

CONSTELLATION OF TRAITS OR DISORDERS?

CHALLENGING OUR DEFINITION
OF **AUTISM** AS AN ADVERSE
OUTCOME

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PEAR-Net Society



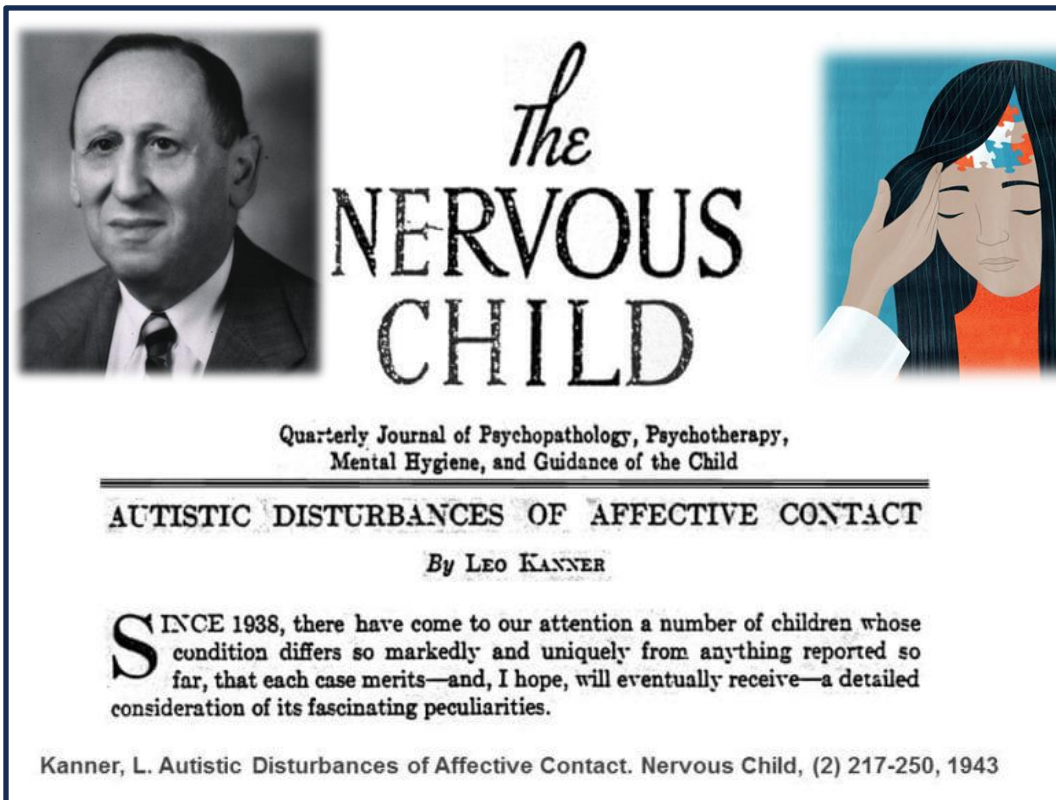
A SHIFT IN NARRATIVE

From “disturbances of affective contact” to pride in neurodiversity

1943



2025

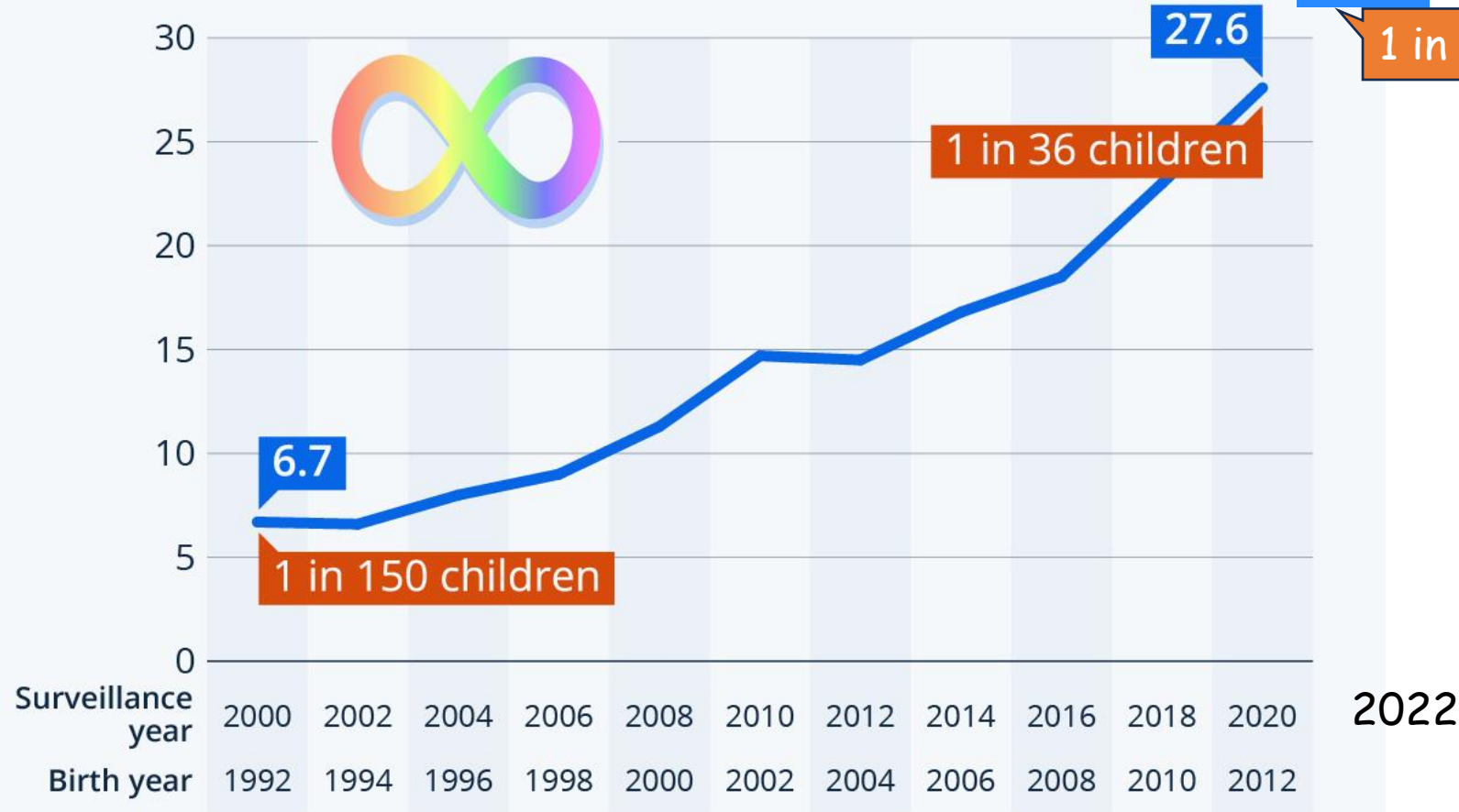




Autism is a difference in how the brain experiences and engages with the world

The Rising Prevalence of Autism

Identified prevalence of Autism Spectrum Disorder (ASD)
per 1,000 children in the U.S.



32.3

1 in 31 children

~ 385%
increase in
frequency.

Surveillance Summaries / April 17, 2025 / 74(2);1–22

1 in 45 adults
in the US are
diagnosed
with ASD

~ 450%
increase in
frequency
since 2011

Source: Autism and Developmental Disabilities Monitoring Network via CDC

JAMA Netw Open

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doi:10.1001/jamanetworkopen.2024.42218

Why is autism on the rise?

- Changes in diagnostic criteria
- Changes in diagnostic substitutions
- Genetics and the Environment
- Rising Awareness and Acceptance

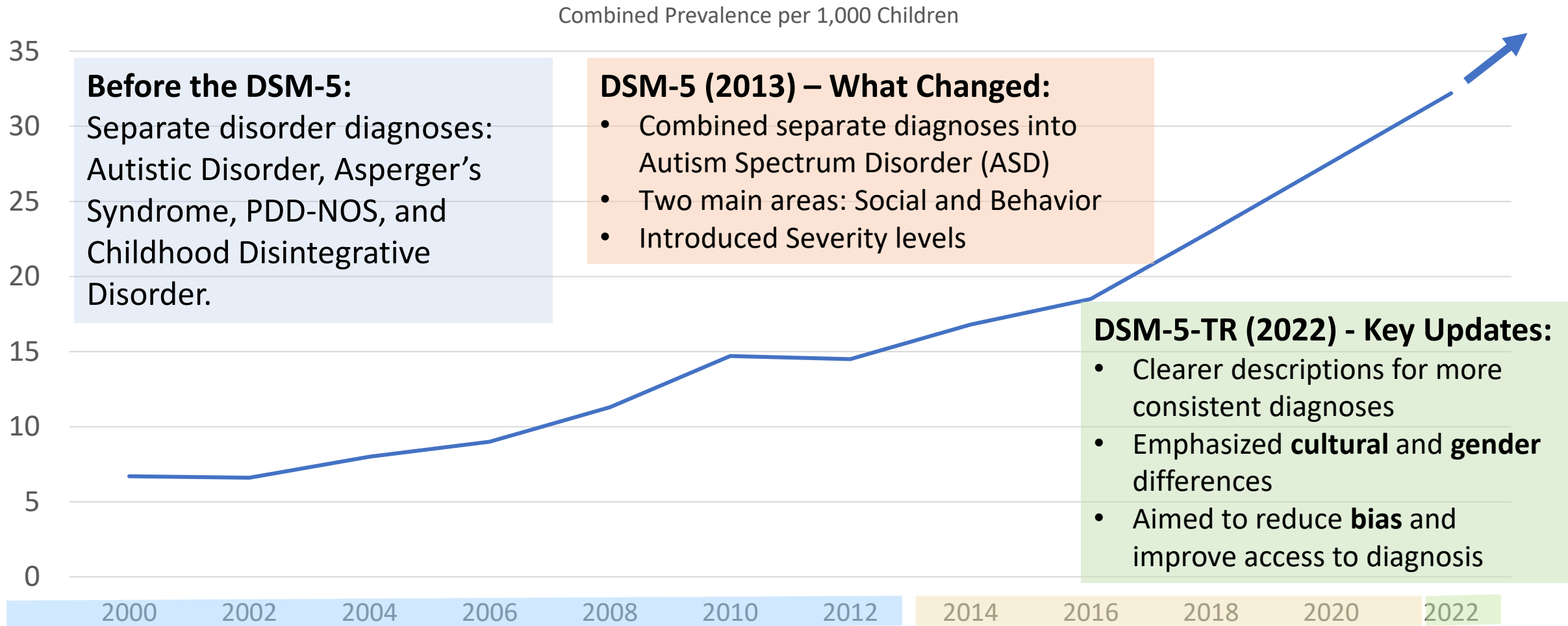


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Autism on the Rise: Changes in Diagnostic Criteria



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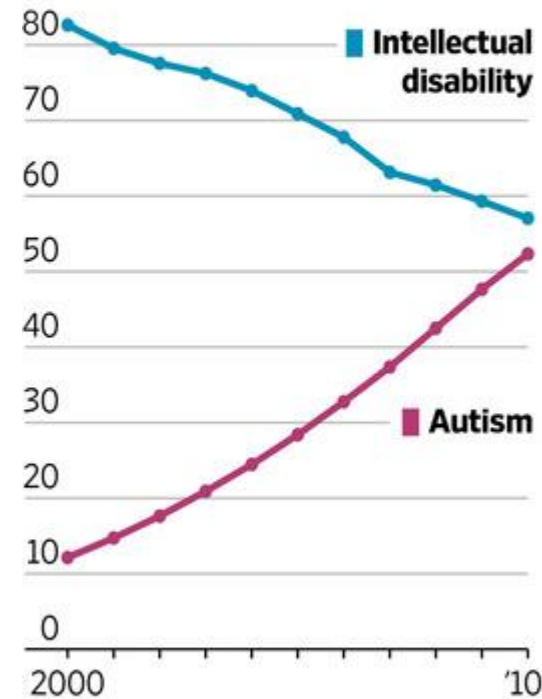
Autism on the Rise: Diagnostic Substitutions

**When individuals previously diagnosed with other conditions (e.g. ID) are now diagnosed with ASD*

- ~ **26% of the increase** in autism diagnoses from 1992 to 2005 could be attributed to diagnostic substitution.

Changing Labels

U.S. special education student diagnoses per 10,000 students



Sources: Pennsylvania State University
THE WALL STREET JOURNAL.

Shattuck, P. T. (2006) *Pediatrics*, **117**(4), 1028–1037.

King, M., & Bearman, P. (2009) *International Journal of Epidemiology*, **38**(5), 1224–1234.

Polyak, A. et al. (2015) *American Journal of Medical Genetics Part B: Neuropsychiatric Genetics*, **168**(7), 600–608.

Is Diagnostic Substitution Still Happening? (Post-2013 / DSM-5 Era)

- Yes, but to a **lesser** extent.
- Recent studies suggest:
(2020-2023)
 - **Continued overlap** in diagnostic boundaries
 - **Children from minority or undeserved communities** are still more likely to be diagnosed with **ID** rather than **ASD**, reflecting disparities and substitution dynamics
 - **Adult autism diagnoses** often replace or add to previous diagnoses, such as ADHD, social anxiety, or personality disorders.



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Autism on the Rise: Genetics

High Heritability

- Genetic factors account for **~80-90%**

Runs in Families

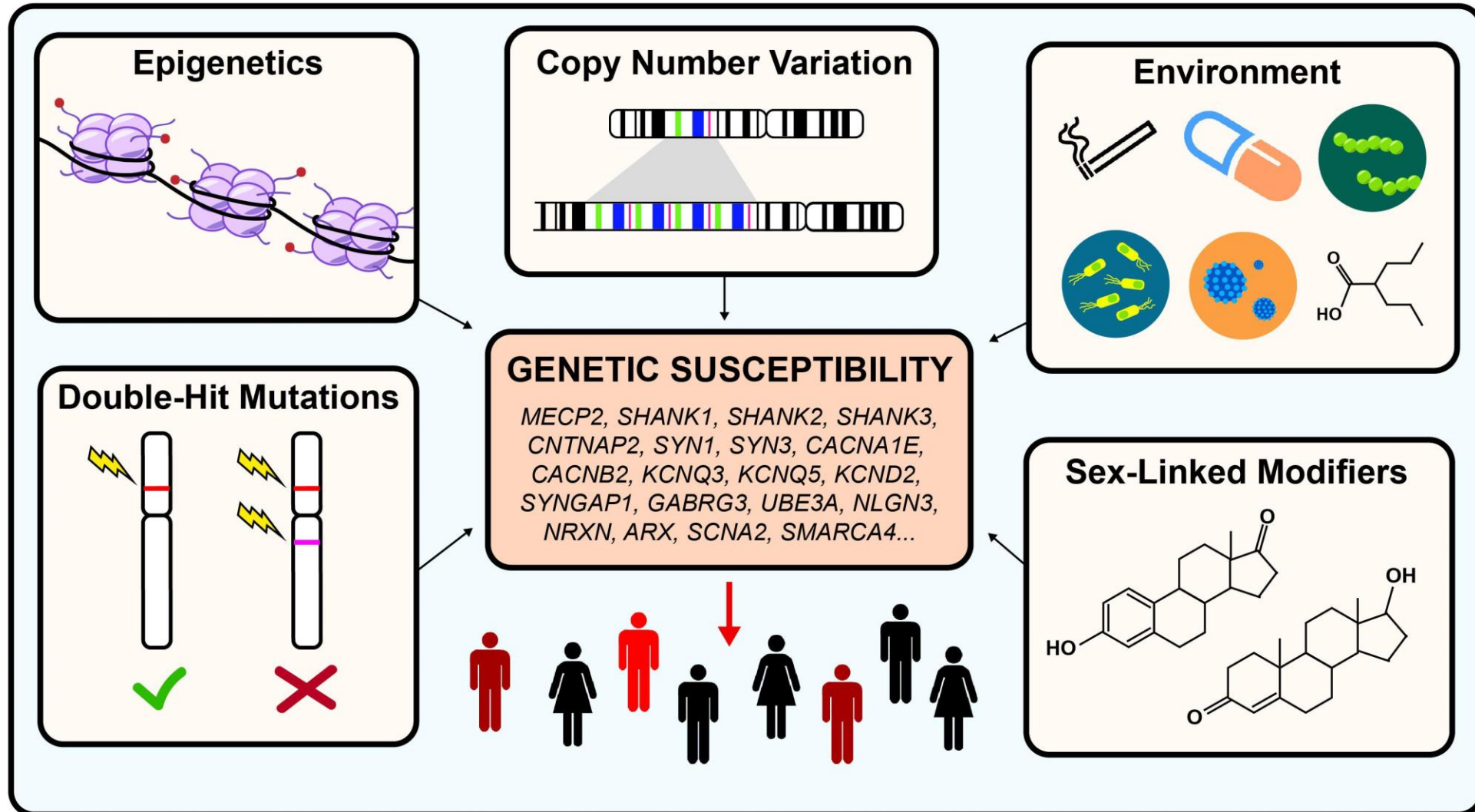
- Siblings of autistic individuals are ~10-20 times more likely to receive a diagnosis.
- Parents and relatives often have autistic traits, and many are starting to get diagnosed in adulthood.

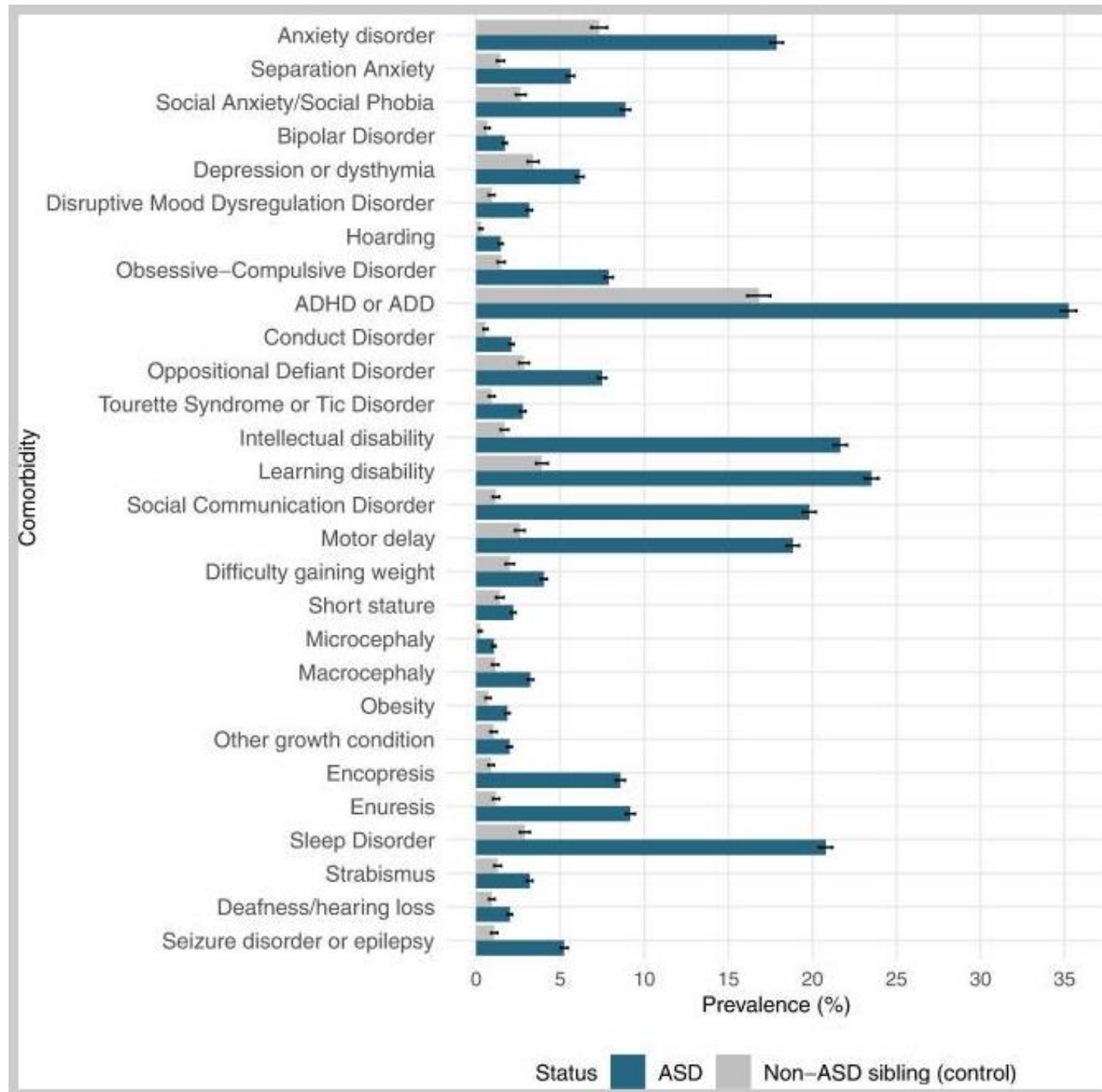
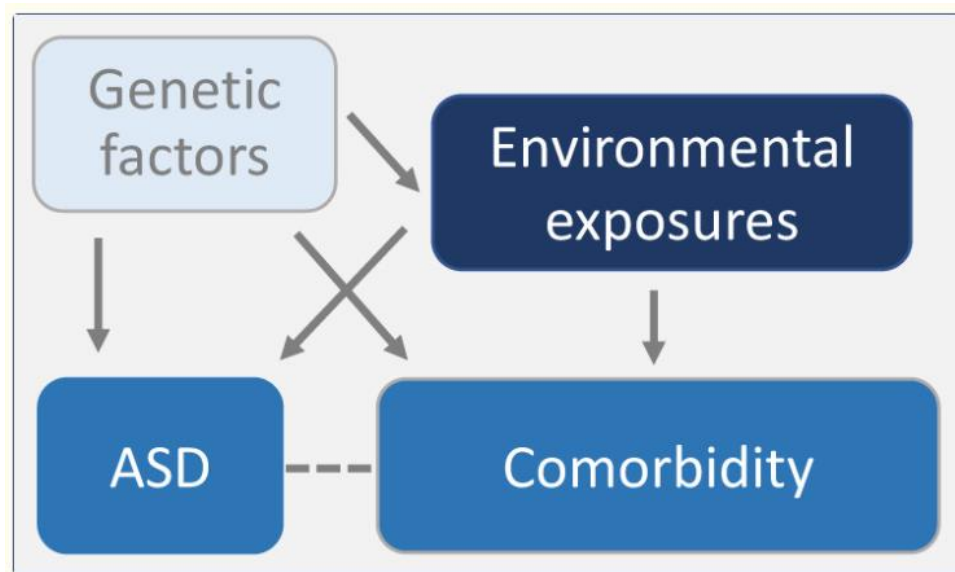
Sandin et al. (2017) *JAMA*, **318**(12), 1182–1184.
Yip et al. (2021) *Autism Research*, **14**(1), 191–202.
Grove et al. (2019) *Nature Genetics*, **51**, 431–444.
Buxbaum et al. (2023) *Cell*, **186**(3), 554–570.e18.



Autism on the Rise:

Complex Interplay of Genetics and the Environment





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Awareness vs. Acceptance ∞



- Greater acceptance of autistic behaviors and individuality
- Services that focus on improving quality of life rather than on imitating the behaviours of neurotypical (non-autistic) peers.
- Recognition of the autistic community as a minority group





A new Autism diagnosis (or the epiphany that you are Autistic) can be very validating. Some Autists describe it as feeling like "finally coming home to myself".

<https://reframingautism.org.au/how-to-navigate-being-newly-diagnosed-as-autistic-as-an-adult/>



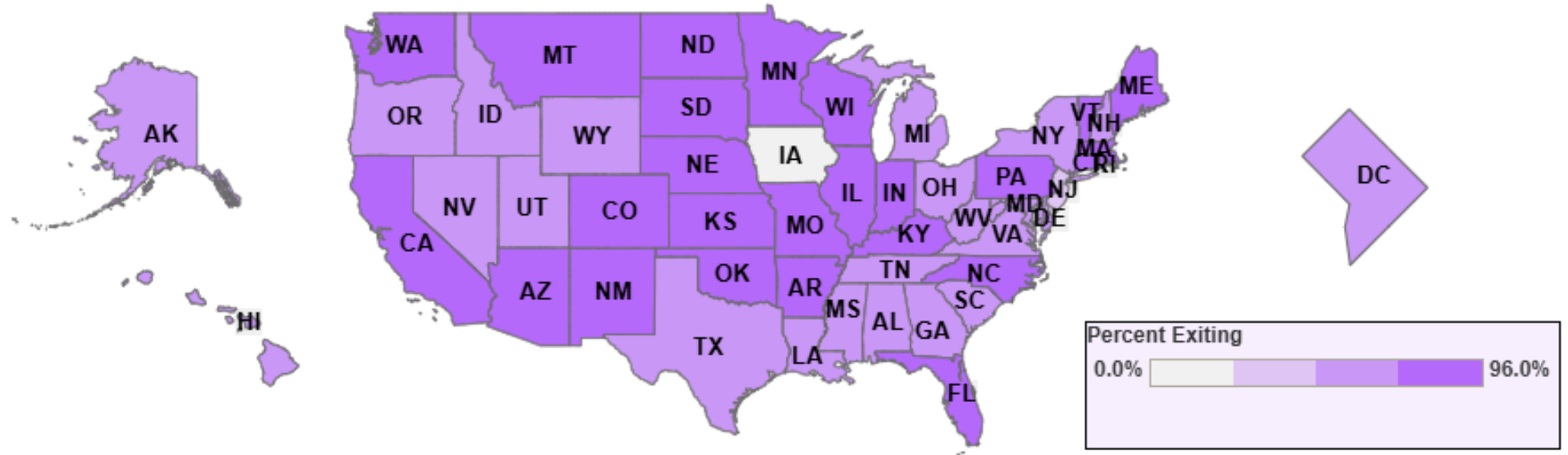
Why are you proud to be Autistic?

Dignity is our soul. Joy is our sustenance.

We have a lot to be proud of, and I say 'we' deliberately because the pride I feel in being Autistic is not a personal pride in myself, but a shared experience as a member of a community.

Stiof MacAmhalghaigh, AUsome Trainer

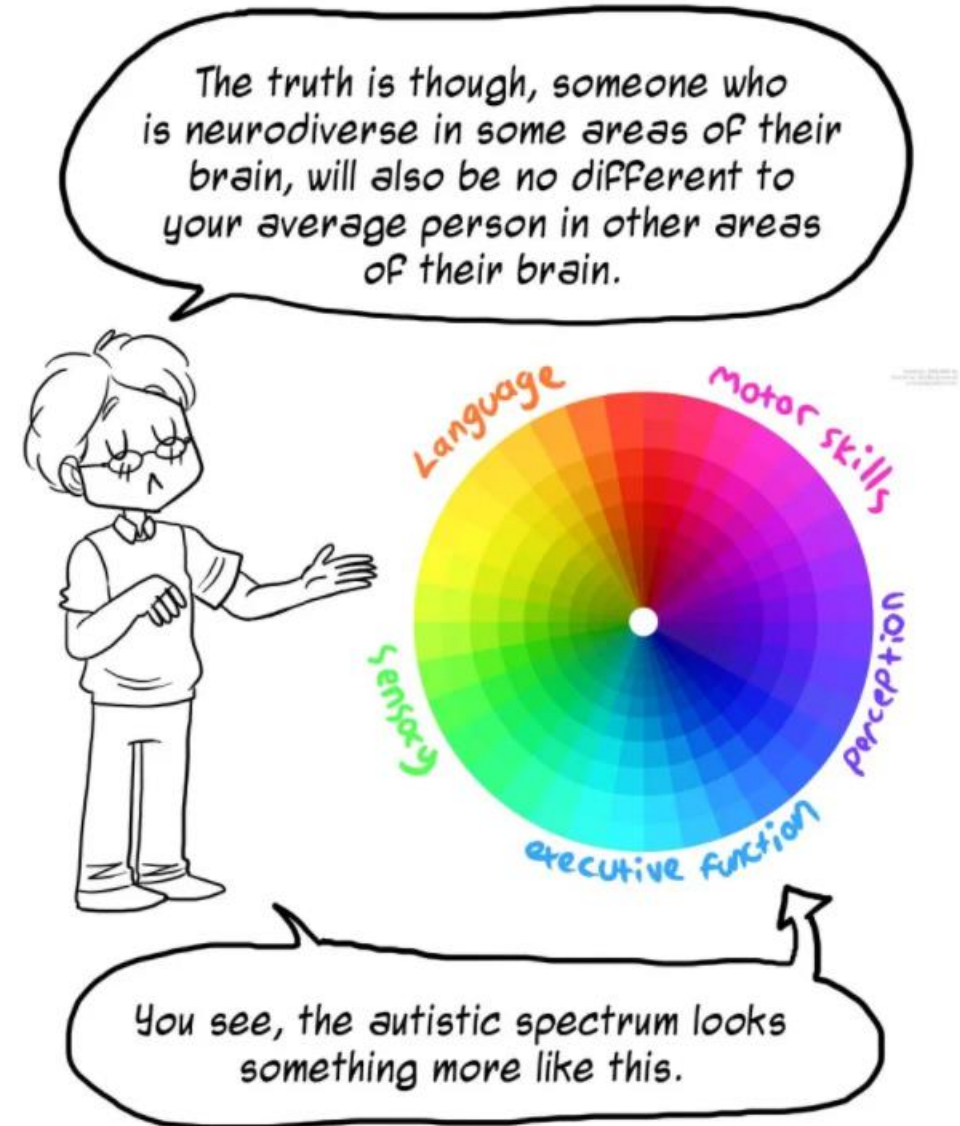
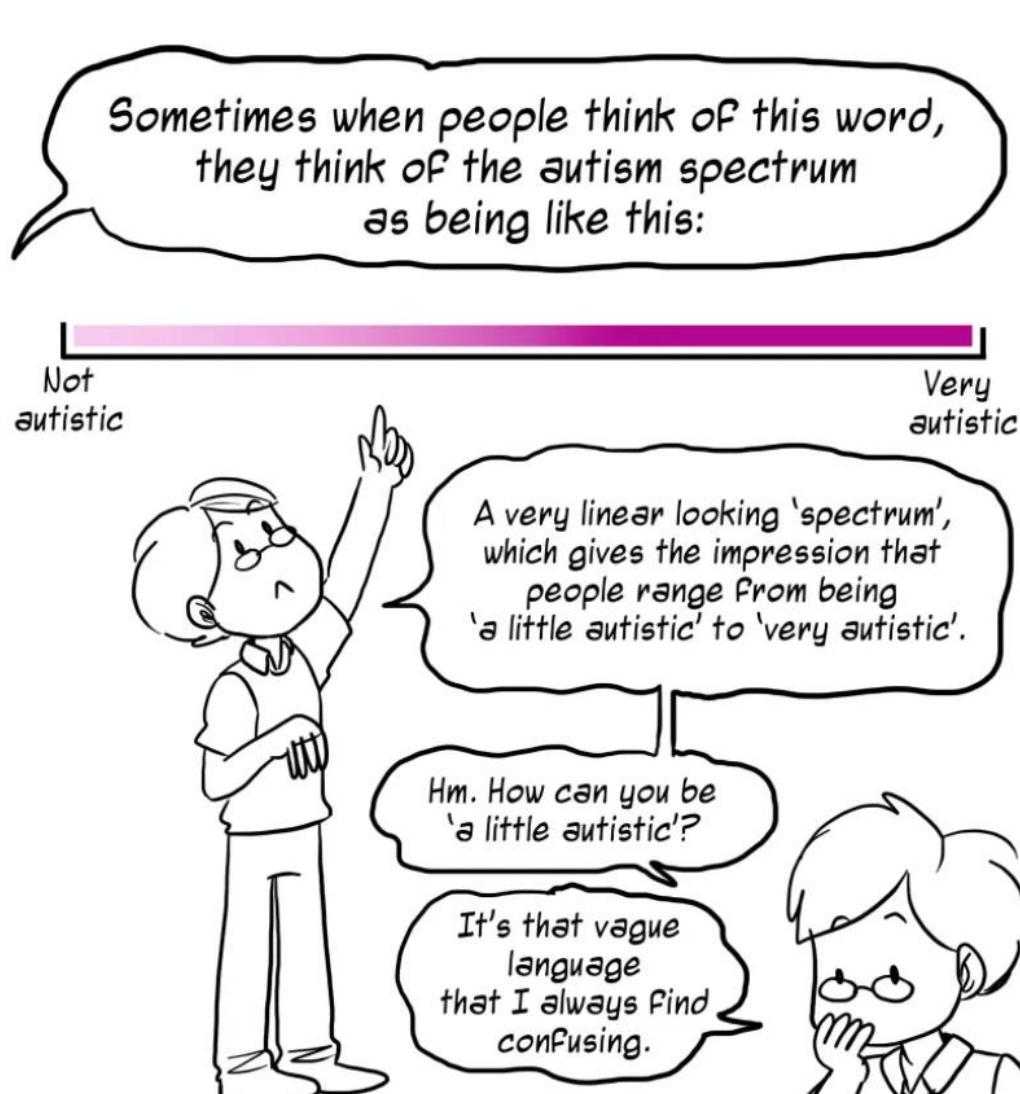
A smiling male graduate in a blue cap and gown with a red stole, wearing a blue superhero mask and holding a blue megaphone.



On average, **6.8%** of autistic students in the US dropped out of high school.

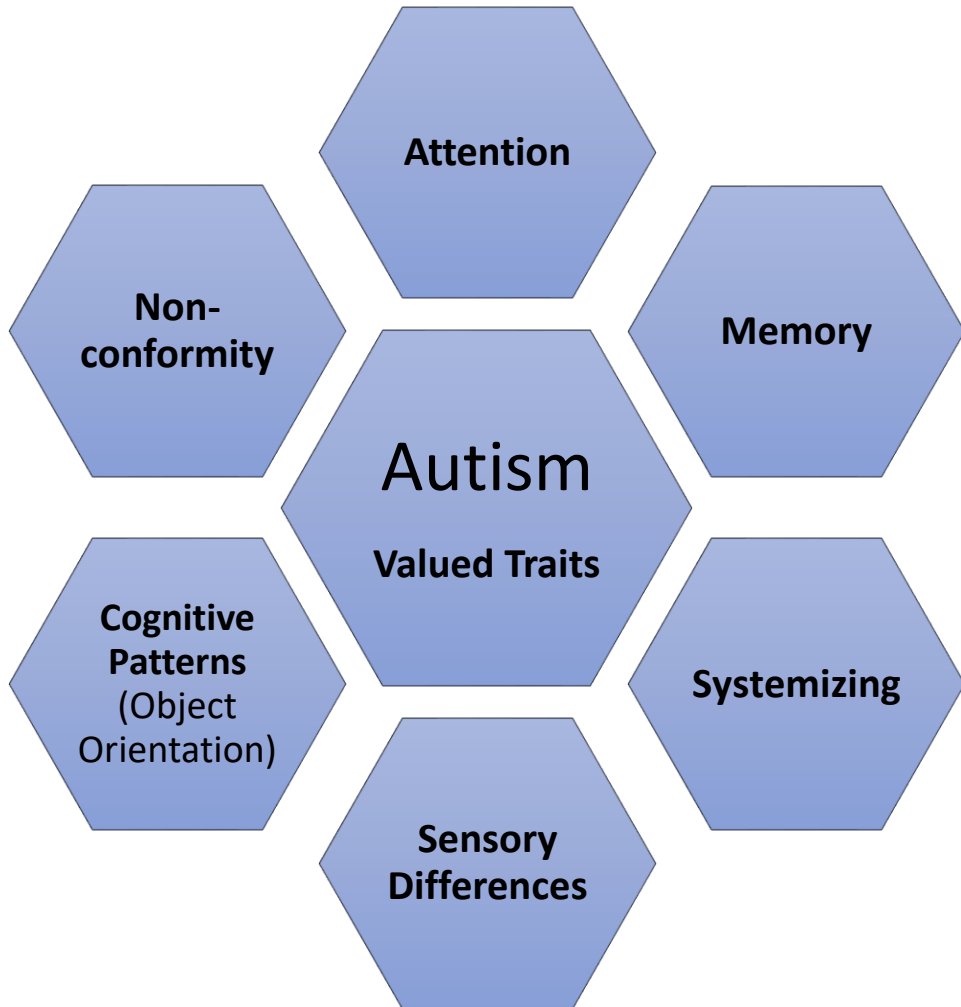


Autism – A Constellation of Traits, Not a Deficit



Autism – A Constellation of Traits, Not a Deficit

Broader Autism Phenotype Constellations (BAPCO)*

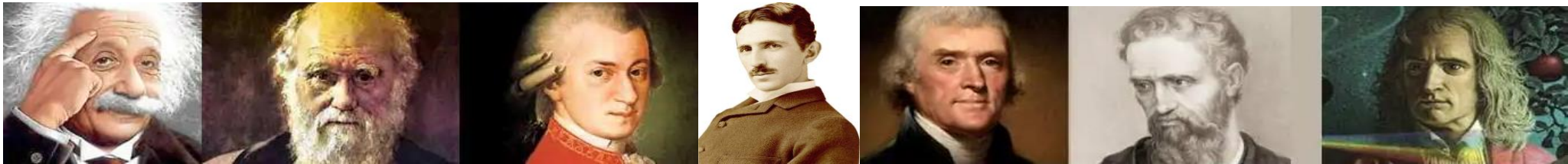


		Degree of BAPCO Traits	
Impairment category	Without co-occurring disability	Low BAPCO	High BAPCO
	With co-occurring disability	Name of Disability (eg, Fragile X; learning/information processing disability)	Autism (with/without <i>identified</i> co-occurring disability)

Moving Beyond the “Disorder” Lens

*“Autism is not a broken version of normal.
It’s a different way of being human.”*

-Steve Silberman (1957-2024)
– Science Writer and Autism Activist



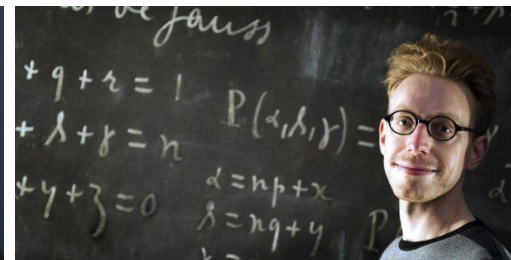
Dr. Henry Markram
Neuroscience



Dr. Temple Grandin
Animal Science /
Autism Advocacy



Dr. Christopher Fischer-Baum
Cognitive Scientist / Linguistics



Dr. Daniel Tammet
Linguist / Savant Syndrome



Dr. Rosalind Picard
Affective Computing /
MIT Media Lab



Dr. Peter Vermeulen
Cognitive Neuroscientist
/ Autism Researcher



Counselling: Reframing Risk and Reducing Fear

1. Start with Empathy

- *"It's natural to worry about your baby's development"*
- Validate their concerns without reinforcing stigma
- Avoid language that portrays autism as a tragedy
- Use Language that's neutral or affirming.

Instead of...	Try...
"Risk of autism"	"Association with differences in neurodevelopment"
"Preventing autism"	"Supporting healthy fetal development" or "Reducing exposure to known developmental disruptors"
"Normal child development"	"Typical developmental pathways" or "varied developmental outcomes"
"Disorder"	"Neurodevelopmental difference" or "condition" (depending on context)
"Suffers from autism"	"Is autistic" or "has an autism diagnosis" (based on identity-first or person-first preferences)



Counselling: Reframing Risk and Reducing Fear

2. Present the Science Responsibly

- No single exposure causes autism.
- Most studied associations (e.g. SSRIs, antiepileptics, infections, acetaminophen) are inconsistent:
 - Bias in study designs
 - Overinterpretation of associations as causal
 - Limited consideration of genetic and familial factors
 - Not considering underlying maternal health conditions
- Emphasize: autism is **multifactorial**, with strong genetic contributions.



Counselling: Reframing Risk and Reducing Fear

3. Reframe the Narrative Around Autism

- Autism is not inherently an adverse outcome.
- It represents **neurodevelopmental diversity**, not pathology
- Many autistic people live rich, meaningful lives – especially with early support and acceptance.



Counselling: Reframing Risk and Reducing Fear

4. Shift Focus on Maternal and Fetal Wellbeing

- Focus on what promotes fetal health:
 - Good nutrition
 - Managing chronic conditions
 - Mental health support
 - Reducing stress
- Caution against avoiding treatment due to exaggerate fears.

Autism – Reframing the Focus in Research and Care

🧠 Autism is not a “disorder” but a **constellation of valued traits** like:

- ✓ Focused Attention
- ✓ Exceptional Memory
- ✓ Systemizing
- ✓ Sensory Differences
- ✓ Distinct Cognitive Style



But these are not what require prevention!

Autism – Reframing the Focus in Research and Care



Autism may also include **co-occurring disabilities** like:

- ◆ Severe intellectual disability
- ◆ Epilepsy/seizure disorders
- ◆ Motor Coordination Disorders
- ◆ Severe language impairment
- ◆ Self-injurious behavior/aggression



These are the conditions **that can affect quality of life** — and where our **research, care, and prevention** are most urgently needed.

*“Our role isn’t to eliminate neurodiversity —
it’s to remove barriers and prevent the disabilities that cause real suffering.”*



Thank you 😊