

They Said It's Asperger's: Now What?

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Goal for Tonight:

- Take the edge off the anxiety that is provoked when receiving the diagnosis.
- Understanding the differences within the spectrum
- Get a plan in motion

We First Need to Understand

What are we talking about?



2013

- Diagnostic and Statistical Manual of Mental Disorders (DSM) published the 5th edition
 - **First Edition 1952**
 - Goal is to classify mental health disorders into clusters of behavioral symptoms that can be distinguished via interview, observation, testing, symptoms reports, or other means so that professionals can agree on and treat the symptoms of the same cluster of symptoms that now has a label.
- Western ideology – if you can name it, you can treat it.

Autism Spectrum Disorders (ASD's)

- The primary authors of the DSM accumulated data and determined that most professionals were not effectively differentiating disorders considered to be part of Autistic Spectrum Disorders.
 - **Previously:**
 - Autism
 - Asperger's
 - Pervasive Developmental Disability, Not Otherwise Specified
 - Several other conditions often included as ASD (i.e. Rhett's, Angelman's, Williams, etc.)

DSM 5 Clustered as One Diagnosis

Autism Spectrum Disorder

A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive, see text):

- 1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.
- 2. Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.
- 3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.
- *Specify* current severity:
 - Severity is based on social communication impairments and restricted repetitive patterns of behavior

B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive; see text):

- 1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).
- 2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat food every day).
- 3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interest).
- 4. Hyper- or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).
- *Specify* current severity:
 - **Severity is based on social communication impairments and restricted, repetitive patterns of behavior**

C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).

D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

- *Specify if:*

- With or without accompanying intellectual impairment
- With or without accompanying language impairment
- Associated with a known medical or genetic condition or environmental factor

Note: Individuals with a well-established DSM-IV diagnosis of autistic disorder, Asperger's disorder, or pervasive developmental disorder not otherwise specified should be given the diagnosis of autism spectrum disorder.

Individuals who have marked deficits in social communication, but whose symptoms do not otherwise meet criteria for autism spectrum disorder, should be evaluated for social (pragmatic) communication disorder.

Social (Pragmatic) Communication Disorder

A. Persistent difficulties in the social use of verbal and nonverbal communication as manifested by all of the following:

- 1. Deficits in using communication for social purposes, such as greeting and sharing information, in a manner that is appropriate for the social context.
- 2. Impairment of the ability to change communication to match context or the needs of the listener, such as speaking differently in a classroom than on the playground, talking differently to a child than to an adult, and avoiding use of overly formal language.
- 3. Difficulties following rules for conversation and storytelling, such as taking turns in conversation, rephrasing when misunderstood, and knowing how to use verbal and nonverbal signals to regulate interaction.
- 4. Difficulties understanding what is not explicitly stated (e.g., making inferences) and nonliteral or ambiguous meanings of language (e.g., idioms, humor, metaphors, multiple meanings that depend on the context for interpretation).

B. The deficits result in functional limitations in effective communication, social participation, social relationships, academic achievement, or occupational performance, individually or in combination.

C. The onset of the symptoms is in the early developmental period (but deficits may not become fully manifest until social communication demands exceed limited capacities).

D. The symptoms are not attributable to another medical or neurological condition or to low abilities in the domains of word structure and grammar, and are not better explained by autism spectrum disorder, intellectual disability (intellectual developmental disorder), global developmental delay, or another mental disorder.

For Review

The U.S. and many countries have been experiencing an epidemic in the diagnosis of ASD's.

- DSM in 2013 consolidates all disorders into one spectrum
 - Add a Social Language Disorder, not previously recognized in DSM, but most insurances exclude from coverage
- And then pass ASD legislation for Autism, no other neurodevelopmental concern
 - And then develop treatment protocols for certain ages (at least in MI)



Makes Sense - Right

- One Size fits all –
 - Well
- One diagnosis centralizes treatment planning
 - Well
- One diagnosis helps predict outcome and adaptive developmental needs
 - Ahhh
- And, one diagnosis clears up the picture for families
 - Em, ya, see ah, well

NO

The Diagnostic Change Does **NONE** of
This

Assessment Leads to Intervention

- Generalities of DSM 4 classifications in the clinical world: Autism vs. Asperger's
- Autism
 - Severe language disturbance
 - Repetitive non-functional behaviors
 - Often associated with cognitive impairment
 - Lack of interest in social interaction unless on their terms
 - Often going to require life long support

- Asperger's Disorder Generalities

- Social language struggles, but not as often severe language delays
- Repetitive behaviors, but often try to manage in social/environmental venues
- Often want to fit in to the group, but always feel like “the odd duck out of water”
- But often learn skills to function more independently



Asperger's tend to be at more risk

- Many with Asperger's experience anxiety/depression especially social anxiety, since they may want to fit in.
- As the children develop they become more aware of differences and desire friends, but still not know how to make connections well.



Language

Differences in:

- Social Conventions
- Understanding sarcasm, humor and irony
- Some understand sarcasm, but still do not know how to respond or use inappropriately
- Blunt, but not intending to be mean
- Poor inferential ability to know where a conversation is leading
- Naive



Executive Functioning

- Perspective taking
- Cognitive flexibility
- Processing speed efficiency
- Multi-tasking
- Organization
- Social awareness
- Application of learned material



Reciprocity

- Not a motivational or attitude issue
- Not “disrespect”
- Not about “responsibility”
- Just not on their radar to do something because “you said so.”



"*Gasp!* I can't take this much honesty in a relationship!
My head is about to explode!"

The easiest thing in life is to love someone.



The hardest part is finding someone who loves you back.



stupidcreations

In Reality

So now What?

- My family member has a diagnosis that no longer exists in the DSM, but I still do not know what to do.
 - Side Note: Several groups have already changed to the ICD-9 and all will change to the ICD-10 shortly where the differentiation is still viable in coding and diagnosis.

Healthcare

- Michigan has passed the Autism Bill
 - This means that state or federally funded health care plans can no longer exclude coverage for services to support rehabilitative and behavioral health supports.
 - Private paid plans may have an exemption
 - Some medicaid/medicare plans may have age limits
 - And there are several hoops to jump through including what treatment(s) deemed appropriate
 - Most will approve Applied Behavioral Analysis (ABA)
- Autism Alliance of Michigan:
<http://autismallianceofmichigan.org/>
- Autism Society of Michigan: <https://www.autism-mi.org/>

Collaboration

- Recognize you just become a partner in a new business. Most common immediate business partners
 - Family including immediate and extended
 - Outpatient treatment professionals (i.e. ABA, counselor, Occupational, Physical, Speech Therapy)
 - School/College/University

Good materials through:

- GVSU: www.gvsu.edu/autismcenter/
- Ohio Initiative:
www.ocali.org/project/ohio_parent_guide_to_ASD

Look to the Pro's

- There are many local agencies working effectively in this area.
 - BRAINS
 - Hope Network Center for Autism (specializes in 0-5 yrs old is my understanding)
 - Center for Child Development
 - Pine Rest
 - Wedgewood Christian Service developing unit
 - Several independent practitioners

Liane Holliday Willey

- ASPIE.COM
- *Safety Skills for Asperger Women: How to Save a Perfectly Good Female Life*, 2011
- *Pretending to be Normal: Living with Asperger's Syndrome*, 1999
- *Asperger Syndrome in the Family: Redefining Normal*, 2001
- *Adolescents and Asperger Syndrome in the Adolescent Years: Living With the Ups and Downs and Things in Between*, 2003

Tony Attwood - expert

- <http://www.tonyattwood.com.au/>
- Complete Guide to
Asperger's Syndrome



Nick Dubin

- *Asperger Syndrome and Bullying: Strategies and Solutions*
- *Asperger Syndrome and Anxiety: A Guide to Successful Stress Management*
- *The Autism Spectrum and Depression*
- *The Autism Spectrum, Sexuality and the Law: What every parent and professional needs to know*

Specifics

- I could present for hours, but other generalities
 - Each person on the spectrum is unique. Working with trained providers will help to customize beyond core approaches
 - Worry less about etiology and more about moving toward independence
 - It is NOT your fault
 - Behaviors will change day to day, but there will often be patterns that hold true – those are the areas to address
 - Most of the time there is a relationship there, but it may feel and act different, be flexible
 - You have now become a coach, welcome to the team!



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