What Is Autism?

A very basic primer for a very complex issue.

Definitions

ASD - Autism Spectrum Disorder

Spectrum - used to classify something, or suggest that it can be classified, in terms of its position on a scale between two extreme or opposite points

DSM - Diagnostic and Statistical Manual

IDEA - Individuals with Disabilities in Education Act 1975 and 1990 - Free and Appropriate Public Education for children with disabilities

Incidence - a measure of the probability of occurrence of a given medical condition in a population

Prevalence - How common or widespread something is

Clinical Diagnosis - A diagnosis based on observation, rather than laboratory type tests such as genetics, blood work or imaging like x-rays, MRI, etc.

Definitions

Receptive Language - The ability to understand language as it is presented to us as individuals

Expressive Language - The ability for us to express thoughts and ideas to others through the use of language

Prosody - how verbal language changes emphasis on a topic or subject with natural pauses, changes of pitch and inflection

Echolalia - repeating words you hear others speak, sometimes verbatim

Sensory Integration/Processing Disorder - a "rewiring" of the of the sensory system that results in a heightened experience of some senses, and decreased experience of others (simplification)

Comorbidity - having one or more additional disorders or diseases at the same time

Disorder - Not Disease

A Disorder is a psychological pattern associated with distress or disability that occurs in an individual and is not a part of normal development or culture.

A Disease can cause a disorder, but is typically caused by external factors, such as pathogens. Culturally, people often think of diseases as infectious.

Disorder is preferred when talking about ASD.

Categories of Autism Spectrum Disorders

Autism - Often called Classic Autism

Aspergers - No longer included in the DSM, sometimes referred to as High Functioning Autism

Pervasive Developmental Disorder Not Otherwise Specified - PDD-NOS is the largest category of ASD. The variations of Autism are so diverse that the most Autism Diagnoses fit into PDD-NOS

Childhood Disintegrative Disorder (CDD) - onset of developmental delays that appear after a child appears to be developing at a typical rate, including development of language - usually around 2-3 years old

Rett Syndrome - genetic brain disorder that often includes physical issues

Williams Syndrome - genetically identifiable developmental disorder

Autism is a Spectrum of Disorders

An individual on the Autism Spectrum may exhibit any combination of some these traits (6000 possible variations):

- Limited eye contact
- Slow response time
- Limited or no expressive verbal language
- Perseverent focus on a singular topic
- Difficulty understanding and/or using prosody in language
- Repetitive motions or behaviors
- Echolalia
- Strict adherence to rigid routines

- Sensory Processing Disorder
- Reciprocity
- Parallel Play
- Sleeping Problems
- Social Communication
- Difficulty interpreting nonverbal signals
- Difficulty developing and maintaining relationships (including friendships)
- Difficulty with transitions
- Difficulty with inferences and idiomatic expressions

Other Factors and Comorbidities

- Hearing Difficulties
- Blindness
- Down Syndrome
- Cerebral Palsy
- Muscular Dystrophy
- ADHD
- Dyslexia
- Fragile-X

The Press vs Dr. Wakefield

In 1998, Dr. Andrew Wakefield published a paper with this title:

Ileal-lymphoid-nodular hyperplasia, non-specific colitis, and pervasive developmental disorder in children.

This is a study about gastrointestinal problems in children with Autism. The only specific mention of vaccines also asserts the following: "No association was made with the vaccine at this time." Multiple studies, including at Harvard, and Oxford have confirmed a higher incidence of GI problems in individuals with Autism.

When anyone tries to argue a point about vaccines and Autism and mentions Dr. Wakefield's retracted study - ask them if they know the title of that study.

Autism and Regression

- Also called CDD
- Generally appears at around 2-3 years
- Presentation may include a loss of expressive language
- Eye contact may disappear
- SPD symptoms may begin to appear
- Sleeping problems may emerge
- We don't know how often this happens, or why

No Authoritative Database of ASD DX In U.S.

- 1. Most US Data on Autism prevalence comes from the IDEA database
- 2. Education Database not medical
- In Oregon schools do not currently the DSM for determining eligibility for public school services based on Autism
- 4. Peaks at around age 11 and then drops off
 - a. Note that this is middle school
- 5. There is no "cure" for Autism
- Autism is lifelong
- 7. CDC uses a small sample of individuals from just 11 us sites to determine prevalence (1 in 59) based on statistical models
- A national reporting database would allow for those models to be confirmed or improved using big data

Autism in Oregon K-12 Schools

Oregon Data on Autism incidence compiled by the Oregon Department of Education.

- Based on public school students receiving educational services for Autism
- Autism diagnosis determined by school staff, not necessarily medical diagnosis
- Does not include students whose parents would not allow services based on this academic categorization
- Does not include home schooled students or students in private schools
- Does not include any student who previously received services based on Autism eligibility but no longer needs those services

These numbers are the best we have, but are inaccurate.

Oregon Census Growth

comparison by category
Numbers from Oregon Department of Education

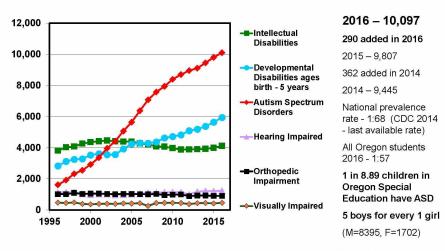


Chart prepared by Autism Research and Resources of Oregon - www.arroautism.org rev.5/4/2017

Adults and Autism

Autism is lifelong.

Adults on the Autism Spectrum may find college difficult.

Consistent employment can be a problem.

Depression among adolescents and adults is very high.

Personal relationships and marriages can be even more difficult.

Some are dependent on family for their entire lives.

There is more We DON'T know than what we DO

While knowledge of Autism Spectrum Disorders has increased dramatically since the 1990s, including its associated symptoms, challenges, treatments, prevalence, comorbidities, skills and needs ...

We still know so little that we cannot consistently, accurately diagnose it.

It is often confused with other conditions, like ADHD.

Different panels of experts, presented with the same information, can draw different conclusions.

What is Autism?

- A neurological disorder that affects at least 1 in 59 in the U.S.
- A unique experience for each individual on the spectrum with thousands of variations
- A set of behaviors that affects people to various degrees for their entire life
- A human experience affecting people around the world
- A disorder that exists alongside other conditions
- A complex set of disorders that is difficult to diagnose
- A collection of challenges and skills that has enormous socio-economic impacts
- A state of being that challenges our preconceptions of being human

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For questions about his work on Autism, you can email him at:

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Sources and Resources

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