

Meeting the Needs of Teens and Adults on the Autism Spectrum

Background Information



What are Autism Spectrum Disorders? Autism spectrum disorder (ASD) is a range of complex neurodevelopment disorders, characterized by social impairments, communication difficulties, and restricted, repetitive, and stereotyped patterns of behavior. Autistic disorder, sometimes called autism or classical ASD, is the most severe form of ASD, while other conditions along the spectrum include a milder form known as Asperger syndrome, the rare condition called Rett syndrome, and childhood dis-integrative disorder and pervasive developmental disorder not otherwise specified (usually referred to as PDD-NOS). Although ASD varies significantly in character and severity, it occurs in all ethnic and socioeconomic groups and affects every age group. ---Nat'l Association of Neurological Disorders

Autism spectrum disorders (ASDs) are a group of developmental disabilities that typically begin before a child is 3 years of age and last throughout a person's life. People with ASDs have substantial challenges in social interaction and communication. They handle information in their brain differently than other people, and might have unusual ways of learning, paying attention, and reacting to different sensations. ASDs are part of the broader category of pervasive developmental disorders (PDDs) and include autistic disorder, Asperger disorder, and pervasive developmental disorder-not otherwise specified (PDD-NOS). Although everyone with an ASD has significant challenges in certain areas of his or her life, some might be gifted in other areas. Also, not everyone with an ASD has the same challenges. Some individuals might have relatively good verbal skills, but have difficulty interacting with other people. Others might not be able to talk or have very little ability or interest in communicating or interacting with others. --Centers for Disease Control



How prevalent is Autism? The Centers for Disease Control estimates that about 1 in 88 children has been identified with an autism spectrum disorder (ASD.) ASDs are reported to occur in all racial, ethnic, and socioeconomic groups. ASDs are almost 5 times more common among boys (1 in 54) than among girls (1 in 252).



What is High-Functioning Autism? High-functioning autism is not a medical term or a specific diagnosis. It is a term used to describe a group of individuals who exhibit some but not all autistic symptoms and characteristics, and who developed speech typically.

Included in this category are those with Asperger's Syndrome and PDD-NOS (Pervasive Developmental Disorder—Not otherwise specified.) The National Autism Society in the UK says this : "Both people with PDD-NOS and AS are affected by the triad of impairments common to all people with autism. Both groups are likely to be of average or above average intelligence." So many people with Asperger's or PDD-NOS

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have high intelligence that it has been called the “Gifted” or “Geek Syndrome.” In fact, many researchers today are concerned that a diagnosis of Asperger’s or PDD-NOS may be preventing access to gifted programs.



Why should this matter to me? Teens and Adults with high-functioning autism are a growing population in the world who are impaired in social communication. Churches run on social communication – there are unspoken expectations of behavior, meaning, roles and communication—and most churches are not prepared for the more organized communication required to incorporate these teens and adults.

The CDC estimates that, by the year 2016, there will be nearly 750,000 ASD teens in the United States. There is no way to estimate the number of adults in the U.S. diagnosed with high-functioning autism, although it is clear the number is growing.

Where can I find more information?

A Special Grace - <http://www.aspecialgrace.com>

Centers for Disease Control – www.cdc.gov/autism

Nat’l Institute of Neurological Disorders – www.ninds.nih.gov

The National Autism Association – www.nationalautismassociation.org

Autism Research Institute – www.autism.com

The Autism Society of America – www.autism-society.org

Asperger’s Association of New England – www.aane.org

LINKS TO INTERESTING ASPIE SITES: - List courtesy of Matt Friedman - www.dudeimanaspie.com

Accepting Asperger's Syndrome - ww.freewebs.com/aspiefrommaine/index.htm

Autistic Self-Advocacy Network - www.autisticadvocacy.org

Autistic Symphony - www.autisticsymphony.com

The Global & Regional Asperger Syndrome Partnership - <http://grasp.org>

John Elder Robison - author - Look Me in The Eye <http://jerobison.blogspot.com>

Neurodiversity.com

Wrong Planet - www.wrongplanet.net

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Teens and Adults with high-functioning Autism are most often:

- Highly intelligent
- Socially awkward
- Prefer visually presented/communicated materials over verbal
- Honest (some say brutally honest)
- Detail oriented

 **Associative Memory** - While many people linearly; those with High-Functioning Autism tend to be visual thinkers. They tend to "think in pictures." Many report that their memory is composed of movies—a sort of video diary unrelated to words, but triggered by association with smells, sights or sounds. Many researchers believe this associative memory is a compensation for delays in the ability to process information quickly. Autistic people do not respond to information at the time it happens, they respond to the situation "from memory" when something remembered in a serial way is triggered.

 **Auditory Processing** - People with Autism, Asperger's, and PDD typically have problems processing things they hear, particularly if it's a large quantity of information. A preference for visually presented material has often led autistic people into creative fields.

 **Perseveration** - Many people with Autism, Asperger's, and PDD get fixated on one subject, such as cars, trains, calendars, or maps. They become experts on their particular subject of interest and will often not tolerate any disagreement that intrudes into their area of expertise.

 **Extremely Literal** - This can often catch you off guard. Autistic adults can sometimes misuse or misunderstand verbal metaphors or colloquialisms. Verbal language meaning is subject to shading by inflection, tone and context. Autistic teens and adults are often unaware of these differences, and have difficulty understanding how they may change the literal meaning of words. This extreme literalness is an integral factor in a number of other characteristics of high-functioning autistic teens and adults.

Generalizing – or more properly lack thereof. Their tendency to extreme literalness is related to an inability to generalize. If taught a rule or ritual in only one location, they may think the rule only applies to one specific place. A simple example of this is thinking that he/she could only eat pizza at home because that was the first place they tried it. Because of their high intelligence however, when the parallels or equivalents of a situation are explained or made explicit, autistic people can readily apply an old concept to a new place.

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Resistance to Change - Maybe a better term would be, "difficulty dealing with change or anything unexpected." This inability to generalize that an action, rule or concept may apply across multiple situations is one of the root causes of an autistic person's strong resistance to changes in routine. Something simple like calling to speak to the Rector on the phone can be a challenge if a secretary answers instead. Imagine for a moment that every situation you entered into in your life was entirely independent of and different from every other! Any change would be not only exhausting but also bewildering. It is always best to warn about any changes ahead of time. And be prepared that autistic people may feel the need to ask a lot of questions to help themselves understand the change and how it will affect them.

Getting Stuck - People with PDD/Autism tend to get "stuck" in doorways. People are often tripping over them because of the sudden stop. They often need to be coaxed into a room, especially when entering for the first time. This is most likely related to delays in processing information, and a resistance to change, even of venue.

 **Sensory Processing** - Sights and sounds that are easily tolerated by "neurotypicals" may cause pain, confusion, and/or fear in people with Autism, Asperger's and PDD. The best way to describe this is to imagine waking up in the middle of the night, thinking you heard a suspicious noise. All of your senses are on heightened alert; and the next sight, sound, or touch could send you through the roof. This is how many people with Autism and PDD feel when they enter a room for the first time, encounter a new situation, or experience stress. Many autistic people live with intense anxiety because of sensory processing issues. One of the most notable ways sensory processing difficulty is manifested in autistic people is the resistance to looking others directly in the eye when speaking or listening to them. Often misunderstood, this simple behavior is a defense mechanism for autistic people. Gazing into eyes is a first source of visual stimulation for human beings. The visual stimulation of eye gazing is powerful and can cause autistic people to completely lose focus of any verbal information being passed, as well as cause sensory overstimulation. Because many human cultures interpret direct eye contact as interest, autistic people can seem aloof or uninterested as they avert their eyes.

 **Theory of Mind** - People with Autism, Asperger's, and PDD have difficulty comprehending that others don't know something. It is quite common for autistic teens or adults to become upset when asking a question of a person if the person does not know the answer. Many autistic people do not understand that other people have their own plans, thoughts, and points of view. They may also have difficulty understanding the beliefs, attitudes, and emotions of others.

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Social Awkwardness – People with high-functioning autism have fewer difficulties with communication than those with classic autistic disorder. However, their ability to engage in social communication is impaired and may manifest itself in a number of ways.

- Has difficulty starting or maintaining a social conversation
- Does not adjust gaze to look at objects that others are looking at
- Does not point to direct others' attention to objects
- Repeats words or memorized passages, such as commercials or lines from movies (and expects that everyone will recognize the quote)
- Does not make friends or seems withdrawn or aloof
- May not respond to eye contact or smiles, or may avoid eye contact
- May treat others as if they are objects
- Prefers to spend time alone, rather than with others
- Shows a lack of understanding/empathy* how words or actions impact others, to the point of seeming rude or offensive
- Easily angered or frustrated
- Gets stuck on a single topic or task (perseveration), gets stuck on or argues about details

The symptoms may vary from moderate to severe.

**Qualifier: Gavin Bollard in his blog: <http://life-with-aspergers.blogspot.com> writes: "The Aspie doesn't really "think on the fly" during conversations. There's a delay and we often don't pick up on non-verbal or non-obvious cues that we're hurting someone. That said, Aspies are the first to notice when people are obviously upset or hurt. When people are physically rather than verbally hurt, Aspies tend to be quite concerned. It's not that we don't understand emotional hurt but rather that we have more difficulty determining that it has happened. "*



Meltdowns - Sometimes, despite best efforts, an autistic teen or adult may have a "meltdown" because he/she just cannot handle something. Without the verbal ability to easily translate feelings into speech, autistic adults and teens have a very difficult time handling conflict, disagreement or overstimulation. The "meltdown" may be completely unrelated to the topic/discussion at hand since it may have been triggered by an associative memory or may be related to sensory distressers in the environment. These meltdowns should not be mistaken for rage/indignation/anger against individuals or concepts. The best thing to do is give him/her a safe place to calm down and regroup. This place should be chosen ahead of time, and it should be as quiet and as soothing/non-stimulating as possible.

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Strengths of those with Autism

People with high-functioning autism are often exceptional in their ability to remember details of situations. For instance, if a discussion on any topic has become heated, the autistic adult is the one most likely to clearly remember who was present. He or she will not have focused on the words said or their emotional content, but on the visual image of the situation.

With a preference and aptitude for visual association between objects and concepts, autistic adults can be exceptional at creating visual presentations of abstract (theological) concepts.

Autistic adults and teens love to share information on their favorite topics. With guidance, their expertise can be channeled and be of benefit to the entire congregation. Their attention to detail is phenomenal. Because they are passionately interested in their chosen subject, and able to sustain their focus for long periods of time, those with high-functioning autism often enter such fields as engineering, computer programming or research.

◆ The following excerpt from a paper by Attwood & Gray called, *The Discovery of "Aspie" Criteria*, further details the strengths of being an "Aspie"...

If Asperger's Syndrome was identified by observation of strengths and talents, it would no longer be in the DSM IV, nor would it be referred to as a syndrome. After all, a reference to someone with special strengths or talents does not use terms with negative connotations (it's artist and poet, not Artistically Arrogant or Poetically Preoccupied), nor does it attach someone's proper name to the word syndrome (it's vocalist or soloist, not Sinatra's Syndrome).

Focusing on strengths requires shedding the former diagnostic term, Asperger's Syndrome, for a new term. The authors feel that Aspie, used in self-reference by Liane Holliday Wiley in her new book, *Pretending to be Normal* (1999), is a term that seems right at home among it's talent-based counterparts: soloist, genius, aspie, dancer. New ways of thinking often lead to discoveries that consequently discard their outdated predecessors. Similarly, the change from Asperger's Syndrome to Aspie holds interesting implications and opportunities. It could result in typical people rethinking their responses and rescuing a missed opportunity to take advantage of the contribution of Aspies to culture and knowledge.

Discovery Criteria for Aspie...

A. Qualitative advantage in social interaction, as manifested by a majority of the following:

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1. Peer relationships characterized by absolute loyalty and impeccable dependability
2. Free of sexist, “age-ist”, or culturalist biases; ability to regard others at “face value”
3. Speaking one’s mind irrespective of social context or adherence to personal beliefs
4. Ability to pursue personal theory or perspective despite conflicting evidence
5. Seeking an audience or friends capable of: enthusiasm for unique interests and topics;
6. Consideration of details; spending time discussing a topic that may not be of primary interest
7. Listening without continual judgement or assumption
8. Interested primarily in significant contributions to conversation; preferring to avoid ‘ritualistic small talk’ or socially trivial statements and superficial conversation.
9. Seeking sincere, positive, genuine friends with an unassuming sense of humour

B. Fluent in “Aspergerese”, a social language characterized by at least three of the following:

1. Determination to seek the truth
2. Conversation free of hidden meaning or agenda
3. Advanced vocabulary and interest in words
4. Fascination with word-based humour, such as puns
5. Advanced use of pictorial metaphor

C. Cognitive skills characterized by at least four of the following:

1. Strong preference for detail over gestalt
2. Original, often unique perspective in problem solving
3. Exceptional memory and/or recall of details often forgotten or disregarded by others, for example: names, dates, schedules, routines
4. Avid perseverance in gathering and cataloguing information on a topic of interest
5. Persistence of thought
6. Encyclopaedic or ‘CD ROM’ knowledge of one or more topics
7. Knowledge of routines and a focused desire to maintain order and accuracy
8. Clarity of values/decision making unaltered by political or financial factors