonder if they have AS or family members of those with AS. I have interacted with AS adults individually, in groups on a weekly basis, at social events or meetings, as co-facilitators, as office volunteers, as teachers of my child, and as friends. It has been my privilege and honor to know the adults whom I have met and who are among the most hard-working people I know. This article is focused on a particular subset of the ASPIE population that often gets overlooked because they are too highly functional and asks the question, "How could these individuals have Asperger Syndrome?"

Many ASPIES appear to have a very high level of functioning—but what does that actually mean? It can mean that one functions very well in some arenas and not well in others. Maybe someone does quite well at work because s/he is extremely bright and well suited to the job. For example, an employee with AS may be successful because the work environment does not overload the person's senses or require

multi-tasking, or because the social contact on the job is minimal or highly structured, with clear expectations, or because the people at work are supportive, accommodating, or have similar/compatible personalities. This same person may not have or know how to create or maintain a satisfying life outside of work. Success for adults in our society usually means success at work; success in that arena may mask the fact that they also struggle in some fundamental ways that could be explained by Asperger Syndrome. There are others who cannot function in a work environment, but can maintain one or a few friendships or acquaintances, be a successful public speaker, and live independently. Maybe someone can neither maintain employment nor sustain friendships, but can produce beautiful art (visual, written, musical). There are infinite combinations and all could be considered Asperger Syndrome, depending on the lens through which you look. At AANE, we suggest that the lens be broad enough to accommodate adults with AS who may not “look the part.”

How is it that some adults can present so well? Adults with Asperger Syndrome grew up before the diagnosis existed in the United States; it appeared in the DSM-IV in 1994. The diagnosis may not have existed but the adults did—and they needed to find ways to survive. The adults that I have met **are** survivors. (See Mark Goodman article *I Am A Survivor*). Without the neurology that supported an intuitive understanding of social behavior, many adult ASPIES learned to spend their time observing their environment and the people around them. They tried to make sense of the confounding behavior of their peers and tried to understand why people were always telling them, “You’re so smart, why can’t you just... (fill in the blank): go to a family function and behave (sensory, social and anxiety), complete this work assignment (executive function, processing speed), just do what’s asked of you (illogical, theory of mind), tell a therapist how you’re feeling (reliance on thinking more than feeling). Through observation and trial and error (after error), many managed to survive into adulthood. Some ASPIES develop an understanding of the world around them, a framework of how and where they fit or don’t, learn and apply skills and strategies to use in particular situations, anticipate and manage disturbing sensory input. Imagine how absolutely **exhausting** it is to do all of those things relying on cognition, not intuition. Nevertheless, after years of applying these skills and strategies, an adult ASPIE can look pretty good, maybe even “passing”—or almost passing—for NT (neurotypical).

So after years of practice and trying to fit or find a comfortable place in the world, some ASPIES have put together a life and many live with the worry that it could all come apart because of how precariously it is crafted. Working so hard to fit in, to understand or hide your neurology comes with a very high price tag. In addition to the exhaustion, mentioned before, there is often a huge overlay of depression and anxiety on top of the basic neurological condition of AS. It is depressing when there is no obvious place in the world where one belongs; when everyone else seems to know the rules by heart and you’ve never been given the manual. The repeated trial and failures to make friends, work, live independently, manage your own affairs and even succeed in therapy are constant reminders of being “less than;” it should be no surprise that these experiences so often lead to depression. Why not be anxious when “the world outside [your] door is scary”. It is unknown, unpredictable, full of people walking down the same sidewalk that you are, crowded MBTA trains, store clerks who may want to talk to you, sensory assaults and a myriad of things that are not within your control. With a lack of intuitive ability to generalize, every time you go out the front door is a new challenge. More or less neurotypical people do not have to think just to function somewhat comfortably in the world. Many ASPIEs operate from a baseline of anxiety. Faced with the additional anxieties that come from living in an unpredictable world, an ASPIE who can look pretty good in one setting can fall apart in another.

And yet with all of these challenges, many adults have learned to approximate neurotypical behavior. Many adults have learned independently what today is currently being explicitly taught to our children with AS. Adults who have learned how to compensate, learned tricks and strategies, crafted some sort of life for themselves, may be denied the diagnosis because they do not quite fit the criteria. They may look too good or, because of the overlays on the ASPIE neurology, they look like something else is going on. AANE board member Gyasi Burks-Abbott refers to the “Aspergers pedigree” i.e., the number of diagnoses someone has received before stumbling upon Asperger Syndrome. These incorrect or

incomplete diagnoses may include: ADHD, Bipolar Disorder, Schizophrenia, Borderline Personality Disorder, Obsessive Compulsive Disorder, Intermittent Explosive Disorder, Major Depression, Generalized Anxiety Disorder, Social Phobia, Narcissistic Personality Disorder, Oppositional Defiant Disorder, Sensory Integration Dysfunction, or Autism: Residual State. There can be genuine co-morbidity (dual or multiple diagnoses simultaneously) but many symptoms can be explained by AS. For many, with the discovery of Asperger Syndrome the myriad of diagnoses fall away, frequently leaving behind the depression and anxiety, often bi-products of Asperger Syndrome.

When people begin to learn the skills, learn what's expected in the NT world plus have an increased understanding of themselves, they can actually change their behaviors, become more outwardly focused, aware of and interested in other people. Does that change the underlying neurology? Should a high functioning adult lose or never receive the diagnosis that could prove to be so helpful?

Considering the diagnostic criteria for AS, many of the adults that I meet would not necessarily fit the diagnosis. Most adults maintain pretty good eye contact. Virtually all of them have a sense of humor—and a quite sophisticated one at that! Some have had successful careers, even careers that demand multitasking—although the ability to juggle multiple tasks may not carry over to their home life. (Multitasking at work was often driven by an intense interest and a clear road map—a highly structured work environment.) Many adults can take part in the give and take of conversation, taking turns speaking and listening. They demonstrate theory of mind in a number of ways (an ability to put oneself in someone else's shoes and even empathize). Some have had intense personal connections (positive and lasting or not). Some have good gross motor skills. Not all are good at math and computers! Some are capable of lying (though generally because it is the “logical” thing to do in the situation). Some avoid certain loud noises but gravitate to others. It is especially difficult to diagnose based on presentation in a therapist's office since that is a setting that would be comfortable to many ASPIES: one on one, talking about oneself, with low environmental stimulation. With anxiety in check, traits may not be evident.

It seems that no one is looking to be in this “club” but many people seek answers to explain the outsider status that has defined their lives. When one welcomes it, it is usually because it fits where other diagnoses have not and because they have endured a lifetime of not understanding why their lives don't seem like others, why they feel they are “from another planet.” So when someone receives the diagnosis of AS as an adult, s/he can begin to look back at his or her life and understand it in a new light. It may explain some of the successes as well as the many challenges. It is often, but not always, a relief. The self-blame (“How can I be so smart and so stupid at the same time?”) can subside; adults can often forgive themselves for some things that went wrong. They can sometimes forgive their caregivers, parents and teachers, who were also operating without full information. Going forward, they can apply the new knowledge to help avoid previous pitfalls. People don't embrace the diagnosis because they want to belong—they embrace it because it fits. The difference it makes in someone's life to have this understanding is profound. It provides a community, a place where ASPIE neurology is typical and being NT is in the minority.

Where will we be in our understanding of AS in the next 10-20 years? It's likely this diagnostic area will be further refined, maybe there will be AS subtypes since the challenges that account for the AS diagnosis show up to different degrees in different people. Let us be open to learning from the adults who've lived undiagnosed or misdiagnosed and learn from them and their stories of survival. Let's encourage adults with Asperger's to understand themselves to the best of their abilities so that they can self advocate, asking for what they need and offering solutions that may alleviate their challenges and leverage their many strengths. AANE will be here as a resource, a support, and a community along the way.

I Am a Survivor

by Mark Morris Goodman

I am a survivor.

As a problem child I did not speak until I was four, spent two chaotic years in Kindergarten, an extra year glued to grade 6. In 1946, when I was twelve, my mother took me to Stanford University for an evaluation. The psychologist who examined me declared nothing was wrong, that I would likely outgrow whatever was troubling me.

Since this was long before Autism and Aspergers came on line so to speak, I lost out. Not only did I not outgrow anything, by age 14 I was heavily into antisocial behavior, as well as being picked on by schoolyard bullies. My increasingly nefarious activities ran the gamut from annoying teachers to intricately fabricated, potentially life-threatening acts of destruction to school property. Sometimes I planned it so that others, bullies in particular, got blamed. In time of course the staff caught on. Punishment was swift and harsh, transforming me into the best-behaved child in the lot albeit not for long. In retrospect it's a wonder I didn't wind up in reform school. Or dead.

I read gobs of science-fiction in those turbulent days, finding myself more at home on impossibly remote, imaginary worlds than the alien world I was strapped to.

By high school I was no longer able or willing to communicate my distress through antisocial means. I became invisible and meek in that oversized learning factory, at the same time ostracized by my classmates. And I was picked on by a sadistic teacher. My father intervened, resulting in my being placed in another class the following day and the teacher promptly fired. Grades were mostly C's along with a jolt of D's and F's, necessitating grinding repeats.

Amazingly, I made it into San Jose State College on what was then called second probation, ended my first semester with 3 F's and one D for a hard semester's workout, followed by expulsion and a stern letter warning me to stay off campus.

While there I had spent precious hours in the stacks researching the subject of intelligence, desperately seeking a way somehow to waken what little intelligence I had, if any. Imagine my dismay when I discovered that giftedness was not something one can acquire but is obtained courtesy of genes. I felt like crying when I read that; how I envied those who came so equipped. Conclusion: you have it or you don't and I didn't, period.

Somewhat daunted, I hied off to San Mateo Junior College twenty-five miles away just in time to begin anew. Dropped out before semester's end. Attended University of North Dakota two thousand miles away, beyond the reach of incriminating transcripts, barely made it through one semester. Attended more colleges, finally eking out a B.S. in electronic engineering eleven grueling, tortuous years after limping out of high school—in engineering of all fields, math being my weakest subject.

Turned out I was utterly incapable of doing electronic engineering, where, like school, everything became a jumble. The field held no meaning for me whatever—notwithstanding my constructing long-range FM broadcast receivers as a hobby, as well as making my own TV station from parts scrounged from

discarded radios and TV's and a discarded iconoscope. I also put together a high-power ham radio station from scratch in the days before single-sideband.

Went back to college in the 70's, managed somehow to wrest a M.A. in English Lit—after flunking my exams and having to hobble back for another try.

Through it all I had consulted twenty—twenty five therapists in the form of school counselors, social workers, psychologists, psychiatrists. Growing increasingly desperate I crashed several times, suffered internment in psychiatric wards in faraway cities where I knew no one. Result was my ending up beached on disability, where I have remained since.

Self esteem got squished nearly to the vanishing point, all but invisible except perhaps under an electron microscope. I could not relate to people except, curiously, those who were highly intelligent, well-educated—which puzzled me greatly as I felt nowhere near to being in their league.

Thoughts of suicide became a constant companion through those dark days of unremitting despondency. Unable to make it on my own I eventually returned to California to live with my aging mother, later to serve as her caretaker as she faced the inevitable decline into the twilight of Alzheimer's.

Fast-forward to March 2003. During a chance conversation the word *autism* came up. My curiosity aroused, I typed autism into *Google* after I got home. Within minutes I ran into a word I'd not heard or seen before: *Aspergers*.

I downloaded a questionnaire, gave it to my landlady and friend Joan who then administered it to me: Lay diagnosis: Mark has Aspergers. What a feeling of excitement that gave me: maybe what had plagued me all my life had a name, and having a name might be something that could be treated, ameliorated, perhaps even fixed pray tell. It was a seminal moment.

Further searching landed me on the *Aspergers Association of New England* site. On submitting an inquiry I received a prompt email suggesting I make an appointment to come in for an interview. I spent at least an hour there, plying Dania with a bevy of questions. She gave me a list of nearby psychiatrists to contact, as I had decided in earnest to seek a formal evaluation. On the way home I wondered what I was getting into; turning back was unthinkable.

I called a handful of these psychiatrists, which proved discouraging since several did not return my calls and those who did said they didn't do evaluations for someone my age. Then I scored: Dr. Daniel Rosenn was receptive to my call. But I was taken aback when he told me his waiting list was eighteen months.

When I explained that I was only a few months in front of my 70th birthday, he said he would see what he could do. Got a call a few days later informing me my appointment was to be four months hence, July 9th, 2003, two days after my birthday. Super! This allowed me ample time to write a detailed summary of my life, as well as cull through other writings I'd done earlier about my childhood. A month before D-day I mailed off a 50-page packet.

Upshot was a diagnosis of both Aspergers *and* high-functioning autism, giving me a solid foot in each camp. Dr. Rosenn said two things that stuck: one, he wished he could've knocked the zero off my age of 70, and two, that I was in the 99th percentile in intelligence in some areas. Me, *that* intelligent? Oh, my.

Soon after, I was informed that a support group made up of other Aspies was being formed at AANE; would I like to join? I jumped for the opportunity, especially since I would not have to depend on others for transportation.

Turns out this has been phenomenal in the budding reconstruction of my life, now underway. Here I was, receiving positive feedback from a group of highly intelligent people for the first time in my life, feedback that proved both consistent and unassailable. I didn't know what to make of it at first, wondered how the

others felt toward me and if I could stay the course. To my amazement I found myself capable of holding up my own end.

I've begun to gather the shards of my long-ago shattered self-esteem, seeing if I can fit them back together. It's been slow going, but going nevertheless.

It has become clear that had I had a proper diagnosis early on followed by the right kind of guidance, I would surely have fared better in my trek through life. I did not fall through the cracks because there were no cracks to fall through—it was free-fall from the start. I had no mentor, no one to champion me through difficult times, no one to show me the way or illuminate the darkness.

My emerging transformation this past year could not have taken place were it not for *AANE* and Dr. Rosenn. It was like coming ashore after a life of bobbing up and down in a sea that seemed to stretch to infinity in all directions, a vast repository of hopelessness and despair. Unaccountably I never went under, never abandoned the struggle despite persistent and overwhelming odds.

My situation shows so clearly why organizations like *AANE* are important—nay, vital. As Ben Franklin quipped during the Revolutionary War, we hang together or we hang separately. Aspies without support hang separately; take it from me. Pick a hundred Aspies at random and you have a hundred Aspies. But link these individuals in a coherent, synergistic pattern with proper guidance and something remarkable begins to happen: a budding gestalt arises. Similar to the way life amounts to more than the sum of its carbon chains, proteins and DNA, consciousness is more than a mere tangle of neurons and synapses and neurotransmitters. Mundane somehow gets transformed into magic.

I've encountered a piece of this magic through *AANE*, for what it has given me and continues to give, something that nobody or anything else has come close to pulling off. Psychotherapy came to naught, school savaged me, various social programs fell short of what I needed, my upbringing left me clueless how to proceed or where to turn next. The outcome was a life of isolation and an improbable career choice that went nowhere.

It's a four-hour, ten-mile walk from Needham to and from *AANE* every Friday morning. To date I missed only one meeting in the past half-year owing to dangerously cold weather. I'd walk twice as far if I had to and I could too. To put it straight I feel I have received more from *AANE* in the last six months than from everything else in my life combined.

Yes, this long-overdue journey comes late, some would say very late, perhaps too late worth fussing over, at a time when most my age think of retirement and the fabled golden years. While I have lost out on much, it is gratifying to know I can still surge forward, still break out of a decades-old, rusting iron mask of repeated setbacks. But—and I can't stress this enough—**I could not have done it alone.**

I need *AANE*, you need *AANE*, and *AANE* needs all the support it can get from all of us—and anyone else we can catch.



ASPERGER'S ASSOCIATION OF NEW ENGLAND

85 Main Street, Suite 101 • Watertown, MA 02472 • P: (617) 393-3824 • F: (617) 393-3827 • info@aane.org • www.aane.org

Dear Friend,

Thank you for contacting the Asperger's Association of New England (AANE). We are sending you this introductory information packet, with an Asperger Syndrome Fact Sheet, to tell you more about AANE's programs and services. We hope that you will join AANE, and become an active member of our community.

AANE was founded in 1996 with a mission of fostering awareness, respect, acceptance, and support for individuals with Asperger Syndrome (AS) and their families. Since then, we have developed a wide range of services and programs for the thousands of individuals and families across New England who live with AS, and the many dedicated professionals who serve them. AANE helps these families and professionals come together into a strong, vibrant, mutually supportive community. We offer programs and connections that can enrich your professional life, and help you help your clients with Asperger Syndrome, HFA, PDD-NOS, and NLD.

AS is still a relatively recent diagnosis. In addition, individuals with AS can both differ greatly from one another and present complex challenges. AANE professional members can contact AANE when their students or clients need specialized resources, or have issues the professional would like to discuss with another professional who understands AS.

- ♥ AANE professional members can also refer adults with AS, or the families of children, teens, or adults with AS, directly to AANE staff for information, support, or referrals, and services including family grants, peer support groups, networking lists, and information packets. (See the back of this page for a summary of our services.)
- ♥ When you become a member, *all* staff at your school, agency, or practice receive discounts when attending AANE conferences, classes, and seminars, where everyone can learn from AS experts. Many events offer professional development credits.
- ♥ Members may request a free information packet, full of valuable information and resources that AANE has gathered and created since our founding in 1996. Professionals who work primarily with children and their families may request our 90-page book **An Introduction to Asperger Syndrome: Information for Families of Children and Adolescents**. Professionals who work mainly with adults may request our 50-page booklet **Living, Loving, and Working: Life Issues, Resources and Solutions for Adults with Asperger Syndrome**.
- ♥ Members receive a subscription to the **AANE Journal**, published twice a year. The journal includes informative, practical and inspirational articles, by parents, educators and AS experts, along with artwork, book reviews, essays and poetry by teens and adults with AS.
- ♥ Members may advertise their services in the **AANE Journal**, the program book of the annual Asperger Connections fall conference, or the program book of the annual spring gala and auction.
- ♥ Members receive our monthly e-newsletters: reminders of upcoming events and late-breaking news about special events with out-of-town authors or AS experts.
- ♥ Members can arrange for on-site professional training, tailored to meet your staff's specific needs, at discounted rates. Trainers will be AANE staff or consultants and, when appropriate, adults with AS. (Letter continues on reverse of page.)

See www.aane.org for articles on AS, and information on upcoming conferences, educator workshops, and professional trainings.

Your support also ensures that the Asperger's community will have a knowledgeable public spokesperson—an AANE staff or board member. AANE educates the public about AS through media interviews, and through trainings at police departments, mental health facilities, schools and universities, government agencies, and many other places. We also advocate with legislators and government officials on behalf of people with AS. We invite you to join the AANE community, and add your voice to ours.

Sincerely,

Dania Jekel

Dania Jekel, MSW
Executive Director
617 393-3824 x 303
Dania.Jekel@aane.org



Summary of AANE Services and Who to Contact

As a professional serving the AS community, we hope you will refer families or individuals directly to AANE for the extra support they need to meet the challenges of living with AS. This guide could help you and your clients know who to call, and what services we offer.

Services for Parents/Family Members of Children or Teens with Asperger Syndrome

- ♥ Parent (and other family members) of children and teens with Asperger Syndrome can call the **Asperger Syndrome Information Line**, 617-393-3824, for free information, support, resources and referrals, 9-5 any weekday.
- ♥ As a child becomes a teen, and a teen becomes an adult, AANE members can contact AANE to request a free, age-appropriate **Asperger's Information Packet** (child, teen or adult version), with a **Family Networking List**, and **College Information** (for teen or adult packets).
- ♥ Parents can attend one of our nineteen free, monthly **face-to-face parent support groups**. There they will meet other parents who really understand what it is like to parent a child with AS—the highs and the lows, the mistakes and the successes, the fears and the humor.
- ♥ Parents of children or teens may choose to join one of our **on-line support groups**.
- ♥ Join other members of our community at Asperger **conferences** in Greater Boston, Western Massachusetts, Maine, Rhode Island, or New Hampshire, where we all learn from the experts—and from each other.
- ♥ Attend **parenting classes** with such outstanding teachers as Lynne Mitchell or Nancy Schwartz, or **professional trainings** with Elsa Abele, Lynne Mitchell, Dot Lucci, Judy Gooen, Sarah Ward, Alex Michaels, Pamela Ely Martins, and Lori Hodgins Brazell.
- ♥ Attend **workshops on special education law** and how to advocate with the schools, offered 5x a year by Jean Stern, and advanced sessions with lawyers from **Massachusetts Advocates for Children**.
- ♥ Keep in touch through the AANE **website**, the **AANE Journal**, and a monthly **e-newsletter**.
- ♥ Join other community members to **advocate** for government-funded services for people with AS.
- ♥ Families of low to moderate income may be eligible to apply to the **Edwin Phillips Family Grants Program**, **Doug Flutie, Jr. Family Grants Program**, or **AANE Family Grants Program**.

Who to contact:

Jean Stern, M.S. Director of Children's Services, 617-393-3824 x 308, Jean.Stern@aane.org
Brenda Dater, MPH, MSW, Coordinator of Children's Services & Moderator of the "Parents of Kids" on-line support group, 617-393-3824 x 311, Brenda.Dater@aane.org

Yolanda Kolinski, Director of Programs for the Latino Community, 617-393-3824 x 312,
Yolanda.Kolinski@aane.org

Stephanie Loo, M.Ed., Director of Teen Services & Moderator of the Parents of Teens on-line support group, 617-393-3824 x 307, Stephanie.Loo@aane.org



Services for Adults with Asperger Syndrome and their Family Members

- ♥ Call the **Asperger Syndrome Information Line**, 617-393-3824, for free information, support, resources and referrals, 9-5 any weekday.
- ♥ Adults with AS (or who suspect they have AS) usually meet with an AANE staff member to learn about AS, about services at AANE, and about community resources to help them manage their lives and move toward their goals.
- ♥ We offer **social activity groups** and **discussion/support groups for adults** with AS based in several locations.
- ♥ Join other members of our community at **Asperger conferences** in a variety of locations.
- ♥ Some adults serve on the AANE board of directors or one of its committees, write for the **AANE Journal**, exhibit at AANE art shows, or speak about their experiences at AANE trainings, conferences, or parent support group meetings.
- ♥ Dania Jekel facilitates a **support group for parents of adults**, often featuring speakers on issues such as employment, housing, or financial planning.
- ♥ We frequently offer **spouse support groups** for women who are married to/partnered with men with AS.

Who to contact:

Jamie Freed, LICSW, Director of Adult Services, 617-393-3824 x 310, Jamie.Freed@aane.org

Gail Kastorf, M.Ed., Director of Vocational Support, 617-393-3824 x 301,
Gail.Kastorf@aane.org

Max Sederer, M.A.T., Coordinator of Adult Services, 617-393-3824 x 302,
Max.Sederer@aane.org



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PROFESSIONAL MEMBERSHIP FORM

Title _____ Name _____

Organization/Program/School _____

Address _____

State _____ Zip _____

Phone(s) _____ Email _____

Type of services provided: _____

Population/age range served: _____

Enclosed please find my annual dues (check one) \$45 for 1 year \$85 for 2 years \$125 for 3 years

Dues \$ _____

Donation* (see below) \$ _____

Total Enclosed (Dues and donations are tax deductible) \$ _____

I have enclosed a check made out to AANE.

I prefer to pay by: MasterCard Visa American Express

Credit Card number _____ Expiration Date ____/____

Name as it appears on card _____

Card billing address if different from above:

_____ Zip _____

* Please do NOT list my donation in the AANE newsletter.

Please list my donation in the AANE newsletter. (Please let us know what name should we list, or in whose memory or in whose honor the gift is made.)

I am connected to or know about a foundation, corporation, business, friend or relative who might donate money to AANE. When making a request, I give permission to use my name: Yes No

Name of organization _____

Contact person: Title _____ Name: _____

Address _____

State _____ Zip _____

Phone _____ Email _____

Section Two: Request for Additional Information

- Please send me the Professional Youth Asperger's information packet OR
- Please send me the Professional Adult Asperger's information packet
- Please send me the booklet **Disclosure & AS: Our Own Stories**. (Price: \$7.00)
- Please send me information about advertising in the AANE Journal, the Asperger Connections conference program book, and the annual gala/auction program book.
- I would be interested in participating in a professional roundtable.
- I would be interested in volunteering or serving on a professional advisory or board committee.
- My school or agency would like to schedule an in-service AS training.

Optional for those professionals who want to be considered an AANE resource:

Check here if you would your name or organization to be given as a referral to people who call AANE, and complete the following information. Please tell us a bit about your program, organization or service. You may also enclose brochures or business cards.

Payment options for patients/clients/consumers (e.g. insurance accepted) _____

Your degrees/titles/credentials _____

Check here if you offer a social skills group and would like to be on our list of Social Skills Groups.

Information about social skills group (e.g. age range, summer, year round) _____

Please provide the names of two people who would be willing to be called as references. This could include a professional colleague, the parent of a child with Asperger's, an adult with AS, etc.

Name: _____ Phone number: _____

Name: _____ Phone number: _____

Staff: Please sign your initials when you complete a task: " Added to mailing list on ___/___/___ () " Thanked for donation on ___/___/___ () " Copy given to Finance for credit card processing ()

Other elements and traits some individuals with AS have

- ♥ Eye contact is difficult, usually distracting, sometimes painful. (If taught poorly, some individuals may stare.)
- ♥ Some people with AS are clumsy and most have poor fine motor skills, although some excel in individual sports, drawing, etc.
- ♥ Some individuals with AS have additional diagnoses, such as ADD, bi-polar, OCD, Tourette's.
- ♥ Some have superior skill in a particular area such as painting, writing, math, music, history, electronics or composing.
- ♥ People with AS may have difficulties working in a group
- ♥ Children with AS may have meltdowns that last between 10 minutes and several hours, when the child is not in control of his/her behavior.
- ♥ Self-esteem can be an issue for individuals with AS, especially during middle school.
- ♥ Many are extremely good at memorizing facts and information.
- ♥ Some like to systematize the world as a way of understanding it.

A Summary of some Basic Interventions that may be helpful for people with AS

- ♥ Accepting the diagnosis and leaning how it impacts who you are
- ♥ Learn how and when to talk about it to others
- ♥ Provide support-for adults in the area of budgeting and housekeeping
- ♥ Look very carefully at the social and physical environment to ensure it is tolerable for the person
- ♥ Learning social and communication skills
- ♥ Learning social behavior
- ♥ Working with skills and interest areas
- ♥ Use of medication
- ♥ Setting up Routines in the person's life and prepare for transition for all changes
- ♥ Minimize transitions and social events with many unknown people
- ♥ Provide organizational supports, visual may be better for some people

JOINT EDUCATION COMMITTEE
TESTIMONY OF JANINE A. SOLOMON, ESQ.
June 1, 2005

My name is Janine Solomon. I am an attorney and I have worked at the Disability Law Center (DLC) in Boston for over ten years. I have worked in special education law for four years at DLC and I have represented numerous families with children diagnosed with Autism Spectrum Disorder (ASD). I am a resident of Milton and I am here today to provide testimony on House Bill No. 1123, An Act to Address the Special Education Needs of Children with Autism Spectrum Disorder.

I work as an attorney at the Disability Law Center in Boston and have done so for the past ten years. I have worked in special education law for four years at DLC and I have represented numerous families with children diagnosed with Autism Spectrum Disorder (ASD). I also am the parent of a seven year child with Autism.

Based on cases that I have handled, as well as other cases handled by the Law Center, I know that there is a tremendous importance for children diagnosed with ASD to receive intensive, coordinated, educational services. Research demonstrates that children with autism can exhibit significant gains, in some cases acquiring skills within typically developing ranges, if they receive services necessary to address the full range of their complex learning needs.

Children with autism require highly specialized and coordinated educational programs in order to gain basic skills that non-disabled children can learn intuitively. Many children with autism have difficulty learning to engage in every day interactions. This social isolation, if not addressed, can greatly affect a person throughout their lifetime.

The number of children diagnosed with ASD have increased exponentially over the last ten years. There has been a 500% increase in the numbers of children ages 6-21 diagnosed with Autism from 1993-2003.

While the number of children diagnosed with ASD is continuing to increase, children with autism frequently fail to receive essential services they need. This bill amends special education law to ensure that a child's Individualized Education Plan (IEP) Team considers and addresses the complex communication, social, behavioral, sensory, and academic needs resulting from Autism Spectrum Disorder. While Teams are still required to make an individualized determination, the Legislation will insure that Teams will look at all aspects of special education services, other than academics.

Case and personal examples:

1. I recently worked with a family of a six year old boy diagnosed with Autism. He was non-verbal and severely cognitively impaired. For several years the Student was receiving intensive services both in school and at home, and was beginning to show some signs of progress. Unfortunately, his family moved and switched school districts and he

received a substantial reduction in the number of hours that he required. His family clinician recommended, at minimum, 30 hours of Applied Behavioral Analysis (ABA) per week and he was only receiving half of that (a total of five hours in school and ten hours at home per week). This drastic reduction of services resulted in a major regression of his skills.

HR 1123 provides safeguards and guidance so that the IEP Team considers the full range of educational needs resulting from Autism Spectrum Disorder. If HR 1123 were to be enacted, families of children with ASD would have more leverage to get appropriate educational services for their children.

2. One student I worked with was a nine year old boy diagnosed with Aspergers Syndrome, ADHD, and Bi-Polar Disorder. The Student's mother also had a mental illness as well as an older son with depression. The district offered no services to the family beyond the school day. During the day the student received services from a behaviorist in a comprehensive setting. However, he was unable to generalize any skills he may have learned during the school day and apply them to activities in the community. The Student was isolated at home and unable to participate in activities with his peers in the community. His behaviors stigmatized him and he had difficulty developing friendships. I was eventually able to get the student full day, full year services and he began to learn to carry over his social skills and behavioral goals he worked on during the school day and apply them to home and the community.

HR 1123 will offer educational Teams the guidance that was sorely lacking in this case by providing a comprehensive, highly specialized and coordinated educational program to assist a student with significant needs to gain basic skills that their non-disabled peers can learn intuitively.

3. My daughter is seven and has a diagnosis of PDD-NOS. She was diagnosed at age 2. Early on, her father and I knew that she had significant needs. She had speech delays and fine motor delays at eighteen months. She continued to mouth objects beyond the point when it was age appropriate. She would scream when people entered into her environment and had extreme difficulty going places or if there was a change in her routine. She had many stereotypical behaviors, including rocking and other self-soothing behaviors. The simplest things became almost impossible. I could not take her out for a walk in her carriage in the neighborhood and stop and talk with a neighbor without her being significantly disturbed. Going out was almost non-existent.

We were fortunate to receive intensive coordinated educational services for our daughter at an early age. She attended our town's local area collaborative and began receiving Applied Behavioral Analysis (ABA) services beginning at age 2.5. These services were initially covered by the Commonwealth under Early Intervention and were later picked up by our district.

My daughter has been receiving intensive services consistently and has made incredible gains. She is currently in first grade in a regular education classroom setting and has made

substantial progress. By addressing her needs early on with provision of intensive, well coordinated services applied to her full range of needs, she has acquired skills in the typically developing range in areas of social language acquisition, nonverbal communication, and reduction of challenging behaviors.

For all of the above reasons, I urge the Committee to report out this bill favorably. Thank you for your time and consideration of these comments.