

horse sense



Wisdom Shared by Autistics
Already Winning the Race of Life

By Stephen M. Shore

To tell or not to tell? That is a frequent topic of conversation among people with autism or Asperger Syndrome. How and when do I disclose? To everyone, or just a select group of people? What do I need to say, and is it *really* necessary? While opinions on the subject are diverse, weighing the pros and cons of disclosure can help an individual with an Autism Spectrum Disorder arrive at a decision appropriate to the situation and his/her own personal beliefs.

What Disclosure Is

Disclosure is much more than just stating to another person “I have autism” or “I have Asperger Syndrome” and hoping they will automatically make an adjustment in the relationship with the person disclosing. Disclosure involves sharing with another person information that is potentially discrediting or stigmatizing to one’s reputation with the goal of better mutual understanding. In order to effect this goal, it’s not enough to just state the facts about autism/AS. For true understanding to develop, the discussion must also include personal information about how it applies to the person on the autism spectrum, the strengths it brings, its challenges, and how it affects daily living.

Who to Disclose to

In *Pretending to Be Normal: Living with Asperger’s Syndrome* (Willey, 1999), author Liane Holiday Willey describes three groups of people to whom disclosure can be made. The first group consists of people who need to know. These are people with whom the person has regular direct contact in such a way that interactions with them are affected by autism. Another author, Robert Stuart, wrote about himself when he still lived at home, “[w]hen it comes to family members, of course the parents should know along with siblings to offer support and understanding (Stuart, 2000, p. 7). Stuart was diagnosed with Asperger Syndrome at the age of 33, at the urging of his wife who lovingly encouraged him to have his “differences” (p. 7) looked into. Others who need to know might include a supervisor, coworkers, and trusted close friends.

However, disclosure may be inappropriate if the information is irrelevant or will have a negative impact on the relationship. Sometimes that negative impact cannot be predicted and a chance has to be taken. Gerald Newport, an adult with Asperger Syndrome and staunch advocate for his peers had a negative experience resulting not so much from outright disclosure on the job, but from a supervisor’s knowledge of Jerry’s position on the autism spectrum. Knowing that his supervisor had a child with autism, Jerry felt secure in working for this supervisor even with this prior knowledge. Jerry’s hope was that they could build a better mutual understanding between them. As he writes in his book, *Your life is not a label*, (2001) in an ironic tone, the supervisor sure knew all about autism... and all the “limitations” that go along with this condition. The result was that Jerry remained in a position way beneath his ability for many years. Fed up with a now dead-end job, he left after 10 years of employment for much more fulfilling work.

The second group consists of people with whom there is frequent contact, including family members, friends, classmates, or teachers, but not enough regularity that the autism might create a problem between them. The third group consists of people who do not need to know about the disorder. This might include the postman, neighbors, the cashier at the corner store, and acquaintances.

Creating a hard and fast rule for whom to disclose to is practically impossible. It is more important that the decision be based on the effect disclosure might have on the relationship with the other person. Trying to determine this effect ahead of time can be particularly challenging for someone with autism. Difficulty in decoding data from social interactions is one of the leading traits of the disorder (Grandin, 1995). Discussing potential disclosures with "wise" (Goffman, 1963, p. 29) people may help in determining when, how, and to whom to disclose.

When to Disclose

Again, it will depend on the situation. Disclosure about autism or Asperger Syndrome is best when a characteristic of the disorder will directly affect a relationship with another person, job performance, or academic success. If things are going along fine, disclosure might not be necessary. However, if the autism/AS has an impact on your ability to function in a relationship or your job, it may be time to talk about it. Hopefully, the anxiety involved in revealing this personal part of yourself will be outweighed by the positive mutual understanding that is the result of the discussion.

What to Disclose

How much do we reveal to another person about being on the autism spectrum? For the most part, I prefer to disclose only the necessary information on a need-to-know basis. For example, suppose that being in a room with florescent lighting makes it impossible for me to work or interact with others at a work meeting. I would then tell my supervisor that my eyes are intolerant of this type of lighting and could we either use incandescent bulbs or move the meeting to another room. Going into a long explanation about autism and how visual sensitivities are a part of being on the autism spectrum is just too much unneeded information for my supervisor.

How to Disclose

Disclosure is usually best accomplished by the person with the disorder, as they are most aware of their own issues. However, sometimes it is appropriate for another person who is knowledgeable about the situation to either break the groundwork for disclosure or do the disclosing itself.

Reasons for having another person handle the disclosure may be that the person with the disorder is for some reason unable to do it—perhaps the stress of disclosing would cause verbal abilities to be impaired or shut down.

Why Disclose?

Disclosure can have a two-pronged effect. The first, and more obvious one as described above, is the hoped-for positive change in interpersonal relationships. However, co-existing with this is a larger, yet more subtle effect.

Each individual disclosure works, one person at a time, towards changing the still-common societal description of a person on the autism spectrum being only the nonverbal, antisocial, self-abusive child flapping his hands in the corner. Effective disclosure helps a partner, a job supervisor, or a family member better understand all that makes up autism. With this understanding, they come to see us as people capable of contributing to society, sometimes in significant ways.

The second effect of disclosure relates to society as a whole. Each disclosure about autism that results in this deeper mutual understanding changes not only the discloser's construct of the disorder but potentially everyone else with whom the discloser comes in contact. In some situations, these people can become ambassadors, passing along their new understanding to others.

For the most part, disclosure is a one-to-one personal event. However, disclosure via articles, autobiographies, and presentations reach a wider audience more quickly. Disclosure defines for the public audience what autism is and how to have better mutual relationships with people on the autism spectrum. The hallmark of a successful disclosure is a positive transformation in the relationship with another person and subsequently, in society as a whole. More successful disclosures will enable the public to construct positive ways of relating to people with autism and Asperger Syndrome. This, in turn, will aid in eliminating the stigma that still surrounds people on the autism spectrum and with other disabilities.

The Risks of Disclosure

All of us have grappled with having to tell someone something about ourselves that could negatively impact the situation or our reputation. Balancing the risk of damaging a relationship with another person with the hope of reaching a greater interpersonal understanding is the dilemma that is part of every disclosure decision. On the one side is the need to reveal information that may damage one's identity, job or partnership. On the other side is the fear that letting someone else

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know this information will cause real damage to the relationship or a stigma applied to the person. There's never an easy answer and each situation must be approached individually.

Implications for the Future

The act of disclosure merits serious thought for the following reasons. First, it involves revealing to oneself a lack of perfection, followed by revealing it to others. Sufficient psychological resources and self-esteem are needed to prevent a sense of inadequacy in the emotional, moral or other domains from creeping in. Once past the barrier of self-disclosure, the challenge is to impart this potentially discrediting information to others in a way that builds mutual understanding, trust, and minimal damage to one's reputation.

The study of how disclosure may be best accomplished for those on the autism spectrum has just begun. This article is merely a seed from which can grow further work on how to inform others of the needs of people on the autism spectrum, develop a better mutual understanding, and deeper, richer, and more meaningful relationships with others.

References

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BIO

Diagnosed with "Atypical Development with strong autistic tendencies" Stephen Shore was viewed as "too sick" to be treated on an outpatient basis and was recommended for institutionalization. He was nonverbal until four. With much help from his parents, teachers, and others, Stephen Shore is now completing his doctoral degree in special education at Boston University, with a focus on helping people on the autism spectrum develop their capacities to the fullest extent possible.

In addition to working with children and talking about life on the autism spectrum, Stephen presents and consults internationally on adult issues pertinent to relationships, employment, and disclosure as discussed in his book *Beyond the Wall: Personal Experiences with Autism and Asperger Syndrome*. (Autism Asperger Publishing Company).

He serves on the board of the Autism Society of America, as board president of the Asperger's Association of New England and is on the Board of Directors for Unlocking Autism, the Autism Services Association of Massachusetts, and the Asperger Syndrome Coalition of the United States.

Stephen's website is
www.autismasperger.info;
he can be contacted at Tumbalaika@aol.com

