Strategies for Success: Supporting Learning and Growth in Youth with Autism

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Goal: To people with autism, by definition of their diagnosis, have difficulties with communication and socialization. This section provides basic suggestions for dealing with these challenges in a youth organization environment.
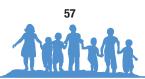
Communication

Communication encompasses a broad range of challenges for people with autism, from intake and processing of information, verbal or representational output, to reading and writing skills. Picking up on non-verbal cues, body language and subtle intent, intonation and interpretation is also difficult for people with autism.

Tips for Supporting Receptive Language Skills

Receptive Language:
To understand what is said or written.

- Make sure you have the youth's attention before you deliver an instruction or ask a question.
- Consider the participant's processing challenges and timing. For example, begin an instruction with the participant's name – this increases the likelihood that he will be focused on what you are saying by the time you deliver the direction.
- Avoid complex verbal directions, information or discussions. Keep instructions short and give information in chunks.
- Minimize the use of don't and stop. Fox example, "Please stay on the sidewalk," is much more effective than "Keep off the grass," because you are being clear about the behavior you desire.
- Be prepared to wait for a response – whether it is an action of an answer. Avoid immediately repeating the instruction or inquiry. Think of it like a computer – when it is processing, hitting the command again does not make it go any faster, but rather causes it to freeze or sends it back to the beginning to start the process all over again.
- Supplement verbal information with pictures, visual schedules, gestures, or written directions.
- Do not reprimand a participant for not listening or responding. That only serves to highlight his or her challenges.

Tips for Supporting Expressive Language

Expressive Language:
Spoken language and communicative output such as written language and picture exchange.

- Take responsibility for finding a way to access the participant's need for communication. Many people with autism have word retrieval issues – even if they know an answer, they may not be able to come up with the words. Offer visual supports, cue cards, or multiple-choice answers.

- Support the youth in saying "I don't know" to reduce the anxiety associated with not being able to answer a question.

- Add visual supports to the environment as necessary.

- If the youth has an augmentative or alternative communication device, learn how to use it. Ask parents or the support team for help.

- Sing! Musical processing occurs separately from language processing, and singing can be used to promote both receptive and expressive skills.

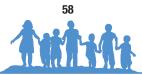- Be aware of echolalia, where someone with autism repeats phrases he has heard before. Sometimes this is a seemingly self-stimulatory behavior, but many people with autism also use functional echolalia to comment, inform or request.

- Many people with autism have a favorite topic or special area of interest that may interfere with social interaction. To shape their expectations and minimize the impact of the obsession:
  – Provide scheduled opportunities to discuss the topic.
  – Establish boundaries on when and where it is appropriate to discuss the topic.
  – Set a timer to establish duration.
  – Reinforce the participant for talking about other subjects or the absence of the topic.

Social Interaction

People with autism often have the desire to interact with others, but they do not have the skills to engage appropriately or may be overwhelmed by the process. Some youth are painfully aware of their social deficits and will avoid interactions even though they may want to connect with others. Or they could go in the opposite direction and engage in attention seeking behavior to connect with others until they build the skills they need to interact. Social challenges in autism go both ways. They may manifest as deficits (a lack of social initiation) or excesses (a one-sided conversation in a highly verbal youth with Asperger's Syndrome).
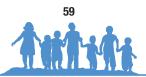
Tips for Supporting Social Interaction

- Extend a feeling of welcome and model for other participants that the youth with autism is a valued part of the group.

- Get to know the youth with autism and meet him where he currently is in terms of social skills and interests.

- Be aware that free play or other unstructured times are the most difficult for people with autism. Think about how to impose some structure on these activities.

- People with autism often have a difficult time maintaining eye contact. Insisting on eye contact can cause additional stress.

- Youth with autism, especially those who are more verbal, can be the target of teasing and bullying. They often do not pick up on non-verbal cues such as tone of voice or the hidden intention of a request or comment. They often go along with the teasing or bullying because they do not identify that it has a negative intent. The desire to make friends and their difficulty doing so, means they often encounter peers with negative intentions. Be on the lookout for this and respond quickly if teasing/bullying becomes an issue.

- Many people with autism are very logical and will always play according to the rules. If the rule is that basketballs are not allowed outside at a particular time, a participant may become agitated if they come out for a special activity. Similarly, he may not understand special circumstances in game play such as penalty shots, and his insistence on following the rules he has learned could become problematic.

- Identify peers who model strong social skills and pair the youth with autism with them. Provide peers with strategies for eliciting communication, but be careful not to turn the peer into a teacher. Strive to keep peer interactions as natural as possible.

- During group activities, define his role and responsibilities within the group. Assign a role or help him mediate with peers as to what he should do. Rotate roles to build flexibility and broaden skills.

- If you leave it up to the group to pick partners, youth with autism are sometime chosen last, causing unnecessary humiliation.

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Challenging Behaviors

Sometimes the difficulties of autism can lead to behaviors that are quite challenging to understand and address. Here are some tips that can be helpful in preventing negative behaviors:
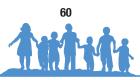
- Recognize behavior as communication. Try to understand the communicative intent of the behavior.
- Catch him being good and reward the behavior!
- Provide organization and support transitions.
- Communicate expectations, use short-term schedules, warn of changes to routine or personnel, and prepare them for unexpected events.
- Offer choices and provide some sense of control.
- Consider sensory needs and interventions.
- Respect her personal space.
- Provide a home base or safe place where he can feel safe and regroup, calm down, or escape overwhelming situations and sensory overload.
- Be flexible.
- Be aware of and work to avoid known triggers that may result in frustration, overload or anxiety. Make a list and share it with the team.
- While they are occurring, ignore attention-seeking behaviors as much as possible. Redirect instead.

Sensory Stimulation

Sensory challenges can affect people with autism's ability to take in information, respond to requests, participate in social situations and maintain calm. Either through internal imbalances or in response to the environment, the sensory and emotional regulation of a person with autism can become overwhelmed and result in anxiety and stress. Working to maintain a modulated state can help the youth remain calm and focused.

Ways to support sensory needs:
- Be aware of sensory issues and alter the environment where possible, such as minimizing exposure to loud noise.
- Some people with autism find standing too close to others difficult. This needs to be addressed when deciding where to place a participant in line or other area among a group of people.
- People with autism may have difficulty looking and listening at the same time.
- Highly decorated areas can be over stimulating and distracting for some people with autism.
- Some people with autism may need to transition earlier than other participants or may need a few minutes to unwind after being in a noisy environment.

Reflect:

There are many things to think about when working with youth with autism. What do you think are the things that will be the easiest and most difficult to incorporate when it comes to your specific organization or program?

With communication:

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With sensory issues:

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With behavior challenges:

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Resources

Association for Positive Behavior Support
Research information, application strategies, information on school-wide PBS programs, fact sheet summaries of PBS practices and a section on autism.
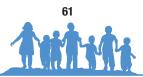**www.apbs.org**

Do2Learn
Easy to use and downloadable resources including social games, organizational tools, picture cards, etc.
www.do2learn.com

Kansas Autism Spectrum Disorders
Free examples and banks of visual strategies, social narratives and power cards, and podcasts of speakers such as Linda Hodgdon and Paula Kluth.
http://kansasasd.com

Solving Behavior Problems in Autism
By Linda Hodgdon (Quirk Roberts Publishing, 1999)
www.usevisualstrategies.com

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 for the vicious cycle of a selffulfilling 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 lefthanded, were labeled as mentally deviant. This led to unfair, inaccurate and unjust myths and stereotypes. All of 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 deficitbased 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.
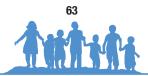
3. *Don't talk about people in front of them.* Have you ever been in conversation with two or more people and someone talks out of turn, interrupting, belittling or disputing your contributions? Or have you temporarily lost the use of your voice as others tried to interpret your wants and needs? How 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 individuals 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.
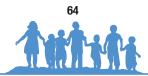
6. *Offer age-appropriate life opportunities.* When we are unpresuming of an individual's intellect, there is a belief that the individual likely possesses a juvenile aptitude, childish thought processes, and skills on par with someone who is chronologically much younger. This stereotype of the "perpetual 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 freetime 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 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, unwelcomed 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 acknowledgment 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 cleanup, 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 for one's future. This may include higher education, virtual employment via the Internet, or self-employment opportunities.
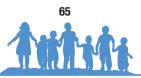
10. *Acknowledge that we are all more alike than different.*
Remember the last time you drove somewhere and, upon arriving, had no recollection of the drive? How about when you hear a song you haven't heard since high school, and memories you associate exclusively with that era come flooding back? Or 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 handflapping, 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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