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# Autism and Neurodiversity

Diane Treadwell-Deering, MD

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## Disclosures

- Presenter Disclosure:
  - Financial: Diane E. Treadwell-Deering is a paid employee of The Nemours Foundation. She serves as the Medical Director of the Swank Autism Center at Nemours duPont Pediatrics. She received grant and research support from numerous organizations that conceptualize autism as a disorder.
  - Non-financial: Diane E. Treadwell-Deering is a member of the Academy of Child and Adolescent Psychiatry. She is a non-member of the American Psychiatric Association, publisher of the DSM-5.

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## Disclosures

- **Content Disclosure:** This learning event does not focus exclusively on any specific product or service.
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## Potential biases

- Because I am trained in a medical model, belong to medical organizations and am the medical director of an autism clinic, there are legitimate worries that I may be biased toward a medical conceptualization of autism and biased against the neurodiversity vantage point.
- In preparing this presentation, I have tried to take a scientific approach—acquiring knowledge through thorough examination of available information, careful consideration, vigorous skepticism and a critical eye regarding all information, applying logic and reason in order to develop conclusions. That, in some way, biased the ways I looked for information about this topic---I utilized databases that include peer-reviewed journals, often sponsored by professional organizations, such as psychologists, psychiatrists, speech and language pathologists, etc.
- I did look on the web, searching for autistic self-advocates. I did reference a book authored by a leading proponent of neurodiversity. I do have collaborative working relationships with autistic people and family members of autistic people with whom I discussed these issues.
- I am keenly aware that I need to guard against my bias. I am keenly aware that the group of people that I see in practice is a subgroup of autistic people. The group of people that I work with is not an accurate representation of autistic people in general.

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## Learning Outcomes

After this course, participants will be able to:

1. describe the application of the term neurodiversity to the autism spectrum.
2. differentiate the terms disease, disorder and disability.
3. apply the medical and neurodiversity models to the autism spectrum.

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## A Brief History of Autism--Kanner

- First described by a child psychiatrist, Leo Kanner, in *The Nervous Child*, in 1943
- A cold, distant style of parenting caused the disorder, an explanation in line with prevailing psychodynamic theories of psychiatry and psychology
- Some writings hinted at biologic and genetic factors
  - Parents had milder manifestations of what was more fully apparent in their child

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## A Brief History of Autism--Asperger

- Hans Asperger reported on a series of his patients in 1944
- Work was largely ignored until 1980s, when Lorna Wing suggests “Asperger’s syndrome”
- Its relationship to autism has always been controversial
- Appeared in DSM-IV; no cognitive impairment or language delay
- Removed in DSM-5

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## A Brief History of Autism--Bettelheim

- 1940s-1970s greatly influenced by Bruno Bettelheim
- A Nazi concentration camp inmate, psychology professor at University of Chicago and director of a residential school for emotionally disturbed children
- He compared life in a concentration camp to the life of a child with autism

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## A Brief History of Autism

- Bernard Rimland and Andrew Wakefield proposed medical models of autism causation, blaming environmental causes, such as vaccines and developing biologic interventions, such as mega-dose vitamins

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## Why is there a medical model of autism causation?

- Research reveals multiple biologic/physiologic risk factors
  - Advanced maternal age
  - Advanced paternal age
  - Short (<12 months) inter-pregnancy intervals
  - Long (60-84 months) inter-pregnancy intervals
  - Maternal infections during pregnancy
  - Small for gestational age
  - Large for gestational age
  - Preterm birth

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## Why a medical model?

- Less well established risk factors also support biologic/physiologic etiology
  - Family history of autoimmune disorders
  - Prenatal air pollution exposure
  - Prenatal pesticide exposure
  - Prenatal exposure to antidepressant medications
  - Caesarean delivery

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## Why is there a Medical Model--- Genetics

- Autism has the highest heritability estimates of any developmental disorder (70-90 %)
- Three main areas of evidence support a genetic etiology of ASD
  - Twin studies
  - Family studies compare the rate of autism in first degree relatives of a person with autism vs the rate in the general population
  - Studies of rare genetic syndromes associated with autism

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## Why is there a Medical Model-- Epigenetics

- DNA modifications that do not affect DNA sequence
- Fragile X, Rett syndrome and Angelman syndrome are all associated with autism and are all caused by epigenetic dysregulation

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## Pathophysiologic factors

- Early brain overgrowth
- Differences in connectivity and hypo-connectivity across brain structures
- Anatomic brain differences
- Frequent co-occurrence with intellectual disability, speech and language disorders, learning disabilities

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## The DSM story



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## The DSM

- A handbook authored and published by the American Psychiatric Association
- Contains descriptions, symptoms and other criteria for diagnosing mental disorders
- Used by healthcare professionals across the country
- Provides a common language
- Allows for consistent and reliable diagnoses that can be used to determine treatment and support research

Q 5

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## The DSM

- Reflects evolving theoretical frameworks
- DSM-II 1952-autism is considered a form of childhood schizophrenia
- DSM-III 1980-autism is a separate disorder with three categories of diagnostic criteria
- DSM-III-R 1987 –the concept of autism is broadened with the introduction of pervasive developmental disorder, not otherwise specified (PDD, NOS)

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## The DSM

- DSM-IV 1994 and DSM-IV-TR 2000 the category now includes five conditions
  - autism, PDD-NOS, Asperger's disorder, childhood disintegrative disorder, Rett syndrome
- DSM-5 2013 autism spectrum disorder (ASD)
  - Classic autism, PDD-NOS and Asperger's disorder were removed from the DSM entirely
  - Childhood disintegrative disorder and Rett syndrome are moved out of ASD into other categories

Q 1

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## Diagnostic Criteria DSM-5 Autism Spectrum Disorder

- A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history:
1. Deficits in social-emotional reciprocity
  2. Deficits in nonverbal communicative behaviors used for social interaction
  3. Deficits in developing, maintaining, and understanding relationships

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## DSM-5 Diagnostic Criteria

- B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history:
1. Stereotyped or repetitive motor movements, use of objects, or speech
  2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior
  3. Highly restricted, fixated interests that are abnormal in intensity or focus
  4. Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment

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## DSM-5 Diagnostic Criteria

- 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.

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## 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
  - (Coding note: Use additional code to identify the associated medical or genetic condition.)
- Associated with another neurodevelopmental, mental, or behavioral disorder
  - (Coding note: Use additional code[s] to identify the associated neurodevelopmental, mental, or behavioral disorder[s].)
- With catatonia (refer to the criteria for catatonia associated with another mental disorder)
  - (Coding note: Use additional code 293.89 catatonia associated with autism spectrum disorder to indicate the presence of the comorbid catatonia.)
- American Psychiatric Association: Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition. Arlington, VA, American Psychiatric Association, 2013., pp 50-59.

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## Words we use

- Definitions/Implications/Semantics
- Language can reflect and also shape our perceptions
- Do terms evoke pity or imply worthiness/value
  - High-functioning and low-functioning ASD
  - Disorders need to be fixed; diseases need to be cured
- Over time, words/terms acquire associations that may be pejorative
  - Moron, imbecile, mentally retarded, intellectually disabled

Q 1

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## Words we use Simon Baron-Cohen

- Disorder—there is nothing positive about the condition; even with environmental modifications, the person is unable to function
- Disability—the person falls below an average level of functioning in one or more areas and needs support or intervention
- Difference—the person is simply atypical relative to a population norm, but the difference does not necessarily affect functioning or well-being
- Disease—a biomedical mechanistic cause of a disorder becomes known through research and testing

Q 2, 3

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## Words we use

- Does “disability” imply we need to fix, cure, prevent?
- The notion of a “spectrum,” which bleeds into neurotypical, is dissatisfying to many autistic individuals.
- Many autistic individuals liked the differentiation of Asperger’s

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## Person-first/disability-first/ identity-first

- Person-first
  - Preferred by medical professionals, family members and friends (Kenny L et al. 2016)
  - Emphasized in medical training since the 1970s as a sign of respect
  - Is felt by some to imply there is a normal person “inside” waiting to get out
  - Rejected by many in deaf and blind communities

Q 7, 8

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CONTINUED

## Person-first/disability-first/ identity-first

- Identity-first
  - Preferred by many, but not all, autistic people
  - "...an autistic person can never, and should never attempt to, be separated from their autism." Jim Sinclair (1999)
  - "Positive adjectives go before the noun" (?)
  - Is felt by some to over-identify a person as his/her/their condition

Q 9

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## Neurodiversity

- A term attributed to Judy Singer, an Australian social scientist who has autism
- First appeared in print in an article in *The Atlantic* (3 September 1998) by Harvey Blume
- Use of this term is coupled with those with the "majority" brain referred to as "neurotypical"
- This term is used differently by different groups and has changed over time

Q 4

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## Neurodiversity--assorted meanings

- Refers to a social justice movement
- Autism is a difference, not a disability, and a cultural movement.
  - Similar to the Deaf community - Dawn Price-Hughes
  - Specific communication style, aided by the Internet, which is more autism compatible than the regular social environment - Joyce Davidson
  - Group-specific rights are needed to accommodate autistic individuals

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## Neurodiversity--assorted meanings

- Autism should be conceptualized using the social model of disability.
  - Some, or all, of the “disability” of the “condition” is caused by society’s response to it, rather than to any internal factors
  - Society is responsible for enabling individuals to live and thrive within the society as disabled people
  - The goal is not to change or fix, but to accommodate and support the individual

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## Neurodiversity--assorted meanings

- Since there is uncertainty about when a neurologically based human behavior crosses the critical threshold from normal human variation to pathology, there can be no ability to discern normal from abnormal (Thomas Armstrong, 2015)
- Atypical neurodevelopment is a normal human difference, a natural form of human variation, such as eye or hair color. (Jaarsma and Welin, 2010)

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## Neurotypicality

- Analysis of 39 self-identified autistic vloggers
  - Neurotypicality is:
    - An accomplishment—a goal; something to strive for and be proud of
    - A masquerade—an effort that may or may not be worth it
    - A curse—a denial of one's true self
    - Very exhausting
- Angulo et al., 2019

Q 10

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## Autism Advantages

- 28 semi-structured interviews with very selected autistic adults
- Half were not identified as autistic until adulthood
- Only 6 were employed
- Identified strengths were also identified as weaknesses, depending on the context
- Ability to modify behaviors when appropriate was mentioned as important
- Most identified autism as a difference, not an illness

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## Autism Advantages

- Ability to hyperfocus
- Attention to detail
- Good memory
- Creativity
- Honesty
- Loyalty
- Empathy for animals and other autistic people
- Russell et al., 2019

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## Autistic Adults as Autism Experts

(Gillespie-Lynch et al., 2017)

- Autistic respondents on an online survey
- Convenience sample of people who were mostly unemployed and willing and able to participate in an hour-long interview for no compensation
  - Interventions for autistic people are not well-aligned with their needs and goals
  - Autistic people diagnosed in adulthood were often relieved to receive the diagnosis, but didn't view it as a disability
  - Autistic youth often were struggling and wanted to be "normal"

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## Autistic Adults as Autism Experts

(Gillespie-Lynch et al., 2017)

- Most, but not all, felt that autism was not a disease
- Most were OK if others wanted a cure, but they did not
- Some reported their autism presented a significant struggle
- Some indicated support for a medical model
- Some saw merits to both the medical and neurodiversity models
- Many coped by selectively masking autistic traits, but found this learned behavior very taxing

Q 10

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## Must these models compete?

- Not “Us vs. Them”
- The heterogeneity of autism spectrum disorder lends support to the notion that some forms are a disorder, some are a disability, some are a difference
- Both the medical model and the neurodiversity paradigm can support a biopsychosocial model
- Both the medical model and the neurodiversity model can endorse services aimed at improving the subjective quality of life and well-being of autistic people

Q 6

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## Impacts of the Neurodiversity Paradigm

- Increased respect and humanity toward autistic people
- Greater emphasis on strengths
- Greater appreciation of word choices
- Interventions and support that align with the goals of autistic people
- Acceptance of and legal protection for differences

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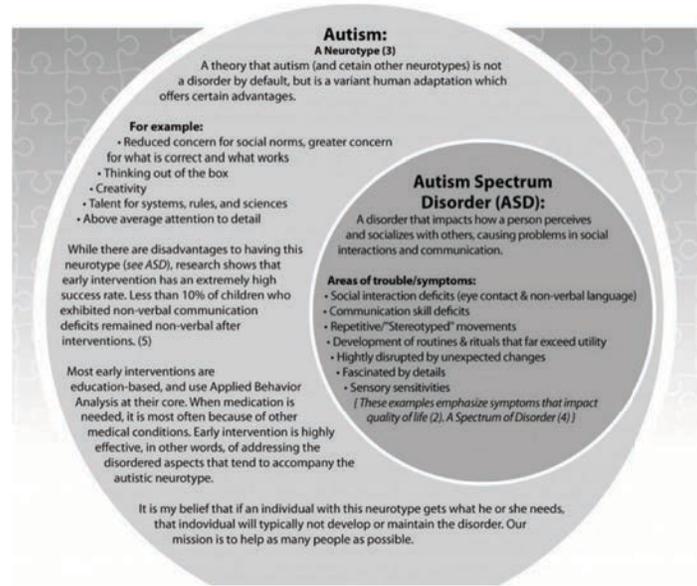
## Concerns/Criticisms of the Neurodiversity Model

- Natural variations are not always benign and are often associated with diseases, disorders and disabilities, not just differences
- Not having clearly defined “normal” does not mean there can be no delineation of “not normal”
- The neurodiversity model may work well for some autistic adults with strong cognitive and language skills, but not for all autistic individuals
- Can and should some members of the autistic community speak for everyone on the spectrum

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### Autism: Neurotype VS Developmental Delay

*Or, "I'm not a disease and neither are my people!"*



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continued

1. [www.Mayoclinic.org/diseases-conditions/autism-spectrum-disorder/symptoms-causes/syc-20352928](http://www.Mayoclinic.org/diseases-conditions/autism-spectrum-disorder/symptoms-causes/syc-20352928)
2. Girls with ASD are often misdiagnosed or undiagnosed because they do not fit ASD stereotypes and they mask symptoms better than boys do.  
[www.childmind.org/article/autistic-girls-overlooked-undiagnosed-autism/](http://www.childmind.org/article/autistic-girls-overlooked-undiagnosed-autism/)
3. [www.HealthLine.com/health/neurotypical#characteristics](http://www.HealthLine.com/health/neurotypical#characteristics)
4. Autism - what we know (and that we don't know yet) | Wendy Chang.  
<https://www.youtube.com/watch?v=wKIMcLqRLs&t=302s>
5. [www.autismparentingmagazine.com/autism-early-intervention-benefits/](http://www.autismparentingmagazine.com/autism-early-intervention-benefits/)



<https://youmemindbodycom/disabilities/i-am-Autistic-and-I-love-ABA>; BeardedBehaviorist.com &/or OhBehavePodcast.com

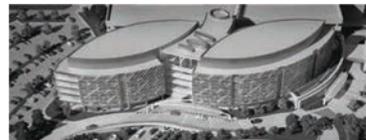
Permission obtained via email 2/6/20

**Biopsychosocial model**---there is an interconnection of biologic, psychologic and socio-environmental factors that impact the development of a human being

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“It is the duty of everyone to do what is within his power to alleviate human suffering.” A.I. duPont



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