

# **THE AUTISM SPECTRUM**

**DR CATHERINE LINDLEY**

**GP FELLOW IN CHILD HEALTH AND NEURODIVERSITY**

**LIZ HORNIBROOK**

**FORMER SCHOOL SENCO AND EALING TRAINING HUB PROJECT MANAGER**

# NEURODIVERSITY

A wider term to represent the diversity in how people think or how their brain is 'wired'

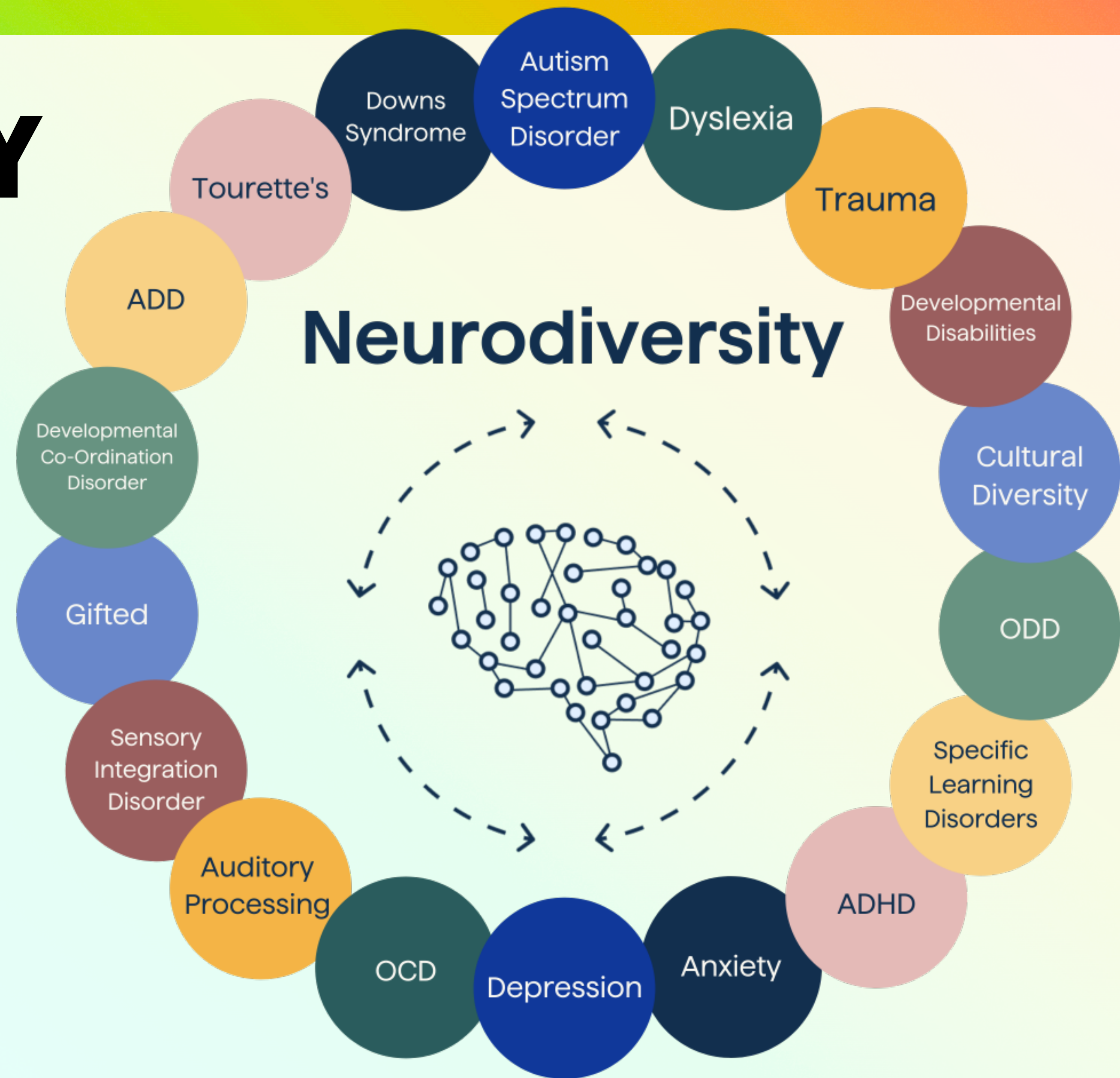
'Neurodivergent' - often used to describe the minority

Alternative is 'Neurotypical' (the majority)

Autism is a type of neurodiversity, as is ADHD, dyscalculia, dyspraxia etc

Can have > one

Many challenges are common



# WHAT IS AUTISM?

A spectrum of neurological differences affecting:

- How the world is perceived
- Interaction with others
- Any IQ level

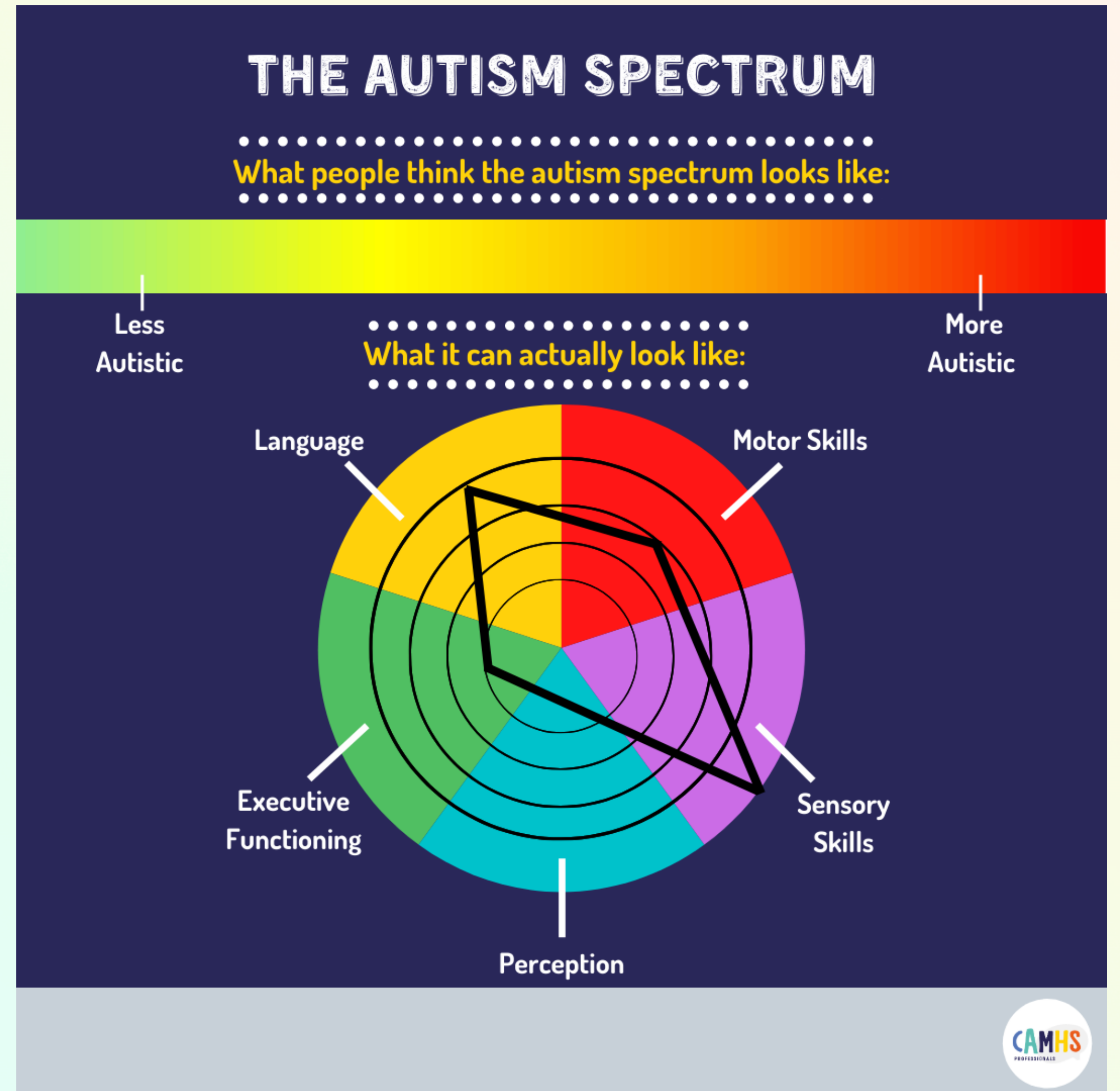
**What is autism?**

**What it is** ✓

- A neurodevelopmental difference (different brain wiring), a natural variation
- Affects every aspect of a person's being: how they perceive, experience, interact with and interpret the world
- A minority neurology
- Lifelong

**What it isn't** ✗

- A learning disability
- An illness or disease
- Bad behaviour/willful defiance
- Bad parenting
- Affects only children



# ABOUT AUTISM

**Around 700,000 people have diagnosis of autism in UK (1/100 children) from BMA, 2020 (1)**

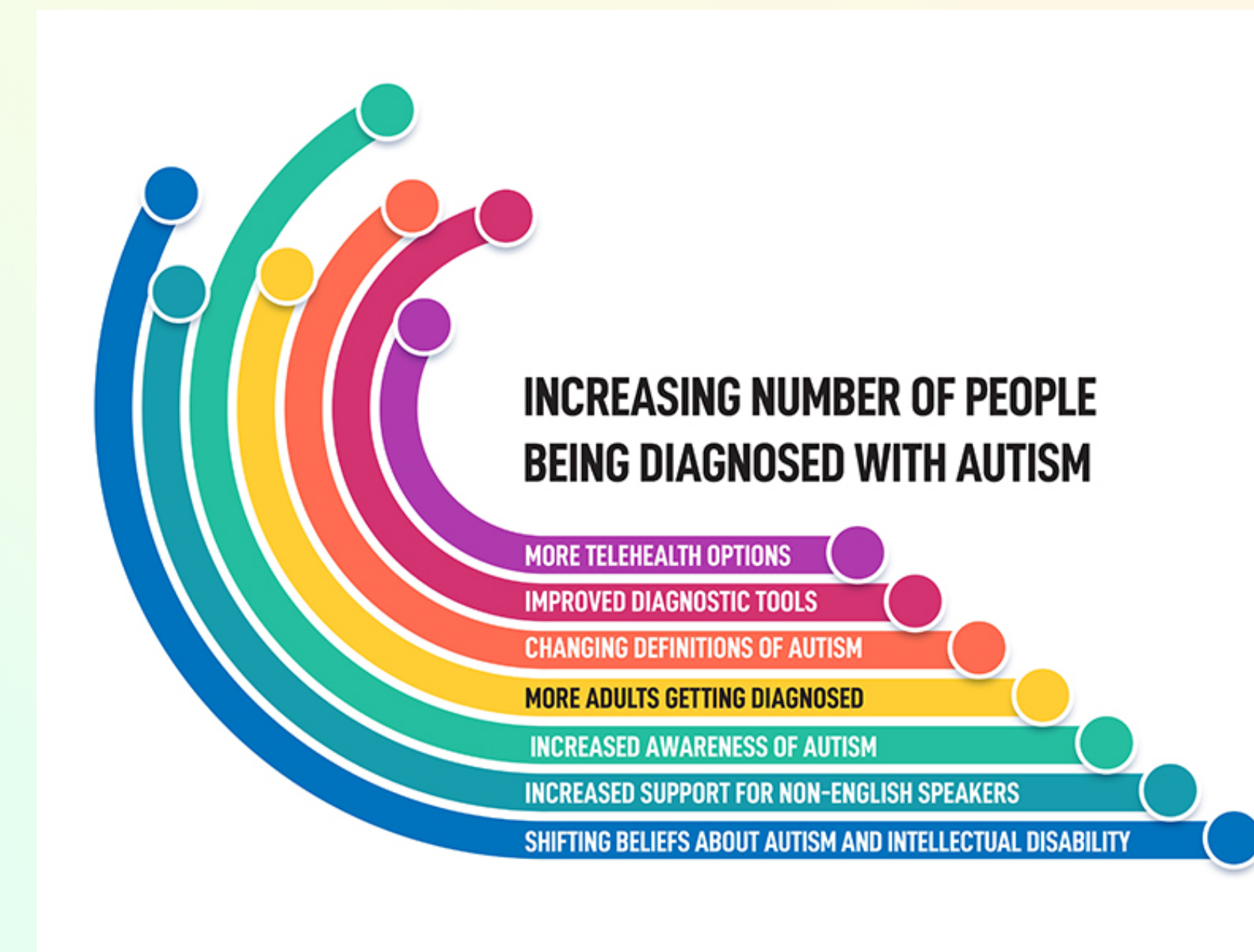
**Boys more commonly diagnosed (4:1 according to ICD-11)**

**However, drive recently to improve diagnosis and diagnostic criteria, especially for women/girls (who may not present typically)**

**Recent survey of 750,000 adults in UK (2) found 11.6% had autistic traits above cut off for autism**

**54% of these were women**

**No one specific 'cause' but tends to run in families**



# DIAGNOSTIC CRITERIA..

ICD-11 (2023) and DSM-V (2013)

Include differences in:

- Social communication and interaction
- Atypical or intense interests
- Inflexible or repetitive behaviour
- Sensory sensitivity
- Present from early childhood (may manifest later)
- Causes impairment
- Full range of IQ and language abilities
- NB Asperger's Syndrome and Autism used to be separate diagnoses but now both under Autism Spectrum Disorder since DSM-5

## ..IN REALITY



















# CO-OCCURRING CONDITIONS

Linked in different ways

Autism and ADHD co-occur in 25-80%

Anxiety very often present



-  ADHD INCLUDING INATTENTION AND OR HYPERACTIVITY
-  INTELLECTUAL DISABILITY
-  LANGUAGE DELAY
-  CHALLENGES WITH FINE AND GROSS MOTOR SKILLS
-  ANXIETY DISORDERS
-  DEPRESSION
-  MANIA
-  OBSESSIVE COMPULSIVE DISORDER
-  PSYCHOTIC DISORDERS
-  EATING DISORDERS
-  SLEEPING ISSUES
-  ATTENTION ISSUES
-  EPILEPSY OR SEIZURE DISORDERS
-  GASTROINTESTINAL ISSUES
-  LANGUAGE DELAY
-  CHALLENGES WITH FINE AND GROSS MOTOR SKILLS

Spectrum | Autism Research News  
<https://www.spectrumnews.org>

NEWS  
Largest study to date confirms overlap between autism and gender diversity  
BY LAURA DATTARO  
14 SEPTEMBER 2020

People who do not identify with the sex they were assigned at birth are three to six times as likely to be autistic as cisgender people are, according to the largest study yet to examine the connection<sup>1</sup>. Gender-diverse people are also more likely to report autism traits and to suspect they have undiagnosed autism.

# COMMUNICATION DIFFERENCES

**Verbal communication:** May be verbal or non-verbal

Talking volume, tone or inflection may be atypical

May talk too much.. or not enough (difficulty with back and forth conversation)

**Non-verbal communication:** Eye contact may or may not be typical

Difficulty picking up on or difference in expressing body language and facial expressions

**Processing:** May need more time to process questions

May prefer written information

**\*\*\*If in doubt - ask what they need\*\*\***

# SENSORY DIFFERENCES

**HYPER- OR HYPO-SENSITIVITY ==>**

**SENSORY SEEKING or SENSORY AVOIDING**

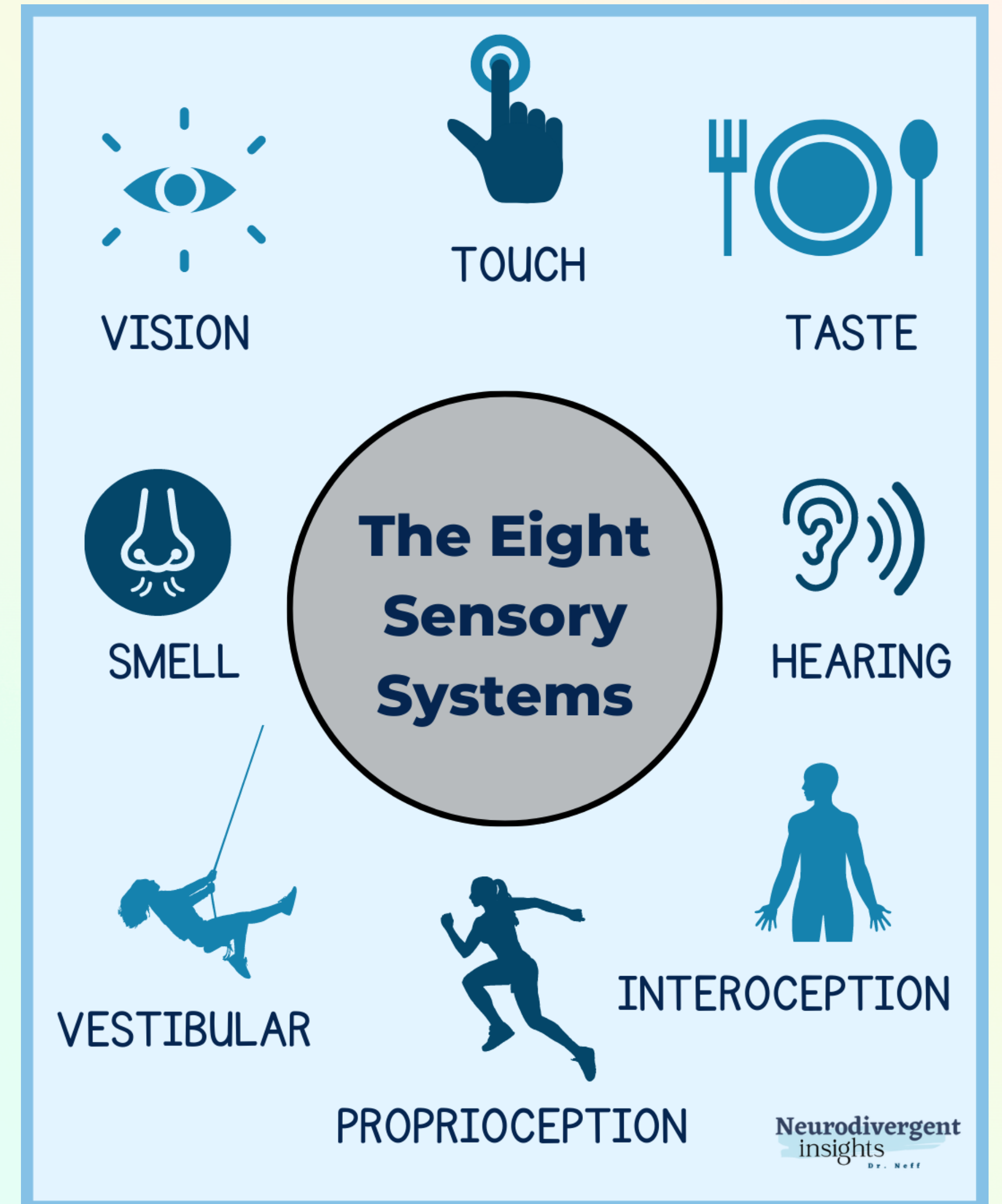
**> 5 senses including:**

*\* proprioception: body position sense*

*\* vestibular: balance/motion*

*\* interoception: understanding body sensations  
(alexithymia: difficulty feeling, understanding or  
expressing emotions)*

**May be sensory avoidant and sensory seeking within  
same sense (eg noise/music)**





## Intro: Invisibly different

You walk out of the aeroplane via the jet bridge. For the past ten hours, you've been sitting in a cramped seat, eating an undefinable meal and watching *Kung Fu Panda* because you didn't have anything better to do anyway. You wanted to sleep, but thanks to the baby three seats down that was only a partial success. Now you're here, on the other side of the world. Billboards are calling out incomprehensible messages and even the bathroom is something to behold with its thousands of buttons, bells and whistles. The musical note produces a noise that vaguely resembles cascading water and what you thought was the flush button turned out to be the setting to wash your bottom. A lukewarm trickle sprays upwards. Eew.

Past customs you're being picked up. You hold out your hand, but the person in front of you doesn't take it. Instead, he bows. You try to make eye contact, but the man in uniform merely looks down. Just as you're about to open the taxi door, it opens by itself. From the back seat you look out the window covered in stickers, past the blaring television screen at the back of the headrest of the seat in front of you.

There are neon billboards everywhere. "Nihon e yokoso!", the driver says. Silence. The driver thinks for a second and then says, "Werukomu tsu Djapan!"

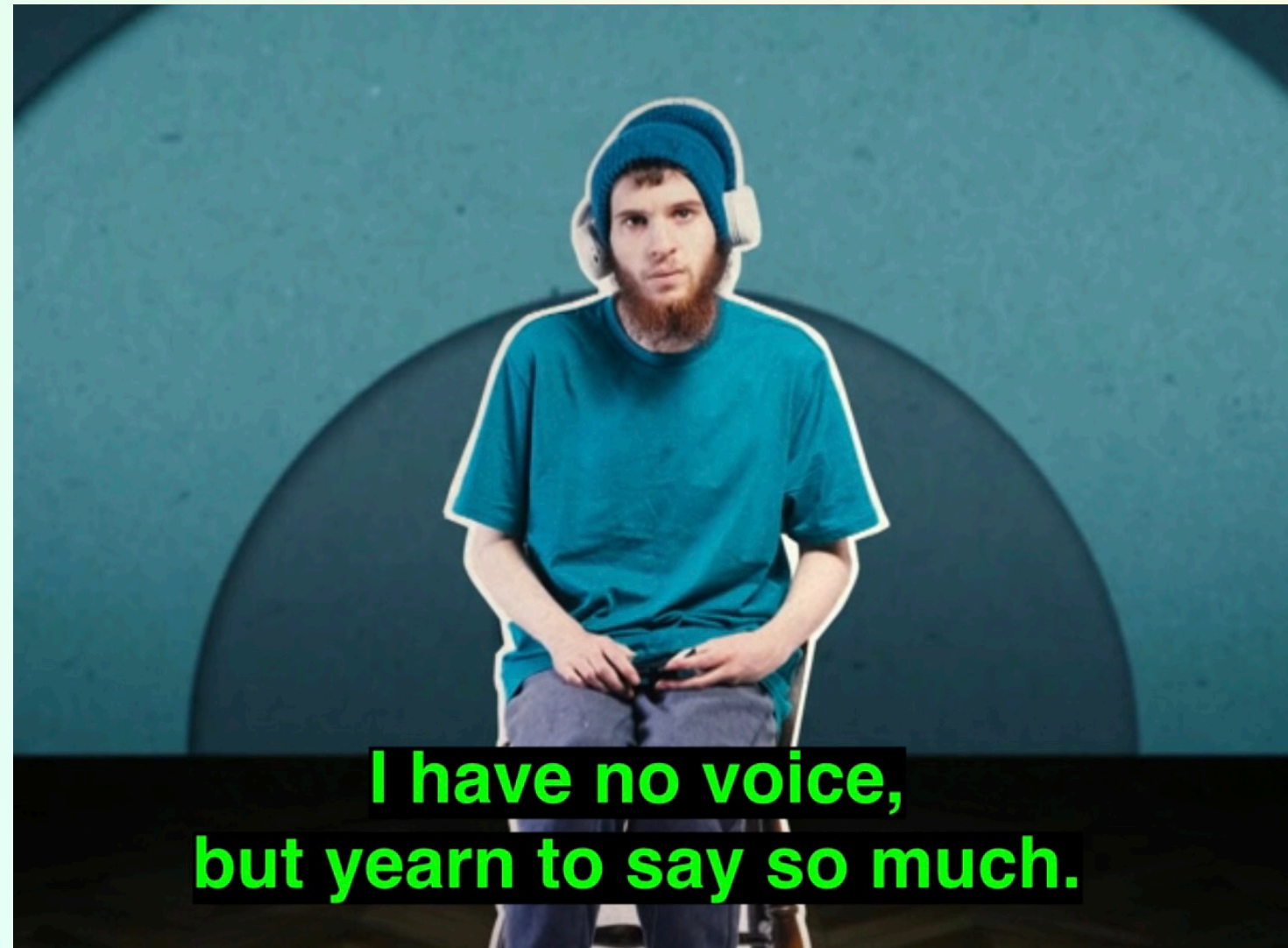
Within thirty minutes, you've probably broken dozens of social rules. You feel like an alien, like a bull in a proverbial china shop. You're tired and overstimulated because of all the signals that are fired at you. Signals you don't understand most of the time. Your saving grace: you're a foreigner. You're clearly not Japanese, so nobody blames you for your mistakes.

But what if you do look Japanese? Ah, different story.

That's what autism feels like to me.

Autism, that's what I have.<sup>1</sup> You can't tell from the outside. So when I tell people about it, that's what I hear all the time: "But... you don't look autistic at all!"

# PERSPECTIVES



**Bianca Toeps:  
introduction  
to book 'But  
You Don't  
Look Autistic  
At All'**

**Account from Murray,  
non-verbal adult from  
BBC documentary  
'Inside our Autistic  
Minds' with Chris  
Packham**

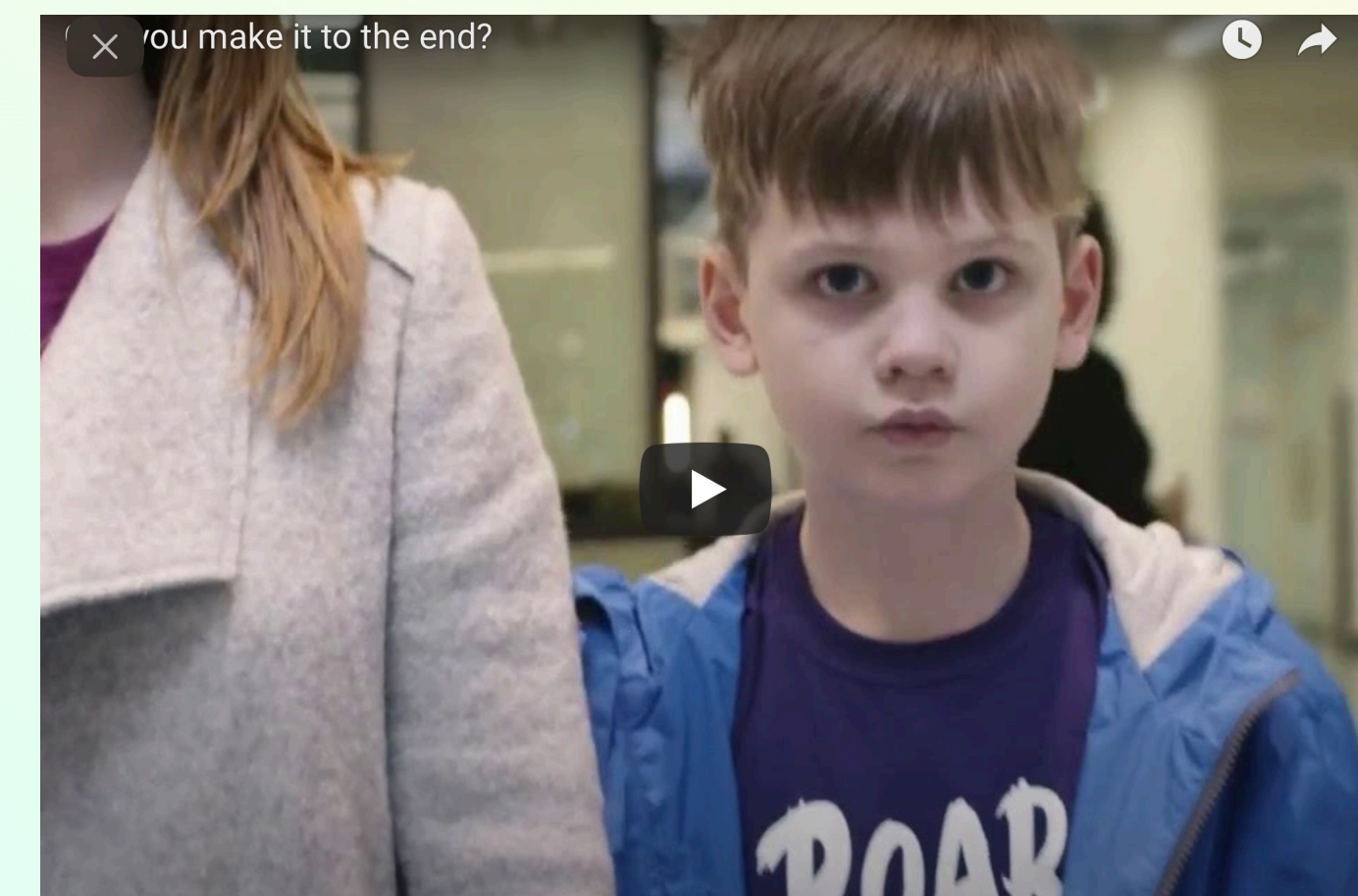
<https://www.youtube.com/watch?v=aPknwW8mPAM>

**From: National Autistic Society by 11 year old Alex Marshall**

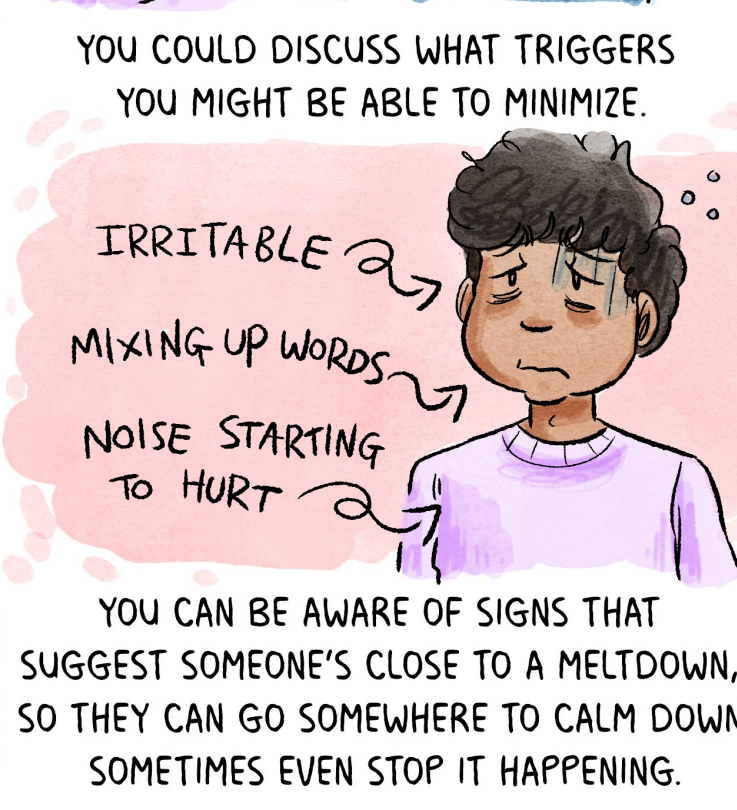
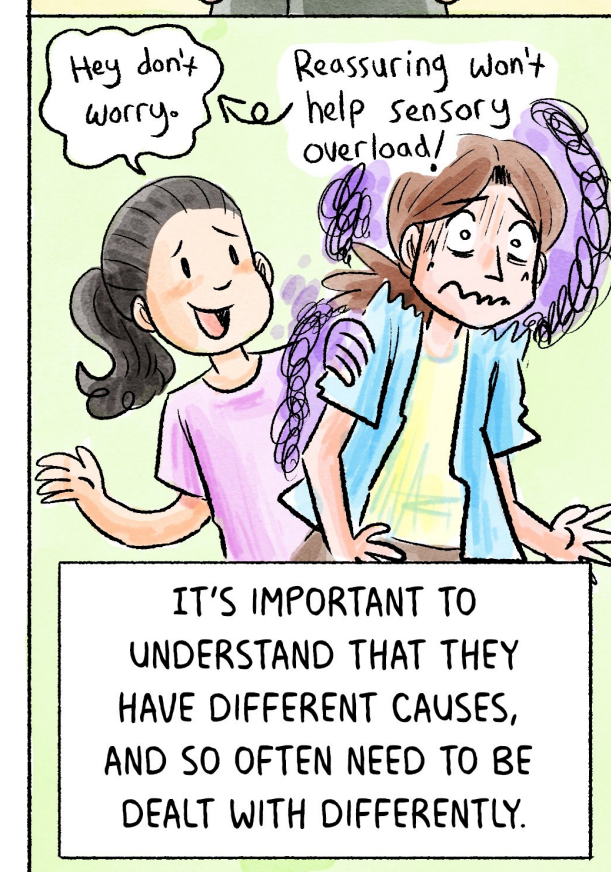
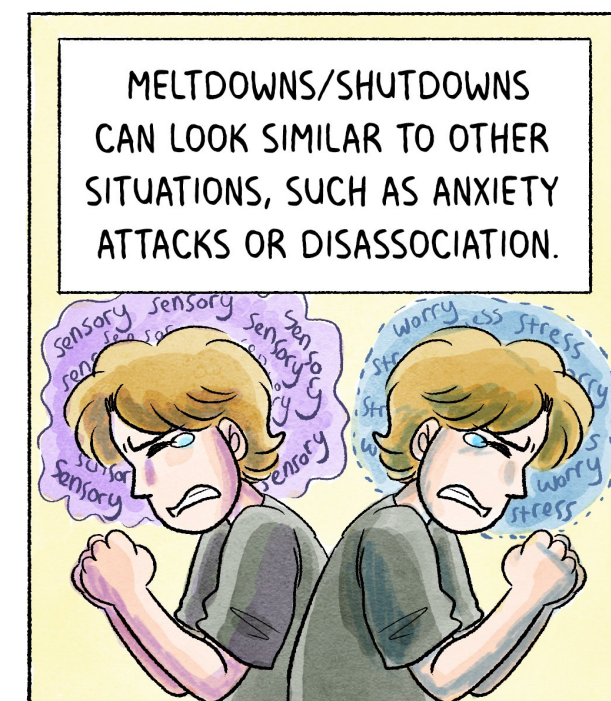
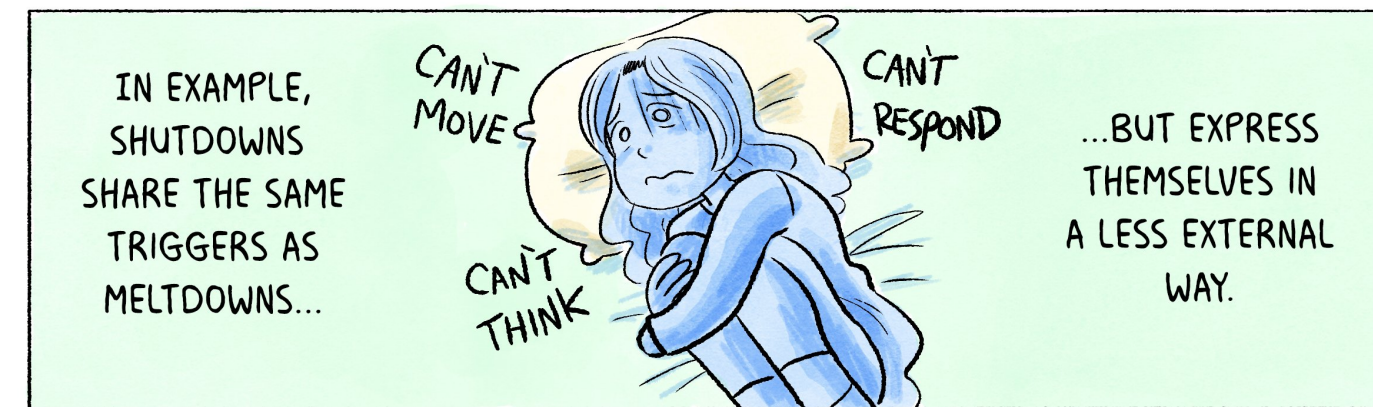
**Consider:**

**Child/Mother/Onlookers**

**Same child in GP / hospital waiting room**



# MELTDOWN/SHUTDOWN



## Important points:

1. A meltdown is **NOT** a tantrum, not something which can be controlled
2. Behaviour is communication - ask what is the reason?
3. Merely trying to 'fix' behaviours can have serious consequences

# STRESS AND ANXIETY

More likely to have had trauma/adverse experiences

Being misunderstood, bullied, not accepted

Hostile sensory environment

Resistance to change / reliance on routines can be a way of managing anxiety

Stimming



# MASKING

When an autistic person consciously or unconsciously hides their differences in an attempt to fit in

Girls can often be better at masking and present later

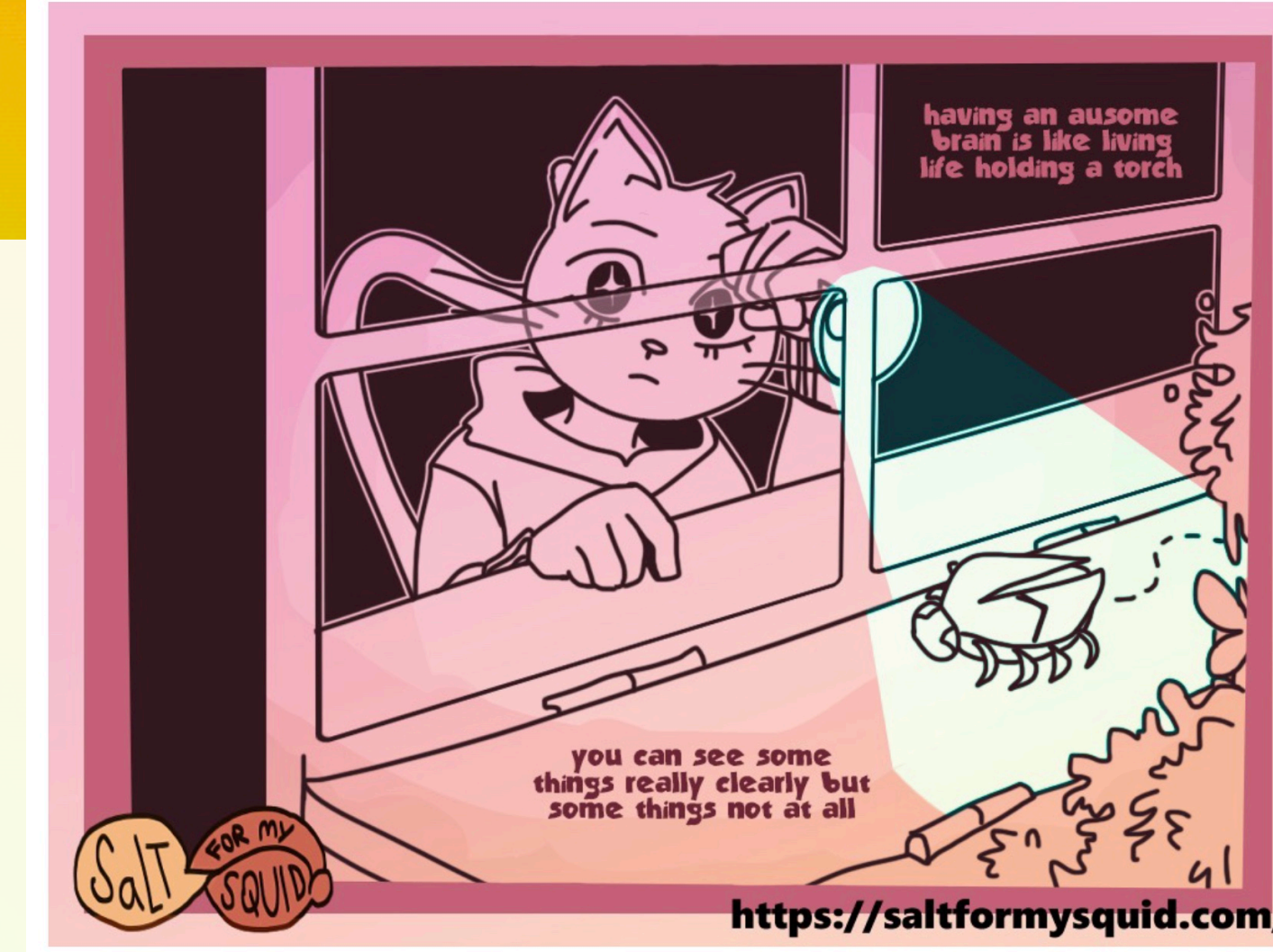
Exhausting and can be harmful

May present as meltdowns eg after masking all day at school

Sometimes this is not believed by others or attributed to bad parenting



# SPECIAL INTERESTS



**Hyperfocus on single interest (Monotropism (3))**

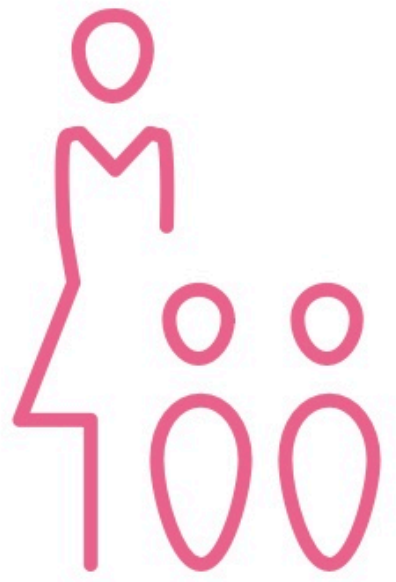
**Can be very reassuring for autistic person to talk about**

**Difficulty shifting attention**

**Can become hyper-specialised in certain area  
'prodigy' or 'expert'**

**May become useful for career or not (autistic people actually have very low levels of employment)**

# MENTAL HEALTH



28 x more likely

Children with autism are 28 times more likely to think about or attempt suicide

Up to 66% of autistic adults have considered suicide

Up to 35% autistic adults have planned or attempted suicide



9 x more likely

Autistic adults who do not have a learning disability are 9 times more likely to die from suicide

(See references 4, 5, 6)

<https://www.autistica.org.uk/what-is-autism/signs-and-symptoms/suicide-and-autism>

# PHYSICAL HEALTH

Swedish study (BJP, 2016) which compared autistic people with matched controls:

- **Average life expectancy 16 years younger (age 54) compared to control group (70)**
- **Autism plus LD average of 30 years younger (age 39.5), most common cause = epilepsy**
- **Autism without LD died on average aged 58, most common cause = suicide**
- **Significantly elevated mortality of all causes except infections (including nervous system, circulatory, endocrine disease)**

## Premature mortality in autism spectrum disorder

Tatja Hirvikoski, Ellenor Mittendorfer-Rutz, Marcus Boman, Henrik Larsson, Paul Lichtenstein and Sven Bölte

### Background

Mortality has been suggested to be increased in autism spectrum disorder (ASD).

### Aims

To examine both all-cause and cause-specific mortality in ASD, as well as investigate moderating role of gender and intellectual ability.

### Method

Odds ratios (ORs) were calculated for a population-based cohort of ASD probands ( $n=27\,122$ , diagnosed between 1987 and 2009) compared with gender-, age- and county of residence-matched controls ( $n=2\,672\,185$ ).

### Results

During the observed period, 24 358 (0.91%) individuals in the

general population died, whereas the corresponding figure for individuals with ASD was 706 (2.60%; OR=2.56; 95% CI 2.38–2.76). Cause-specific analyses showed elevated mortality in ASD for almost all analysed diagnostic categories. Mortality and patterns for cause-specific mortality were partly moderated by gender and general intellectual ability.

### Conclusions

Premature mortality was markedly increased in ASD owing to a multitude of medical conditions.

### Declaration of interest

None.

### Copyright and usage

© The Royal College of Psychiatrists 2016.

# WHY?

**Multi-factorial but access to healthcare is a big factor**

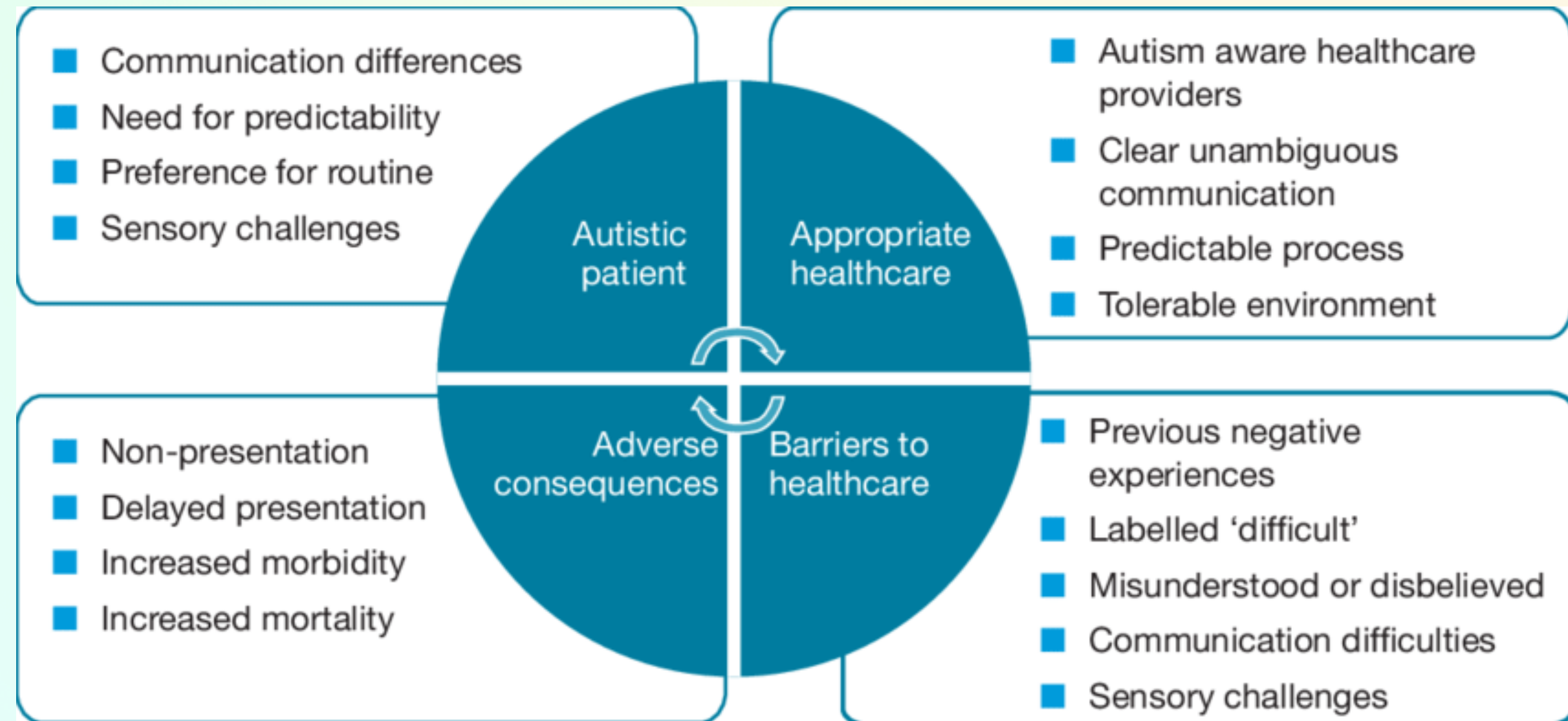
**Survey in 2022 (BMJ) found 80% autistic adults reported difficulty visiting a GP - reasons included:**

- **difficulty booking**
- **not feeling understood**
- **sensory challenges,**
- **communication difficulty**
- **organisation challenges (7)**

<https://undercoverautism.org/2022/12/17/autism-does-not-reduce-your-life-expectancy-being-autistic-does/>

## Autism does NOT reduce your life expectancy – being Autistic does...

This is an issue of equality, not biology or neurology. The life expectancy of autistic people is devastatingly low – yet it shouldn't be.



[https://www.researchgate.net/profile/Ian-Davidson-7/publication/356888831\\_Autism\\_making\\_reasonable\\_adjustments\\_in\\_healthcare/links/61c067fe4b318a6970f43793/Autism-making-reasonable-adjustments-in-healthcare.pdf?origin=publication\\_detail](https://www.researchgate.net/profile/Ian-Davidson-7/publication/356888831_Autism_making_reasonable_adjustments_in_healthcare/links/61c067fe4b318a6970f43793/Autism-making-reasonable-adjustments-in-healthcare.pdf?origin=publication_detail)

# HOW CAN WE HELP?

## APPOINTMENTS:

Identification/health passports

Support with booking

Extra time for appointments

Adjusted timings eg when quieter

Consider proactive healthcare

Offer written information if wanted

Distractions for procedures

## ENVIRONMENTAL:

Think about sensory environment

Quiet room to wait if needed, or able to wait outside and be phoned to come in

Distractions such as TV screen, toys

### Autism: making reasonable adjustments in healthcare

#### Abstract

The accompanying article set out why it is important to identify autistic people and the negative consequences of not recognising or understanding autism, including more severe illness and premature death. This article sets out what clinicians can do to help reduce those negative consequences by making 'reasonable adjustments' in any healthcare service in which they work.

**Key words:** Autism; Autistic; Integrated Care; Mental health; Physical health; Reasonable adjustments

Submitted: 26 May 2021; accepted following double-blind peer review: 31 August 2021

Clair Haydon<sup>1</sup>

Mary Doherty<sup>2</sup>

Ian A Davidson<sup>3</sup>

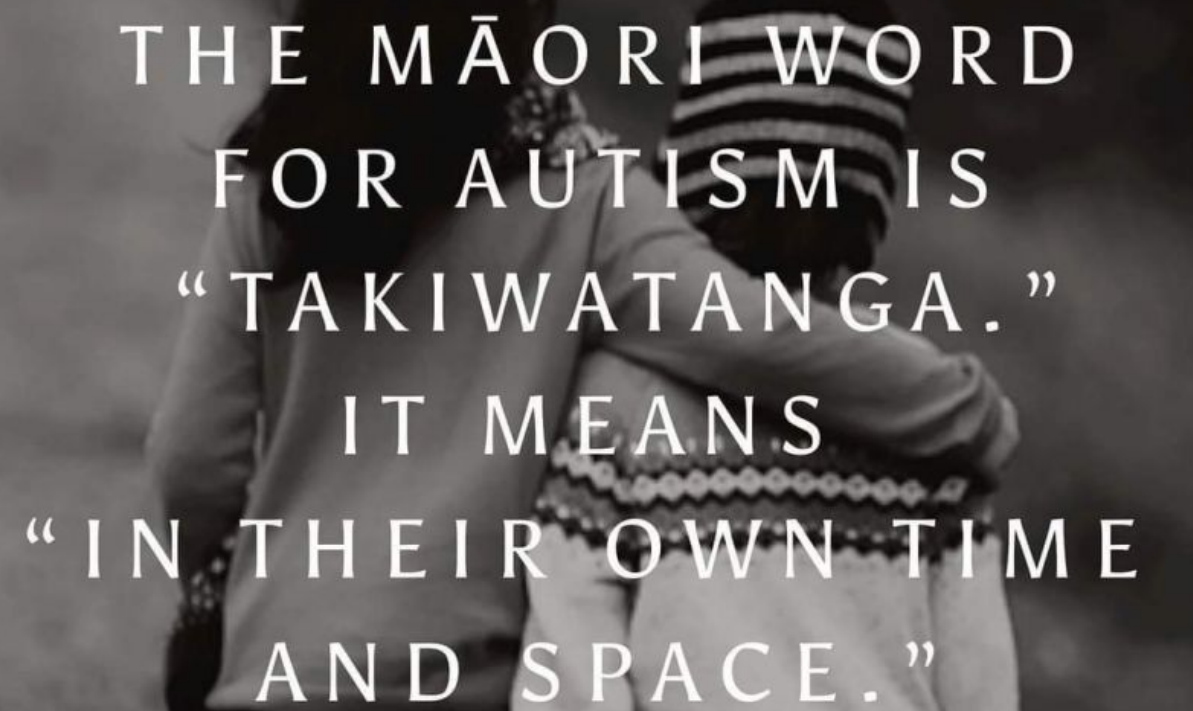
Author details can be found at the end of this article

Correspondence to:  
Ian A Davidson;  
ian.davidson11@nhs.net



# LANGUAGE WE USE

Negative	Non-judgemental
Deficit, impairment, disorder	Difference
Restricted interests	Focused interests/passions
Talking about 'Cure' for autism or 'suffering' from autism	Autism is part of identity not a disease
High/low functioning, levels, mild/severe	Describe support needs in different situations



THE MĀORI WORD  
FOR AUTISM IS  
“TAKIWATANGA.”  
IT MEANS  
“IN THEIR OWN TIME  
AND SPACE.”

[https://www.linkedin.com/  
posts/  
amandalynngray\\_image-  
description-the-maori-  
word-for-autism-  
activity-702054084299816  
9600-WIZx](https://www.linkedin.com/posts/amandalynngray_image-description-the-maori-word-for-autism-activity-7020540842998169600-WIZx)

# **DIAGNOSIS** in Ealing:

## **Children:**

**Age 5 and under or 6+ with a Learning Disability - via Community Paediatrics**

**Age 6-17 without a Learning Disability- via CAMHS Neurodevelopmental Service**

**Decision support flowchart: [https://www.nwlondonicb.nhs.uk/application/files/6516/8736/1492/Autism\\_Spectrum\\_Disorder\\_ASD\\_-\\_April\\_2023.pdf](https://www.nwlondonicb.nhs.uk/application/files/6516/8736/1492/Autism_Spectrum_Disorder_ASD_-_April_2023.pdf)**

## **Adults:**

**Via Ealing Adult Autism Assessment Service (EAAAS): <https://www.westlondon.nhs.uk/our-services/adult/ealing-community-partners/adult-services/psychological-medicine-support/ealing-adult-autism-assessment-service>**

.....

**Both can have long waiting lists, up to 2 years**

**Generally discharged after diagnosis as there is no medication, so support from schools/community is most important ongoing**

# LOCAL AND NATIONAL ORGANISATIONS

**Ealing Community Partners (Includes child development team, community paediatrics, OT, PT, SALT, social communication assessment):** <https://www.westlondon.nhs.uk/our-services/adult/ealing-community-partners/childrens-services>

**Social Communication Assessment in Ealing:** <https://www.westlondon.nhs.uk/our-services/adult/ealing-community-partners/childrens-services/social-communication-assessment>

**West London CAMHS:** <https://www.westlondon.nhs.uk/our-services/child-and-adolescent/camhs/how-we-help/treatments>

**ASD and ADHD decision support flowcharts:** <https://www.nwlondonicb.nhs.uk/professionals/children-and-young-people/mental-health/navigate/6906/7817#ccm-block-document-library-6906>

**West London Neurodevelopment Team (leaflet about referral pathways):** [https://www.westlondon.nhs.uk/application/files/4916/3550/1704/Ealing\\_CAMHS\\_Referral\\_leaflet\\_260821\\_-\\_Copy\\_1.pdf](https://www.westlondon.nhs.uk/application/files/4916/3550/1704/Ealing_CAMHS_Referral_leaflet_260821_-_Copy_1.pdf)

**Centre for ADHD and Autism Support:** <https://adhdandautism.org>

**Ealing Autism Hub:** <https://www.westlondon.nhs.uk/our-services/adult/ealing-community-partners/referral-hub/ealing-autism-hub>

**Contact Ealing / Helping Hands including autism group/sessions:** [https://www.ealingfamiliesdirectory.org.uk/kb5/ealing/directory/service.page?id=Ah\\_K2KokCl4](https://www.ealingfamiliesdirectory.org.uk/kb5/ealing/directory/service.page?id=Ah_K2KokCl4)

**Ealing Best for You (local support services):** <https://bestforyou.org.uk/mental-health-support-in-ealing>

**The Circle: Mental Health Cafe for young people including up to age 25 with neurodiversity:** <https://www.hfehmind.org.uk/get-support/service-for-schools/support-for-children-young-people/circle/>

**Mental Health Support Teams in Schools (covers 90% Ealing schools):** <https://www.westlondon.nhs.uk/our-services/child-and-adolescent/camhs/school-support/ealing-mental-health-support-team>

**WYSA (Chatbot offering emotional support to 13-18yo):** <https://www.hfehmind.org.uk/get-support/service-for-schools/support-for-children-young-people/wysa/>

**Safe Evolve (early therapeutic intervention for mental health needs):** <https://www.egfl.org.uk/services-to-schools/safe-evolve-202425>

**Healthy Child Resources by age:** <https://www.nwlondonicb.nhs.uk/professionals/children-and-young-people/guidelinesresources>

**Ealing Local Offer (services for young people 0-25 with SEND):** <https://www.ealingfamiliesdirectory.org.uk/kb5/ealing/directory/localoffer.page?localofferchannel=0>

**Ealing SENDIASS:** Information and support up to age 25 including with EHCP process: <https://www.ealingsendiass.org.uk>

**Sikh Neurodiversity Network:** <https://shrg.ngo/neurodiversity-network/>

**Resources for autism (London and W Midlands):** <https://www.resourcesforautism.org.uk>

**National autistic society:** <https://www.autism.org.uk>

**Autistic girls' network:** <https://autisticgirlsnetwork.org/keeping-it-all-inside.pdf?fbclid=IwAR2rS14p1beFhStg3X5xhogP78LAVGP E0l8cyfsmANkJeCXjIG3e2HKWZhA>

# CPD/FURTHER READING

## DOCUMENTARIES

Christine McGuinness: unmasking my autism

Christine and Paddy McGuinness: Our Family and Autism

Inside our Autistic Minds (with Chris Packham)

The Walk that Made Me (Chris Packham)

Are You Autistic? (channel 4)

Just add water documentary (surfing)

## TV SERIES

A Kind of Spark - Elle McNichol (CBBC) - about a young autistic girl

The Good Doctor - about an autistic doctor

## BOOKS FOR CHILDREN

A Different Sort of Normal - Abigail Balfe

Frankie's World/Finding my Voice - Aoife Dooley

Different Like Me - my book of autism heroes

The Boy Who Dreamed of Infinity - Alznauer/Miyares

My Mixed Emotions - DK books

Ways to be me/Can you see me/ Do you know me/All the Pieces of me - Libby Scott

The Panda on PDA

Wired Differently - Joe Wells

## BOOKS FOR ADULTS

Funny, you don't look autistic - Michael McReary \* also suitable for older children but with PG - some swear words

But you don't look autistic at all - Bianca Toeps

The Autistic Brain - Temple Grandin

Thinking in pictures - Temple Grandin

How to Raise a Happy Autistic Child - Jessie Hewiston

Unmasking Autism - Dr Devon Price

Un-Typical - Pete Wharmby

Taking off the Mask - Dr Hannah Louise Belcher

The Electricity of Every Living Thing - Katherine May

Wintering - Katherine May

Marching to a Different Beat - Sarah Ziegel

Sincerely, your autistic child - edited by Ballou, daVanport, Onaiwu

The Reason I Jump - Naoshi Higashida/David Mitchell

Different, not Less - Chloe Hayden

The Educator's Experience of Pathological Demand Avoidance - Laura Kerbey/Eliza Fricker

Can't not won't - Eliza Fricker

Avoiding anxiety in autistic children - Dr Luke Beardon

A different way to learn - Naomi Fisher

Extremely Loud and Incredibly Close - Jonathan Safran (book and film)

# REFERENCES

1. <https://www.bma.org.uk/what-we-do/population-health/improving-the-health-of-specific-groups/autism-spectrum-disorder#:~:text=It%20is%20estimated%20that%20around,diagnosis%20of%20autism%20spectrum%20disorder>
2. <https://happiful.com/half-of-undiagnosed-autistic-adults-could-be-women>
3. <https://journals.sagepub.com/doi/epdf/10.1177/1362361305051398>
4. <https://www.sciencedirect.com/science/article/pii/S1750946712000931>
5. <https://link.springer.com/article/10.1007/s40474-018-0133-6>
6. <https://www.cambridge.org/core/services/aop-cambridge-core/content/view/4C9260DB64DFC29AF945D32D1C15E8F2/S0007125000279385a.pdf/premature-mortality-in-autism-spectrum-disorder.pdf>
7. <https://bmjopen.bmj.com/content/bmjopen/12/2/e056904.full.pdf>

Autistica Report on mortality in autism: <https://www.autistica.org.uk/downloads/files/Personal-tragedies-public-crisis-ONLINE.pdf#asset:1499>

**THANK YOU**