

AUTISM AMBASSADORS CORPS
EXPOSITORY OF THE PRACTICES THE AAC SUPPORTS

1) Providing a SCIENTIFIC, CLINICAL & EXPERIENTIAL Based Defense of “Neurodiversity”: Sue Golubock¹ first explained to me the root science of autism IN A WAY THAT SHOWS THE PLAUSIBILITY OF NEURODIVERSITY. The next paragraph is based on what Sue taught me. It is also what shared with Dr. David C. Hubbard, PhD P.L.C.² who confirmed that its accuracy. The two paragraphs that follows it is my own assessments of autism based on this basic understand, my personal experiences, the experiences that other autistics have shared with me and my own personal research into this subject.

The brain has billions of neural-receptors that are giving off signals at all times. We are not born with all of these receptors, but are continually growing more over the years which enable our brain to increase in its ability to function at higher levels. In the autistic brain, some parts of our brain are slower in the development of these receptors than a neurotypical brain does. As a result, these parts of the autistic's brain are less active than the same parts of the brain of neurotypicals. However, other parts of our brains grow neural receptors faster. Therefore, the parts of our brain that have more receptors are more active than the same areas of the brain of a neurotypical.

So if you were to rate the activity levels of the brain on a 1-10 scale, a neurotypical might rate 4-6 straight across the board. The autistic brain on the other hand might rate 1-3 in some areas and 7-10 in others. When we are in a situation where our 1-3 come out, we are labeled handicapped. When we are in situation where our 7-10 come out, we are proclaimed geniuses. This leads me to a point that is most sensitive to us autistics, do we need to be “cured” or do we need to be cut some slack with our 1-3s and given more opportunity to utilize our 7-10s?

It is my firm conviction that my 140 IQ and my autism are interwoven into the fabric of who I am as a person. I believe that to “cure” me of my autism is to “cure” me of my 140 IQ. I must therefore ask; do you really want to “cure” me of my 140 IQ? This is why self-advocating autistics who embrace neurodiversity, like me, are opposed to such efforts. Whether or not neurodiversity is a credible view of autism is a matter of debate. Autistics, parents, teachers, etc cannot make an informed decision about where they stand on this issue unless they have the opportunity to hear both sides.

The autistic neurological model also explains why we have neurological overloads. Manifestations of these include seizures, sensory processing issues, as well as increased difficulties in dealing with stress and emotions. This does not mean that we do not have emotion, but that highly emotional situation can overwhelm our ability to express them.

The scientific fact that our brains are constantly growing new neural-receptors, and the personal experiences of myself as well as other autistics, gives me reason to believe that some of the areas that autistics struggle with may self-correct to various degrees over time. In other words, just because we may be deficient in some areas of our brains early in our live does not mean that we will always be deficient.

2) Helping Autistics Develop Effective Self-Management Skills: The building and preserving of basic human dignity is essential for the emotional wellbeing of everybody. Helping someone obtain and maintain the greatest level of possible is key in that endeavor. Personal independence is as necessary for an 80 year old as it is for someone with a developmental disability.

When discussing the possibility of autistic self-development, it is important to note the fact that I did progress in my development in spite of not being diagnosed as autistic until I was forty years old. How did I do so? Through working a Twelve Step program for codependency. Why was this able to help me? IN SPITE OF MY NEUROLOGICAL DIFFERENCES, I AM STILL A HUMAN BEING. The struggles I have as an autistic is the same struggles that I other human beings have. My struggles may be more severe, but that just means that I have to do what all humans should do anyways: develop effective skills in stress management, conflict resolution, organizational, etc. Some neurotypicals may be able to get away with using dysfunctional alterative to developing effective skills in these areas for quite some time, but they would be better off developing them anyways. As for autistics, developing these skills are a matter of life and death.

I am very aware that not all autistics develop neurologically the same way I have. Therefore, there is no guarantee that every autistic can be taught to function entirely on their own without any special assistance. Nevertheless, all autistics should be given the benefit of the doubt and the opportunity to try to develop beyond what they are. Yes, they should use whatever special assistance is available to them for as long as they need it, but an effort should be made to help them learn what we can do so we will not need to use them anymore then absolutely necessary.

3) Teaching Autistics Who Can Advocate for Themselves How to so: Many autistics function at a high enough level to be able to educate others about themselves. This requires them to combine their PERSONAL EXPERIENCES with a

¹ An autistic friend who is an Occupational Therapist with autistic individuals.

² At one of my month autism support group meetings on June 12, 2010.

SCIENTIFIC UNDERSTANDING OF AUTISM'S NEUROLOGICAL ROOTS. This approach is the only feasible way for many autistics to self-advocate because if the autistic cannot understand their autism, they will never be able to effectively self-advocate so others understand them. Therefore, the goal is to simplify the subject of autism so autistics are talking about issues that are within their capacity to understand. This allows them to...

- a. ...have hope that many of their struggles may self-correct in time or at the very least be managed.
- b. ...convey this hope to their loved ones.
- c. ...help autistics develop so that they need as little special assistance as possible, especially professional and governmental.
- d. ...learn what special gifts that their autistic neural configuration gives them.
- e. ...help others understand their autism and what can be done to manage it more effectively.
- f. ...help others to recognize their unique strengths so they can be better utilized.
- g. ...work with those who are open to embracing, as much as humanly possible, a "team" concept for getting things done. They allow autistics to focus more of their energies on what they are best at while letting others "have their back" in areas of their greatest weaknesses.
- h. ...defend themselves from false allegations about their atypical tendencies by enabling them to give a scientific explanation as to why they are the way they are.
- i. ...express to others the devastating effects of mistreatment they have suffered as well as wrongful judgments made about them. These have had a devastating effect on their emotional wellbeing.
- j. ...remind those whom they interact with of the concept of "late bloomers." There is an abundance of documented evidence that many children who were viewed as developmentally delayed early in life blossomed later on. Some of these late bloomers have been regarded as some of the greatest geniuses of all time.

Some autistics who do not function at as high of a level may at the very least be able to be taught to express some of their thoughts that they would like others to know about themselves. Just because they may not be able to express themselves verbally, does not mean that they may not be able to express themselves in other ways. Some may be able to be taught to use a speaking devise, writing, typing, signing, picture cards, etc.

4) Speaking on Behalf of Autistics Who Cannot Speak for Themselves: This does not just apply to us speaking on behalf of "lower functioning" autistics who may never develop the ability for communication. This also includes autistic children who are not old enough to understand, let alone explain, their autistic ways; especially to skeptical adults and peers. Our efforts will be guided by two primary principles:

- a. Our techniques are educational, not confrontational.
- b. We do not presume that we need to battle neurotypicals on behalf of autistics. Instead, we hope to help both sides to gain mutual understanding and respect for each other. This means that WE AUTISTICS NEED TO TRY AS HARD TO UNDERSTAND THE NEUROTYPICAL'S VIEWPOINT AS THEY NEED TO TRY AND UNDERSTAND OURS.

5) Providing Informed Referrals for Who Need Them: One of the most frustrating endeavors for anyone seeking information, whether about autism or any other need, is being told by everyone that they call that they should call someone else. Even those organizations that do have employees who will go the extra mile for anyone that seeks their assistance, there is still the problem of few such employees having a solid understand of what others are doing. The AAC will make it a priority to understand the kind of services that other organizations provide that we would be able to actually sell their services to others. This is not to say that we would actually be successful selling other's programs, but that we would have the knowledge necessary so the person we refer could be confident that the place that we are referring them what they are looking for.

6) Solutions for Parents Who Need Childcare to Attend Meetings: One of the biggest problems facing parents of autistic children is finding childcare, especially when they need it to attend meetings so they can get the support they need. This problem is faced by the parents who most need to attend these meetings; the youngest and most inexperienced with the child who are the youngest and in most need of direct supervision. These parents have the hardest time finding meetings that they can attend because it's hard to find one that can provide childcare due to liability issues.

The autism community needs to rid itself of the excessive influence of lawyers as much as humanly possible so we focus the needs of the community. If we focus on developing caregiver you are well equipped to deal with any issues that may occur while autistics are under their care, then there should be no reason to worry about liabilities, lawyers and lawsuits. The AAC supports the creation an accreditation program specifically geared towards providing

childcare for autistics. This accreditation program should be developed by a committee comprise of the following elements:

- a. **Autistics:** We need to make sure that our viewpoints of autism are taken into account while this curriculum is being developed.
- b. **Parents:** Their viewpoints of autism also need to be taken into account while this curriculum is being developed.
- c. **Teachers:** This would include those whose teaching background is from public schools, privet schools, daycare, Sunday school, childcare for special programs and events, etc. Their participation is crucial for pointing out the unique situations faced in such venues; as well scrutinizing the expectations being placed on childcare providers.
- d. **Therapists who specialize in autism:** There are many therapists, but few who specialize in autism and therefore understand all of its complexities and paradoxes.

Furthermore, the AAC recognizes the need to maintain an effect means of referring childcare providers with this accreditation to those groups who would wish to utilize them. Although the AAC would assist in providing such referral, I believe that it would be better if there were one or more organization(s) whose sole purpose was to provide such services.

7) **Working to Bring More Uniformity in Autism Diagnoses:** I know autistics who have been diagnosed with more than a dozen different aliments. Autism, something else with autistic features or just something else altogether. Some have been diagnosed as autistic by one counselor only to have the next counselors say it's something different. There is just too much subjectivity to how autism is diagnosed and its causing a lot of frustration and confusion amongst us who identify as autistic, but may not have the official diagnosis. If we do have the diagnosis, a change of counselors can change all of that. THIS NEEDS TO STOP!

A brain scan enabling doctors to accurately diagnose autism by examining the neurological activity in the brain is still in the works. Due to my lack of confidence in the accuracy of subjective behavioral analysis leads, I urge for there to be more research effort in perfecting a much less subjective brain scan.

8) **Autistics Providing Direct Input to Researchers...**

- a. **...when they are deciding what projects to pursue:** The research that I am aware of deals with autism from an "adversarial" viewpoint; that it is a defect that must be cured. However, many Autistics would like more research done for the sole purpose of improving the quality of our life.
- b. **...about the consistency of their findings with our own personal experiences:** Some of the research findings that have been published are not 100% consistent with our personal experiences. This is not to say that these research findings are necessarily totally off base. We autistics might be able to share with the researchers some insights about our autistic experiences that they did not come across in their laboratory or clinical experiments.
- c. **...by providing them with an autism database for the purposes of statistical analysis and developing strategies for how to help autistics:** This database could be accessed on line by anyone wanting a better understanding of autism at both a statistical and personal affect aspect. Information would be provided by autistics who possess the ability for self-advocacy, parents of autistics, teachers and anyone else who desires to provide observations about specific autistics that they know and care about.
- d. **...in order to come up with a complete list of agitates that effect many autistics as well as effective countermeasures that will bring relief to autistics and their loved ones who are effected by them:** The most gut wrenching aspect of autism is watching them suffer from some discomfort that seems impossible for anyone to explain. These issues, as well as some of the "behavioral" issues that many autistics have, are often the result of them having an adverse reaction to something around them. Although this is a proven fact, no one has as of yet come up with a complete list of these agitates nor countermeasures.

9) **Bringing Recognition to those Who Provide Actual Support and Services:** There a number of "reputable" autism organizations whose reputation has more to do with their PR and fund raising abilities then actual services to the autism community. The AAC wants to highlight those organizations whose reputation is based on their performance rather than their PR. We especially want to help get the word out about the smaller organizations that cannot afford an expensive PR campaign.

This does not mean that we will attack the organizations that we do not endorse, but that we put them in the same category as those organizations that we do not know enough about to have an opinion about them. Therefore, when we say we have no comment about a certain organization, it will not be correct to assume that we disapprove of it.

10) **Replacing "Autism Spectrum Disorder" with "Autism Paradox":** The term, "Autism Spectrum Disorder," may work in professional venues; but I can make a strong case it is a detriment to autistics in the real world. Then again, I

am not so sure that it works in professional venues either. The problem lays with the practice of the use of absolute labels the gage an autistic's, or any other person's, level of functionality. My reason for this is spelled out in detail in "Point 3" of, "Practices the AAC Opposes."

CONTACT INFORMATION

For additional literature, questions or comments; please contact:

Jason Bunn-Parsons — (623) 205-7961

AutismAmbassadors@yahoo.com or www.AutismAmbassadors.Wordpress.com