

Demystifying Autism

Notes from workshop presented by
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Presuming Intellect: Ten ways to Enrich Our Relationships Through a Belief in Competence (by William Stillman)

1. ***Don't define people by their diagnosis:*** Remember playing tag? Nobody wanted to be IT. And if you were IT, you wanted to get rid of IT because being IT was stigmatizing, a detriment, and something undesirable—that was the game; being IT was to be avoided and feared. Remaining IT longer than we'd like becomes challenging to catch up to the others, to belong, and to feel accepted. When we define someone by their diagnosis, our perception of them may become something to be dreaded; someone defective, someone who has the IT with which we don't wish to risk an association of any sort. For that person, this attitude is the lubricant that greases the wheel of the vicious cycle of a self-fulfilling prophecy. That is, when people define you as having IT and that's all you know of yourself, you will reflect back precisely what others project upon you. This is a natural and defensive reaction; and if you don't speak or can't articulate your feelings, your outpourings of "behaviors" will only further validate the diagnosis (hence the vicious cycle).
2. ***Shatter myths and stereotypes:*** Clinical diagnosis is but a framework for explaining "behaviors" or atypical attributes. This may include judgments about severe intellectual and physical limitations, and further speculation about other incapacities. It can also set a negative precedent of using "us and them" language in labeling someone as different, retarded, autistic or mentally unstable. However, it wasn't so long ago that persons who were epileptic, homosexual, or even those left-handed, were labeled as mentally deviant. This led to unfair, inaccurate, and unjust myths and stereotypes. All of the psychology and psychiatry is educated guesswork; no single clinician can state with absolute authority what someone experiences in the way that medical science usually can. In considering three factors, insight, foresight and hindsight, we need to encourage others and ourselves to look beyond our history of deficit-based labeling in favor of perceiving a person's humanity — regardless of their diagnosis or way of being. The label which may perpetuate clinical myths and stereotypes is an incomplete truth; it should be but one point of reference in fully supporting the whole person.
3. ***Don't talk about people in front of them.*** Have you ever been in a conversation with two or more people and someone talks out of turn, interrupting, belittling or disputing your contributions? Or have you temporarily lost the use of your voice as others tried to interpret your wants and needs? How did either instance make you feel? If we don't value what people have to offer, especially if they are unable to speak at all, we send a message of superiority versus inferiority. When we define people by their diagnosis and perpetuate myths and stereotypes, we presume the authority to talk about them in front of them as an entitlement. After all, it shouldn't matter if we share information about someone's "behaviors" with their parents, doctors, and others in front of them because they are retarded, autistic, and unaware—right? Wrong!

Presuming intellect requires us to believe an individual's intellectual competence is intact. This means we do not speak about them in front of them in ways that are hurtful, embarrassing or humiliating. We must also gently but firmly advocate by disallowing others from doing it as well. We need to include people in conversation by directing questions to them not about and around them. It also means we employ person-first language (boy with autism, not autistic boy) because it compels us to be conscious of the words we use when discussing someone. So, before you speak, ask yourself if you would welcome someone talking about you in precisely the same way

without a voice to defend yourself. We cannot have a mutually respectful and trusting relationship if we talk about someone in front of them.

4. **Interpret “behavior” as communication.** Have you ever been so angered that words escaped you in the moment, and the only way you could express yourself was by screaming or throwing something? You probably felt justified in your actions because it was the only way you could vent your expression of extreme upset. But what would life be like if you could never retrieve the words you wanted when you needed them and you always seemed to be grappling with overwhelming or frustrating circumstances that caused you to react in extreme ways as the only option? In the same way you could rationalize your own behavior, let's remember that we all have good reasons for doing what we're doing, and we're doing the best we know how to do in the moment. You wouldn't want to be defined or stereotyped by the times you just had to yell and shout would you? We need to extend the same courtesy to others by not jumping to conclusions about their “behaviors” as willful misconduct, noncompliance, or “attention seeking”. You may respectfully deconstruct “behavior” in terms of communication by appreciating the following three reasons why people may engage in what others call “acting out” or “aggressive behaviors.” 1) The inability to communicate in ways that are effective, reliable and universally understandable. 2) The inability to communicate one's own physical pain and discomfort in ways that are effective, reliable and universally understandable. 3) And the inability to communicate one's own mental health experience in ways that are effective, reliable and universally understandable.
5. **Offer communication enhancements and options.** We have become a culture that values instantaneous, rapid-fire response to our need for information. This includes the immediacy with which we communicate to one another through e-mail, instant messaging, text messaging, and round-the-clock accessibility via cellular telephones. When others do not communicate with us on par with the manner with which we've become accustomed, we may lose patience, become bored or distracted, or dismiss their communication attempts altogether. This may be especially true of those challenged in articulating language such as small children, the elderly, and those with a neurological difference resulting from stroke, Tourette's, Alzheimer's, Cerebral Palsy or autism. We may wrongly interpret the inability of others to speak as quickly as we'd like as an incapacity when, in fact, most often just sensitively allowing for process time beyond what is standard is all that is required for those individual to cognitively retrieve spoken language.

In providing support to others, we must acknowledge that not everyone is neurologically “wired” for verbal communication; this is not the same as not having something to say. It is unacceptable to accept that because someone doesn't speak, there's nothing we can or should do. There are myriad communication options and opportunities to offer as speech alternatives. These may include pointing to “yes” and “no”; some basic sign language; photographs and symbols; computers and other keyboards; and technology of all kinds. The person will guide us to the device, or combination thereof, that makes sense for her. Engaging in conversation by discussing someone's most passionate of interests in the context of a mutually-pleasing relationship is a great incentive to entice someone into trying a communication alternative that is new and different. Honoring another's communication requires us to acknowledge that we might not like what we hear.
6. **Offer age-appropriate life opportunities.** When we are unpresuming of an individual's intellect, there is a belief that the individual likely possesses a juvenile aptitude, childish thought processes, and skills on par with someone who is chronologically much younger. This stereotype of the “perpetual child” leads some to interact with the stigmatized individual in ways that are pretentious, patronizing, and insulting. It also means that we limit the life opportunities that we offer someone in favor of preserving the “perpetual child” mindset. Instead, we provide adolescents, adults, and even persons who are elderly, with dolls and toys, and reading and viewing material suited and intended for very young children.

You can only know what you know; and if someone is only ever afforded such opportunities, a childlike affect persists and permeates our interactions. But, if we presume intellect and acknowledge that an individual's "behaviors" might really be cries of boredom or offense with educational curriculum, vocational options, or recreational activities that are dehumanizing, we will know better how to partner with an individual in planning *age-appropriate* learning, work and free-time opportunities. The greatest obstacle to implementing this is our own attitude in how we perceive supporting someone with a different way of being.

7. ***Make compassionate accommodations.*** Have you ever been trying to read or listen attentively to something, and something, and someone near you is constantly coughing? You can react one of two ways: either with annoyance, or with consideration. Reacting with annoyance will only foster bad feelings between both parties; you may feel as if the person should know to be more socially considerate, and the person, who may be struggling to care for themselves, may feel hurt or attacked. Reacting with consideration may include gently approaching the individual to offer them a cup of water, a mint or lozenge, or to simply commiserate about a human experience we've all endured at one time or another. Responding with the latter approach requires discounting initial impressions and making a compassionate accommodation, not only in our thoughts but in our deeds.

In considering compassionate accommodations for the individual with a different way of being, think in terms of prevention instead of intervention. Prevention means knowing fully what an individual requires in advance of a situation, environment, or activity in order to feel safe and comfortable and able to participate. This relates to the ability to think, communicate, motor-plan movement, and assimilate with the senses. It means foregoing the antiquated model of multiple, overwhelming community integrations (which often sets the overloaded individual up for an intervention) in favor of simple, subtle, and interest-based activities in a qualitative relationship context.

8. ***Respect personal space and touch.*** If we perceive someone in our care to be less than equal, be it a child, adult or someone elderly, we seem to take ownership of touching their physical being with a sense of entitlement in order to gratify our own needs. For example, instead of allowing someone the time required to bathe, eat or dress for themselves, we may grow impatient and begin handling them ourselves to "get the job done." Or, in desiring to be affirmed, we initiate physical touch by embracing, back-rubbing or hair-tousling—all of which may be intrusive, un-welcomed and without permission. (In recent years, some colleges have even implemented "touch protocols" for dating co-eds to avoid misinterpretation of any sexual intent.) Conversely, many of us are extremely uncomfortable brushing against others in the cramped quarters of an airplane, bus, subway, or train.

Personal space and touch are a matter of individualized perception for each of us based upon our culture, upbringing, and relationship experiences. A friendly slap on the back, which you've been conditioned to convey as communicating "hello," may send shock waves through the nervous system of the recipient. Instead, respectfully await the invitation in. Await the acknowledgement that coming closer, touching, even eye gazing, is welcomed once it's communicated by the person with whom you are developing a relationship. The invitation in may be as subtle as someone who rarely makes eye contact locking eyes with you and tracking your movement, or the individual who carefully, gently, extends a finger to initiate touching you. Be very mindful of the mixed messages we send to children whom we routinely embrace and then confuse once we define such as "inappropriate" come adolescence. It is also fair to state your own acceptable preferences for touch limitations.

9. ***Seek viable employment for others.*** The system that serves people with different ways of being endeavors to be altruistic and well-intentioned but it is an industry nonetheless; one that, in seeking viable employment opportunities for its clients, attempts to conjoin with mainstream industries that may be unpresuming of intellect. More often than not, this translates to menial tasks that are believed to require no thought: adult training facilities, repetitive factory work,

janitorial clean-up, emptying trash receptacles, or replenishing the fast-food salad bar to name a few. For most others, such jobs are temporary steppingstones; but for persons who are perceived as largely incapable, these employments have become a norm that perpetuates stereotypes.

In seeking to pursue viable employment, we need to think in terms of cultivating gifts, strengths, and talent areas as early on in one's life as possible. Begin by identifying an individual's most passionate of interests—those subjects or topics for which she wants most to talk about, watch, draw or write, reenact, engage with, and read about. When we value passions instead of labeling them as obsessions (unless they seriously impair one's quality of life), we are better poised to creatively envision a blueprint of possibilities or one's future. This may include higher education, virtual employment via the Internet, or self-employment opportunities.

10. Acknowledge that we are all more alike than different. Remember the last time you drove somewhere and, upon arriving, had no recollection of the drive? How about when you hear a song you haven't heard since high school, and memories you associate exclusively with that era come flooding back? Or what about the times you've halted, blocked, stuttered or stammered over calling up someone's name? These are examples of common neurological blips, misfires, and disconnects that make us all kindred in our humanity. While others may have traits that appear more exaggerated, like physically rocking or hand-flapping, you may catch yourself engaging in a similar action if you've been shaking your leg, tapping a pen, or twirling your hair or a piece of jewelry.

When we embrace the philosophy of presuming intellect we are in a position to become agents of transformation. Doing so requires forgiveness of our own ignorance—which need not hold negative connotations—as well as seeking the forgiveness of others whom we have not held in the same regard as our typical peers. We have become a culture that elevates perfectionism to exalted heights, which is an unrealistic and potentially damaging aspiration. When we acknowledge the kinship we share with one another, we are most apt to value diversity in our lives within the context of mutual respect, co-collaboration for greater good, and the presumption of intellect.

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Stillman's 7 Golden Rules

1. Presume Intellect (*The Golden Rule*)

"My plea is that we shift our thinking of the autistic experience as one would consider a person with Cerebral Palsy. The person's body or outward 'shell' works in ways that are unreliable and atypical. That person may be unable to speak or gesticulate, or may require total assistance in all self-care skills (eating, bathing, & dressing). The person with Cerebral Palsy may even be unable to ambulate without support of a cane, a walker, or a wheelchair. It does not follow that the person's intellect is necessarily impaired to the same degree."

"Presuming Intellect is about belief in competence. It is as simple as interacting and being with others in the same ways that you would welcome from anyone else. In short, do unto others as you would have them do unto you. . . . that includes not speaking about someone in front of them as if they were not present at all. "

"Presuming Intellect also requires that we speak to someone with the belief that they understand what is being said. It means using fewer words, and allowing the individual time to process what we've just said. It means abandoning our own agenda and showing regard for an individual's personal, physical space by not intruding upon it suddenly and without warning, as so many caregivers have been

trained to do (e.g., grabbing someone's face to command eye contact with the words 'Look at me!' Remember, that if the scenario were reversed, we'd call it physical aggression)."

"The First Miracle: . . . the first miracle is self reflection, but self reflection alone is not enough. The next step is to privately, gently, and respectfully approach the individual you know you've hurt or offended—intentionally or not. Offer your humble, genuine, sincere, and heartfelt apologies. If you do this truly, the next miracle will occur."

"The Second Miracle: . . . the second miracle is forgiveness. And you will be forgiven. People tell me frequently that they perceived their relationship with those in their care to be on one level or in a good place. But they discover, upon seeking absolution, that the relationship soars and attains a plateau they never before dreamed possible. This is the miracle of forgiveness."

"The Third Miracle: . . . the third miracle is to perpetuate the message."

2. **People have good reasons for doing what they are doing.** "He seemed to knock the books off the table for *No Apparent Reason*" -- (there is a reason, we need to figure out what that reason is.)

Behavior as Communication: What Drives "Behaviors"?

- *The inability to communicate in ways that are effective, reliable, and universally understandable.*
- *The inability to communicate one's own pain and discomfort in ways that are effective, reliable, and universally understandable.*
- *The inability to communicate one's own mental health experience in ways that are effective, reliable, and universally understandable.*

3. **People are doing the best they know how.**

- Misinterpreting "Disruptive Behavior": "It's not *behavior*, it's communication!"
- The Myth of Eye Contact: "*Look at Me!*" "*If you look (direct eye contact) at someone you are too busy to hear them*". (Many people on the autism spectrum are so distracted by direct eye contact that if they succeed in making eye contact they are so distracted that they don't hear what is being said)

4. **I need to feel safe and always in control.** "I fought hard to hold on to the one thing that I could control"

- The Importance of Establishing Trust and Safety Within the Relationship: "Neuro-typicals often take trust and safety for granted because they expect it."

5. **I can't stand anything unpredictable.**

- Build upon passions (Topics or subject areas of special interest)
- But, "Don't use passions as rewards"
- If having trouble identifying passions, first look to these things: Nature, animals, music/lyrics, family, religion/spiritual.

6. **There is safety in sameness and comfort in which that is familiar.**

7. **When I know what to expect from my environment, I can better adapt to it.**

Communication

William Stillman

The Right to Communicate

The absence of speech certainly does not mean that people are without a desire to communicate. The right to communicate is one of the most essential of all human rights. It is critically urgent that all alternative modes of communication be exhausted in seeking a “match” or “matches” that best suit each unique individual without a voice.

1. **Speech Therapy** is recommended for anyone who puts forth the effort to articulate language.
2. **Music** is a necessary part of life that heals and soothes.
3. **Self-Expression** through **art** is another universal language
4. **Sign Language**
5. **Picture Exchange Communication Systems (PECS)** comprise pictures, icons, and words on personal, manageable cards accessible at all times by the user. . . . limited to the parameters set for what we think someone wishes to communicate.
6. **Augmentative and Alternative Communication (AAC)** includes computer programs, pre-programmed products, or small portable word processors.

Facilitated Communication

“**Facilitated Communication (FC)** is another AAC communication method. It is predicated upon safe and trusting relationships and a belief in competence. An individual unable to speak, or with limited or unreliable speech, is physically supported at the hand, wrist, elbow, or shoulder by a loyal communication partner with as much or as little support as needed. The partner or ‘facilitator’ does not guide the person, or make choices for them in this way. Instead, they physical support is a catalyst that trips an internal switch, allowing an individual to tap their confidence and initiate motor-coordination capabilities in order to forcefully touch pictures, icons, words, objects, or a keyboard. (It is also not unusual for verbal speech to come as a result of this ‘rewiring’ process.) Unlike some methods, use of a keyboard to express one’s wants and needs, thoughts, feelings, and desires is a boundless communication opportunity. FC is not a ‘cure,’ rather it allows a person’s true individuality to surface while creating strong bonds between the individual and his or her communication partner. We may authenticate an individual’s communications as her own when unique or surprising patterns, phrases, or words emerge; words are misspelled, spelled phonetically, or spelled ‘shorthand’ style (you = u); someone refers to themselves in the third person, or by pet names; or we verify what has been communicated as founded in fact.

The ultimate goal of FC is independence in communication free of any physical support, such as many have achieved. In this way, persons with autism are shattering antiquated perceptions by revealing their true intellect and explaining away misunderstood, stereotypical ‘behaviors.’”

Examples (from Stillman’s book, *Autism and the God Connection*):

Jenn: for years, she was thought to be MR, she is now a successful college student in her senior year majoring in psychology.

I am so happy to be able to communicate and let my thoughts be known, whether I am happy, sad angry, frustrated, or horrified. It was raging frustration all the years I was silent. My behavior showed it. Life is very different. I don’t carry that frustration with me anymore. I have my moments, but not weeks of bad times.

“Dr. Douglas Biklen is the director of Syracuse University Facilitated Communication Institute, dean of the university’s School of Education, and co-producer of the 2005 Academy Award-nominated

short subject *Autism is a World*. As early as 1991, Biklen, who first introduced FC to the US, observed, 'What we are discovering is that most of the people that we work with already are literate. It's particularly surprising to see these literacy skills in very young children, even three-year-olds.' Stillman's friend Mark responds to those who would question his ability to read and spell, 'I was a sponge and absorbed the world around me. Because I couldn't speak or ask questions, I took everything in and filed it in my brain for future use. I believed that someday I would be able to communicate.' To further explain, Matthew, a 36 year old man, reflected, 'I read by keeping my eyes on the page as it goes by me. I read the whole page at a time. You read one sentence at a time.'"

Interesting quotes from Bill Stillman's books

"Autism is a lifelong experience, and is neither contagious nor curable. It is quite simply, a part of someone's being, every bit as much as eye or hair color, flesh pigmentation, and ancestral heritage—as unique and individual as each individual is unique. It manifests on a broad, multicolored spectrum that stretches from those who 'appear' to be significantly challenged to those with very mild experiences."

"Many parents tell me their child's diagnosis is a 'death sentence.' Some are deeply embittered or resentful of their child's autism and the confusing, sometimes violent, behaviors that may ensue. This is a great disparity in the field. The focus so frequently becomes how to best manage and control those with autism for the sake of conformity and 'normalcy' that we become oblivious to the obvious. And the obvious is the extraordinary and monumental offerings provided by those who are inherently gently and exquisitely sensitive. . . , "From a theological perspective, if our souls are on a path of perpetual learning in a journey toward attaining spiritual perfection, it may be congruent that those individuals with the greatest life challenges are among the most advanced of souls." . . . , "A grieving process may begin in which the dream for whom the child was suppose to be gives way to worries and concerns over his or her way of being in life and the responsibility for perpetual caregiving. Mourn not, for the dream needn't be surrendered in its entirety. It needs only to be modified to better match the unique personality traits and abilities of the person with autism. In redefining the dream, that individual will surely bear unexpected, surprising nuances that will be fulfilling and rewarding. Because of this, many parents and caregivers realize their lives have forever altered in profound, loving ways. They are different, yes, better people for parenting the individual with autism."

"My purpose for pursuing this topic is to enlighten others about a unique and glorious facet of the autistic experience. It is in keeping with our collective pursuit of shattering myths and stereotypes about such experiences being a product of intellectual impairment or mental illness. And it speaks to the principal that people with different ways of being are often **our** teachers, here to guide our understanding of compassion, sensitivity, and unconditional love—the most vital lessons of the human condition. Many are possessed of a divine spiritual connection of which we must be open to learning about. It is time."

"I am sometimes asked if I subscribe to behavior management. Yes, I believe in behavior management; I believe in managing the behavior of those around the individual with autism in an effort to teach these most salient concept from 'inside out'."