What are we talking about when we talk about Asperger’s?

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Autism

• A neurodevelopmental disorder (that is – inborn, abnormality of the nervous system, that unfolds with maturation)

• Characterized by:
  – Impaired communication
  – Impaired social interaction
  – Repetitive behavior (stereotypies, compulsions)
  – Restricted interests
Leo Kanner

Described eleven children in his 1943 paper titled “Autistic Disturbances of Affective Contact”

Kanner used the term “autism” which was then applied in psychiatry to persons with schizophrenia and other psychoses to describe the sense of not being able to socially or emotionally engage the other person – but he amended it with the descriptor “infantile autism.”
Kanner’s Infantile Autism

- Extreme autism
- Obsessiveness
- Stereotypies
- Echolalia – gradually “abandoned” by age 5-6
- Relate typically to objects, but anxiously or “imperviously” to people
- Powerful desire for aloneness and sameness
- Intolerant of change in routine
A long and unfortunate detour...

- “Refrigerator mothers”
- Psychoanalytic theory vs. Genetic inheritance of similar ways of processing information
Hans Asperger

• Published a definition of “autistic psychopathy” in 1944 describing four boys with:
  – Lack of empathy
  – Little ability to form friendships
  – One-sided conversations
  – Intense absorption in a special interest
  – Clumsy movements
  – *Referred to the children as “little professors”*
Just one of those things...
In 1981…

• I graduated from medical school and Lorna Wing, OBE, MD, FRCPsych (1928-2014)
• published the first paper in the English language on Asperger’s Syndrome.

• “Asperger’s Syndrome: A Clinical Account”
What Parents Know

- Half of parents of an ASD child know something is wrong by 18 months; most (3/4) by 24 months.
- Studies have shown that when mothers bring a child to a pediatrician and say “Something is wrong,” the mother is correct 90% of the time.
Despite knowing something was wrong, many parents tell stories of a long search for a diagnosis.
When Lorna Wing and her husband had a daughter and something was wrong,

*Dr. Wing began to search for answers --- which led to world-changing events...*
Before we go on –
Current Screening for Autism:

- No babbling by 12 months
- No gesturing (pointing, waving, etc.) by 12 months
- No single words by 16 months
- No spontaneous (not just echolalic) 2-word phrases by 24 months
- Any loss of language or social skills at any age
Asperger’s DX quickly adopted

• Following the publication of Lorna Wing’s paper in 1981, and the publication of Uta Frith’s translation of Asperger’s paper in 1991, the diagnosis of “Asperger’s Syndrome” gained a lot of momentum.

• Included in the ICD-10 in 1993

• Included in the DSM-IV in 1994
Identification of a disorder leads to more research.

• 2000 articles on autism spectrum disorder published in 10 years prior to publication of DSM-IV in 1994

• 2000 articles in 2013 alone

“Science happens at the bubbly edge of the pancake.”
Problems with the Asperger’s Syndrome diagnosis

• Some people understood it to be the “high functioning” end of the autism spectrum

• Others considered it a qualitatively different disorder (Gillberg)

• DSM-IV diagnosis specified normal language development, but otherwise same as “autism”

• Diagnostic instruments were not developed that clearly distinguished Asperger’s from autism
Diagnostic Accuracy

**Sensitivity**

- Making sure that you find ALL the cases

- Example: If we were looking for all the dogs in the state, we might gather up wolves, coyotes, and foxes as well.

**Specificity**

- Making sure that you ONLY find cases of autism

- Example: If we were looking for only dogs, we might leave out chihuahuas and Great Danes on the grounds that they are too small and too large to be dogs.
The ideal diagnostic test is both sensitive (finds all cases) and specific (finds only cases).
DSM-5 Criteria for Autism Spectrum Disorders

• No longer distinguishes among Asperger’s, PDD, NOS and autism.
• May exclude some individuals on the higher functioning end of the spectrum.
• (Excludes Rhett Syndrome on the grounds that this is primarily a genetic diagnosis.)
Lumpers Vs. Splitters
Given that the diagnosis no longer exists, **WHY ARE YOU TALKING ABOUT ASPERGER’S?**
Gillberg Diagnostic Criteria for Asperger’s

- Impaired reciprocal social interaction
- All-absorbing narrow interest in some topic
- Imposition of routines and interests on self or others
- Speech and language problems: delayed development; formal and pedantic; superficially perfect
- Problems with non-verbal communication
- Motor clumsiness
Once again, the personal gets in the way....

- In 1996, a pediatrician and sociologist questioned Gillberg’s published research on a diagnostic category, DAMP, which described an uncommon condition (about 1.5% of children) with both ADHD and motor clumsiness. They demanded access to Gillberg’s original data.
- Gillberg and his colleagues refused because families had been promised confidentiality. The University requested that the two persons demanding access agree to abide by the family’s willingness to have their records reviewed.
- The Swedish court ordered documents released.
- A higher court refused to hear the University’s appeal.
- University administrators and others destroyed the records.
- Gillberg found guilty and fined.
Results:

• Gillberg’s work is thrown into disrepute in the U.S.
• Controversy over who has access to medical records and medical study data rages in Sweden for years (television documentary in 2008)
• Swedish medical communities now require strict coding of all data in medical studies to avoid identifying subjects if cases are reviewed by outsiders
• Laws introduced in Sweden requiring individuals to show an ethical need for examining data from medical studies before being granted access to records
• Gillberg is awarded the King’s Medal by Carl XVI Gustav in 2009
Asperger’s or HFA has much to teach us --

• Social skills
• Executive functions
• Pragmatic language
• Non-verbal communication
• Handwriting
• Non-literal language
• Theory of Mind
• Context Blindness

• Sensory sensitivities
• OCD vs. “stuck”
• OCD vs. narrow interests
• Tics/fidgets/stereotypies
• Bullying
• Motor clumsiness/dyspraxias
Meet the teacher day:

“Wallace has special needs.”

“Don’t worry, I’ve worked with autistic kids before.”
If you’ve met one student with ASD...

YOU’VE MET ONE STUDENT WITH ASD.
Who knew we had social skills?

- Like noticing the air...It’s not a “thing” until it’s not there.
- Learned effortlessly, like language, from exposure
- Sons of Nerds are at a disadvantage.
- The water balloon test
- Look at me when I talk to you!
- “You be the architect and I’ll be the manager.”
Executive Functions: Mel Levine

• Pediatrician who wrote *All Kinds of Minds* and several other good books on kids with learning disabilities and ADHD

• Avoided diagnostic labels as potentially injurious to kids’ self-esteem

• Developed methods for helping the next 10%
Executive Functions: The operating system of the mind

- Mental Energy controls
- Processing controls
- Production controls
- Temporal-sequential awareness and ordering
- Spatial ordering
- Memory (short term, working, long term)
- Language (Receptive processing; Expressive)
- Social Cognition
- Higher Order Cognition
- Neuromotor Functions (Gross motor, fine motor, kinesthetic perception)
Executive Functions may be measured by the BRIEF
Pragmatic Language

• New diagnosis in DSM-5 “Social (pragmatic) communication disorder”
• Persistent difficulty with verbal and non-verbal communication that cannot be explained by low ability
• Diagnosis of autism must be excluded
• Succeeds the previous “Semantic pragmatic disorder” and “Pragmatic Language Impairment”
Pragmatic Language - *Say what?*

- Hearing is not the problem
- Difficulty understanding spoken language
- Tendency to be concrete and prefer facts to stories
- Difficulty with non-literal language
- Difficult with some types of grammatical constructions
- Often quite talkative and fluent in speech production
“Maybe he doesn’t know what you mean by that.”

If you don’t understand an Aspie’s behavior, have the next Aspie you meet explain it to you.
Social (Pragmatic) Communication Disorder

Deficits in social communication such as greeting and sharing information, in a manner appropriate for the social context

Impairment of the ability to change communication to match the context or needs of the listener

Difficulties following rules for conversation and story-telling

Difficulty understanding what is not explicitly stated

The deficits result in functional limitations (IMPAIRMENT)

Onset is in the early developmental period (although may not be appreciated until later)

Not attributable to another disorder

• Persistent difficulties in the social use of verbal and nonverbal communication
Handwriting

• Eye-hand coordination issue?
• Expressive language issue?

• Work of Virginia Berninger, at the University of Washington, shows that the labored handwriting of kids with HFA is likely an expressive language disorder.
Same Kid – Handwriting improves with changes in neurotransmitters

• Off meds

• On stimulant
Understanding what’s happening inside the child

• *The Reason I Jump*
• By Naoiki Higashida; translated by David Mitchell
Language issues in Autism spectrum disorders

• Carol Gray: “Neurotypicals mean what they say, and sometimes say what they mean.”

• Tone of voice
• Facial expression
• Gesture
• Posture
Examples of non-literal language

- Metaphors, similes
- Mistakes
- Sarcasm, irony
- Puns
- Lies and “white lies”
- Mixed feelings
- Social growlers
- Hidden intentions
- Omissions

- “Spit it out!”
- “He kicked the bucket.”
- Yeah, right.
- He hit a low spot.
- “She’s a bit matronly…”
- We’ll do lunch sometime
- “I’m so mad I could scream!”
Sensory Sensitivities – another piece of the puzzle

More sensitive
• Certain Noises
• Fabric textures on body (light touch)
• Food textures
• Skin pain (sharp)
• Florescent/ flickering light sources

Less sensitive/ sensory seeking
• Deep pressure
• Vestibular
• Organ (bone/bowel/inner ear) pain
Restricted Range of Interests

- WWF wrestling
- Vacuum cleaners
- Water coming out of downspouts
- Cats
- Aquarium fish
- Action figures
- Video games
- Manga
Being “obsessed” is not obsessive-compulsive disorder

The *obsessions* of OCD are accompanied by anxiety --

Examples: avoidance of buttons, need to count, germ avoidance, need for symmetry, need for reassurance

A *restricted interest* in ASD is actively pursued --

Examples: hobbies, collections, fascinations
Unable to transition from one activity to another
Uncertain or fearful about next activity
Unwilling to transition because they just got started
Uncertain about whether the desired object/activity will be there another time
Uncertain about time passing and worried about missing something desired

MANY KIDS WITH ASD GET “STUCK”
Being stuck is not OCD
Tics
• Rapid, repetitive and purposeless, involving restricted muscle groups

Fidgets
• Semi-purposeful, but often only partly conscious

Habits
• Semi-purposeful, often with a sense of relief

Stereotyped Habits
• Rapid, repeated, may be purposeful or not, engaged in with a sense of relief, usually involving extremities
Theory of Mind

– See the baby.
– See the girl.
– What is the baby thinking about the girl?
Context Blindness
Context Blindness can explain many of the inconvenient behaviors of persons with ASD.
Motor Dyspraxias and Clumsiness

Many Aspies are late in learning to ride a 2-wheeled bicycle.

Getting dressed involves a lot of steps that must be done in the right order.
WE’VE TALKED ABOUT A LOT OF ASPECTS OF ASPERGER’S
Why does this matter?
The rate of ASD is increasing

- The incidence of ASD is increasing
- We don’t know why
- 1 in 68 according to the CDC
- And the ASDs are growing up
ASD adults need different types of services.

• Job training and placement
• Assistance with money management
• Training in interpersonal skills
• Help with obtaining a driver’s license
• Socialization and dating

• They don’t do well in programs for persons with ID
ASD is highly co-morbid

- Anxiety disorders – especially social anxiety
- Depression
- Attention-deficit/hyperactivity disorder
- Learning disabilities
- Psychosis can develop
- Seizures can develop
- Complications with medical issues: appendicitis
Asperger’s syndrome dropped from the DSM-5.
BUT THEY’RE STILL HERE!
Many Thanks to:

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