



Tuesdays with Nexus:

Autism Spectrum Disorder and Substance use disorders – the hidden comorbidity

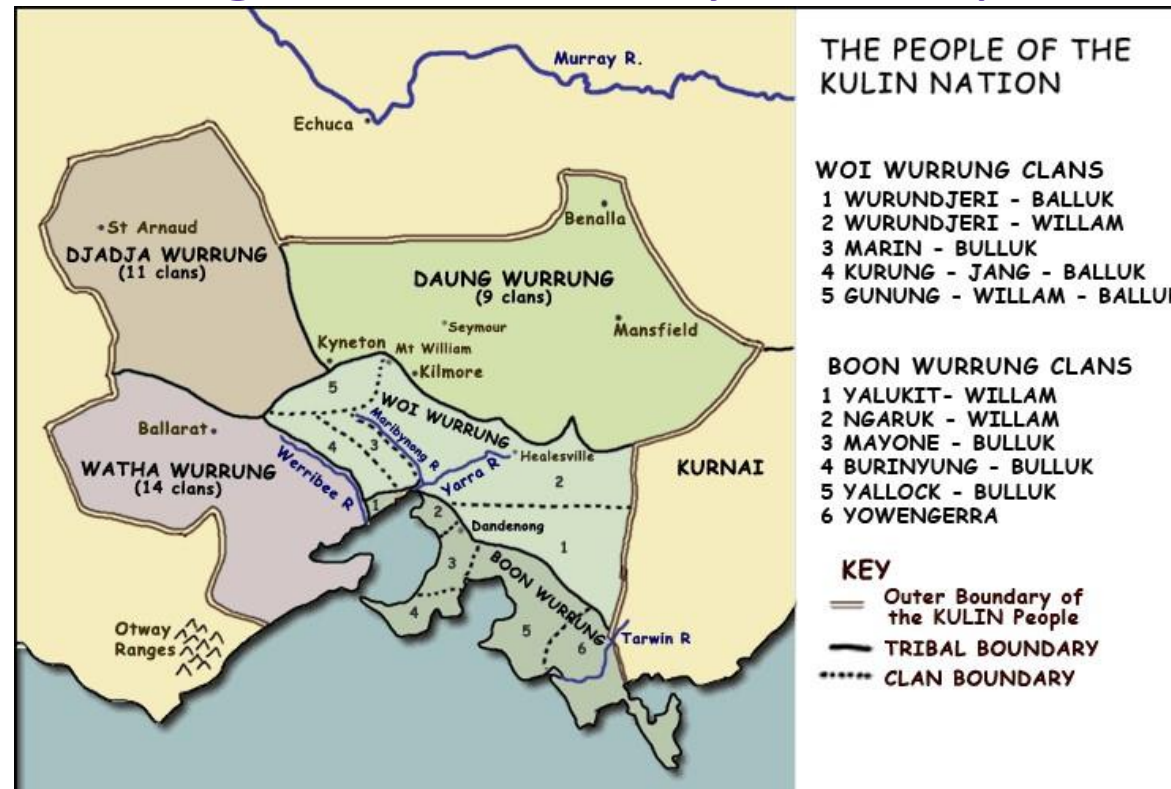
Kah-Seong Loke,
Consultant Psychiatrist, Nexus

Tuesday 27/6/2023 – 9.30 am



Acknowledgement of Country

We respectfully acknowledge the Traditional custodians of the land on which we meet today, the Wurundjeri people of the Kulin Nation, and we pay respect to all Aboriginal Community Elders, past and present.



Terminology & Language

Leo Kanner – ‘Autistic Disturbances of Affective Contact’ (1943)

DSM-5 (2013) – consolidation of autistic disorder, Asperger's disorder, and pervasive developmental disorder into autism spectrum disorder

Person-first language ("a person with autism," "a person with diabetes")

Identity-first language ("an autistic person," "autistics") – some research found the majority of the autistic community prefers identity-first language

Neurodiverse / Neurodivergent vs Neurotypical

Neurodiversity affirming / Neuroaffirming

Stimming (self-stimulatory behaviour) – repetitive or unusual body movement or noises in response to positive and negative emotions

Less favoured terms

Asperger's disorder – 'autistic psychopaths' in 1938 [Nazi Austria] ; “cooperated extensively with the Nazi regime and may have sent dozens of children to their deaths.” [eugenics, euthanasia].

Aspies(?)

High/Low-functioning autism

What is Autism Spectrum Disorder?

ASD – a lifelong neurodevelopmental condition with childhood-onset

Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, Text Revision (DSM-5-TR)

The *essential features* of autism spectrum disorder are:

- (A) persistent impairment in reciprocal social communication and social interaction, and
- (B) restricted, repetitive patterns of behavior, interests, or activities.

These symptoms are present from early childhood and limit or impair everyday functioning (Criteria C and D).

DSM-5 – language is medical, deficit-based (like NDIS, DSP)

Autism affects everyone differently

Traits bring both strengths and challenges (depending on context, life stage, etc.)

Common thread: Felt different to other people / Difficulty fitting in (when growing up)

Diagnostic criteria for Autism Spectrum Disorder (1/3)

<p>Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, Text Revision (DSM-5-TR). Edited by: American Psychiatric Association, 2022</p> <p>https://dsm.psychiatryonline.org/doi/book/10.1176/appi.books.9780890425787</p>	<p>The DSM diagnostic criteria written from a Neurodiversity perspective Yenn Purkis, 2022</p> <p>https://yennpurkis.home.blog/2022/06/11/the-dsm-diagnostic-criteria-written-from-a-neurodiversity-perspective/</p>
<p>A. Persistent deficits in social communication and interaction across multiple contexts, as manifested by all of the following (currently or by history):</p>	<p>A (Awesome). Different ways of communicating and relating to others.</p>
<p>1. Deficits in social-emotional reciprocity</p>	<p>Different ways of relating and experiencing emotions</p>
<p>2. Deficits in nonverbal communication behaviours used for social interaction</p>	<p>Interacting in different ways.</p>
<p>3. Deficits in developing, maintaining, and understanding relationships</p>	<p>Approaching relationships differently to non-Autistic people</p>

Diagnostic criteria for Autism Spectrum Disorder (2/3)

B. Restrictive, repetitive patterns of behaviour, interests or activities, as manifested by at least two of the following, currently or by history:	B (Beautiful) May be experts in a particular area, have a strong focus, passion and determination [resulting in a great sense of joy and satisfaction]
1. Stereotyped or repetitive motor movements, use of objects, or speech	Innovative and imaginative use of objects. Creativity.
2. Insistence on sameness, inflexible adherence to routines, or ritualised patterns of verbal or nonverbal behaviour	The ability to follow a schedule. Seeing patterns in things. [police investigator, mathematician or climate scientist]
3. Highly restricted, fixated interests that are abnormal in intensity or focus	Passionate engagement in a particular interest. As life progresses, Autists can develop a huge general knowledge based on all the topics they may have been interested in. [university professor; interests as a self-soothing tool when depressed or anxious]
4. Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment	Exceptional, accurate and perceptive sensory skills. [catering, viticulture]

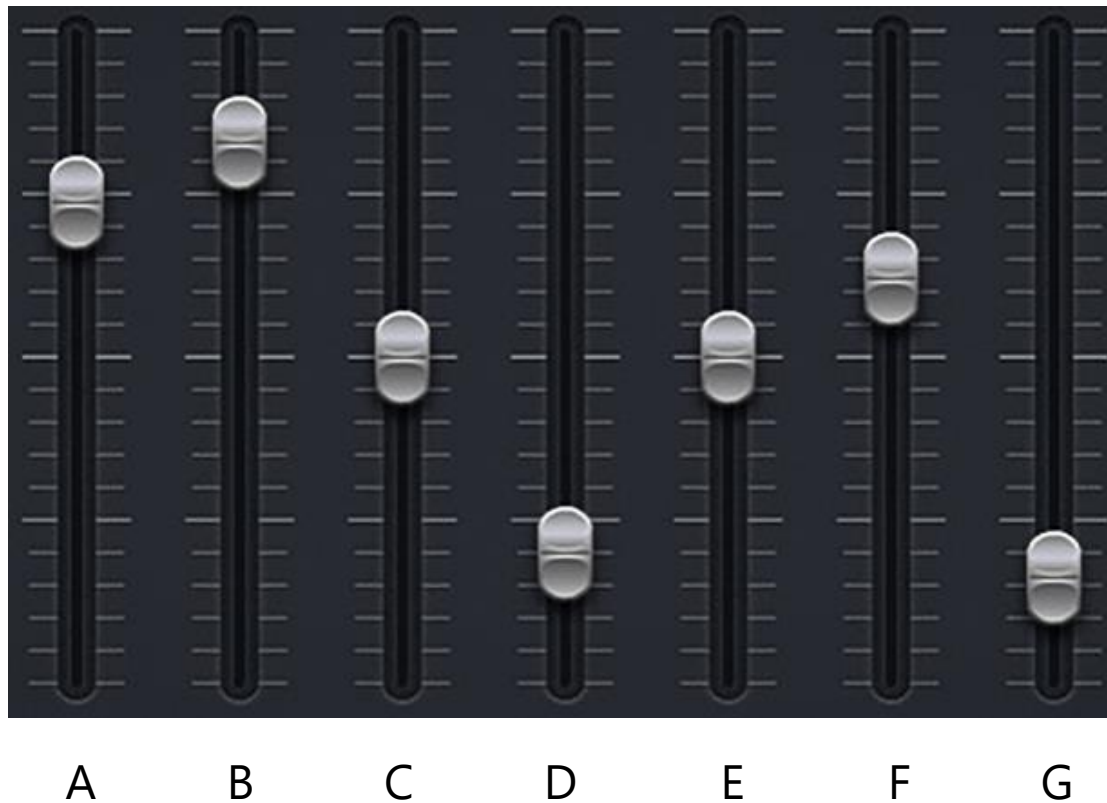
Diagnostic criteria for Autism Spectrum Disorder (3/3)

C. Symptoms must <u>be present in the early developmental period</u> (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).	C (Curious and Clever) Young children may be quirky, smart and individual. As they grow older, the world can dampen their amazing spirit but do not be disheartened as Autistic people are often wonderfully resilient and resourceful.
D. Symptoms cause <u>clinically significant distress or impairment in social, occupational, or other important areas of current functioning</u> .	D (Diverse) The weight of a world which often does not value or respect Autistic people can mean that they struggle to navigate life. This is not due to their inherent deficiencies, rather it is mostly a result of societies focus on some arbitrary 'norm'. With the right support, understanding and self-confidence, Autistic people can rise above this and be their best 'them'. This is an area for further work.
E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay.	E (Exceptional) Autistic people are Autistic people. They are amazing as is and defy this sort of diagnostic negativity through their brilliance.

Autism affects everyone differently – no two people with ASD are the same; every person with ASD is unique

"If you know one person with autism, you only know one person with autism"

"Autistic traits can be seen as normal human traits but expressed with a particular intensity and frequency."*



A – Mathematical skills

B – Empathy

C – Spelling

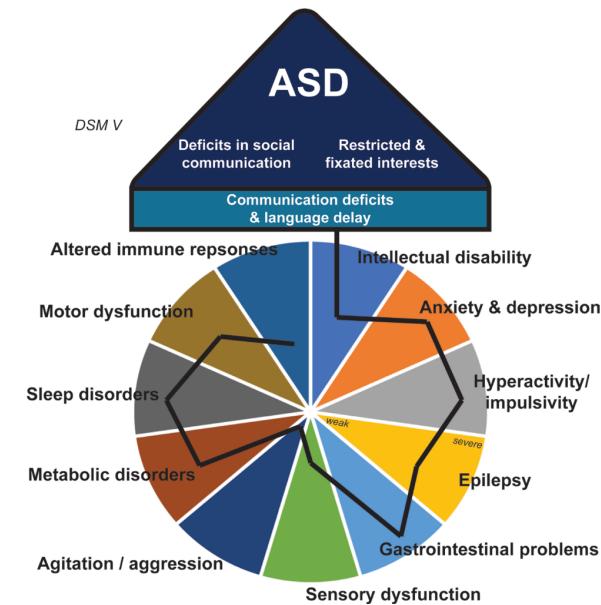
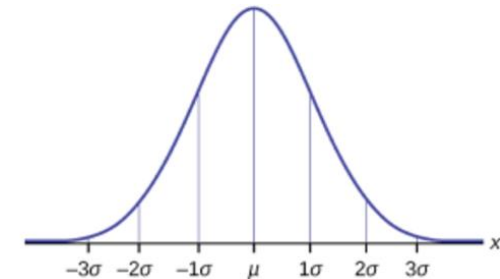
D – Full scale IQ

E – Sensitivity to noise

F – Sensitivity to light

G – Social skills

etc., etc.



*Mindful Adult Autism Introductory course

Why is ASD often missed/overlooked?

- Subtler manifestation of social and communication difficulties in girls / ASD seen as a male disorder
- Typical for **learning and compensation** to continue throughout life.
Symptoms may be masked by learned compensation strategies and coping mechanisms in later life
- May find a niche that matches their special interests and skills ⇒ masks other functional deficits
- Health/social interventions as well as current supports, may **mask** these difficulties (in some areas).
- ASD deficits become more apparent when: social demands exceed limited capacities, loss of supports, comorbid conditions develop/worsen (incl. SUD)
- Diagnostic overshadowing: occurs when the salience of one disorder (e.g., intellectual disability, BPD) 'overshadows' consideration or recognition of another disorder, with all symptoms being attributed to the primary disorder
- Overlapping symptoms: symptoms that commonly occur during the course of two or more distinct disorders



Autistic traits & Broader autism phenotype

Broader autism phenotype

- presence of milder autism-related language, cognitive and personality traits in undiagnosed family members of individuals with autism spectrum disorder (ASD)
- most common finding is mild impairments in social and communication skills that are similar to those shown by individuals with autism, but less prominent
- more often in male than female relatives
- grandparents, aunt/uncles, and first cousins of individuals with ASD
- Clinically relevant with treatment planning (family dynamics, parental issues) – *Family inclusive practice*

Nat Genet. 2016 May ; 48(5): 552–555. doi:10.1038/ng.3529.

Genetic risk for autism spectrum disorders and neuropsychiatric variation in the general population

... “Everyone Is a Little Autistic” “Everyone is on the Spectrum” ...

Subclinical – do *not* cause “...clinically significant distress or impairment in social, occupational, or other important areas of functioning”

Diagnosis in Adults

• Screening

- “No single score on any [of our] tests or questionnaires indicates that an individual is autistic. Diagnosis is made on the basis of a clinical assessment including using clinical judgement.”
- Ritvo Autism Asperger Diagnostic Scale–Revised (RAADS–R)
- Autism Spectrum Quotient (AQ), Empathy Quotient (EQ), Relatives Questionnaire (RQ)
- <https://www.autismresearchcentre.com/tests/>
- <https://embrace-autism.com/autism-tests/>
- <https://www.aspietests.org/>

• Diagnosis

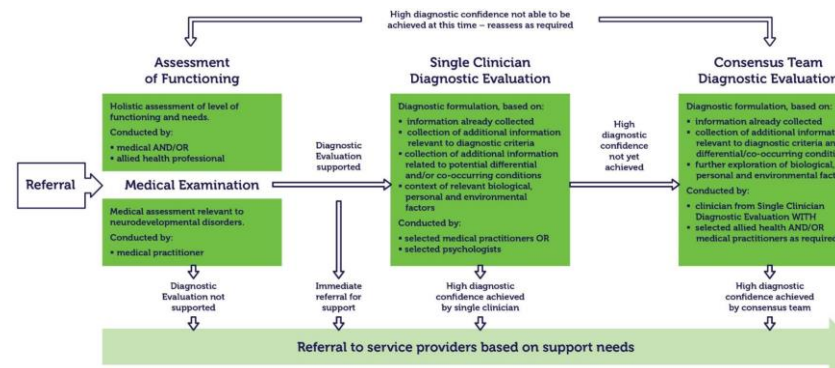
- [DSM-5-TR](#), [ICD-11](#)
- Autism Diagnostic Observation Schedule – 2nd ed. (ADOS-2) Module 4 (for adolescents and adults with fluent language ability)
- [Royal College of Psychiatrists \(UK\) Diagnostic Interview Guide for the Assessment of Adults with Autism Spectrum Disorder](#)

• Collateral Hx

- Parents

• Comorbidity Screening

Assessment	Examples of standardised assessment instruments
Developmental surveillance • At every health visit (eg, immunisation and routine checkups), observe communication, interaction, and behaviour and ask if there are any concerns. • Monitor development over time	Developmental screeners: CREDI*, GMCD*, ASQ, PEDS, MDAT*, TQSP*, ITC* Emotional and behavioural screeners: SDQ*, ASEBA* ASD screeners: M-CHAT*, PAAAS*, TIDOS*, SCQ*, SRS1, AQ1*
Brief needs assessment • Ask the family open questions about their support needs and resources • Brief assessment of the individual's strengths, challenges, and needs	Brief screening: SDQ with Impact Supplement*, WHODAS*, ASEBA* More specific screening or comprehensive assessment: VABS1, ABAS1, CAR1
In-depth (diagnostic) assessment Estimate level of verbal and non-verbal development • Apply at least one verbal and one non-verbal problem-solving test from a cognitive or developmental assessment Estimate level of language functioning • Observe and ask caregivers about complexity of speech (eg, few to no words, some words up to simple phrases, flexible phrases, or fluent) Assess ASD signs by history and in current daily life • Gather information from parents or other caregivers • If possible, gather information from multiple settings (eg, home and school) Assess ASD signs by observational assessment • Directly observe and interact with the individual in structured and unstructured interactive activities appropriate to developmental level Estimate level of adaptive functioning • Ask questions about the individual's adaptive functioning at home and in other everyday life settings Screen for emotional and behavioural problems and stressful life events • Query about anxiousness, mood, concentration, hyperactivity, disruptive behaviour, thought problems, eating, sleeping, and adverse life events Screen for medical problems • Assess medical history and physical examination as a minimum	Brief screening: WASII, SBS Routing subtests*, KBIT1, BINS, INTER-NDA* More specific screening or comprehensive assessment: WPPSI, WISC, WAIS, DAS, RPPM1, MSEL, Bayley, M-P-III, PEP, RINDA Brief screening: CELF screening test1, PLS screening, CDI More specific screening or comprehensive assessment: CELF1, PLS, OSEL Brief screening: SRS11, SCQ11, M-CHAT*, AQ11, CCC, PAAAS*, CAST*, ASRS, ASSQ*, SCDC More specific screening or comprehensive assessment: ADI-R1, DISCOT, 2.5H Brief screening: STAT, SORF, ADOS, CAR11, BOSCC1, AMSE1*, TIDOS* More specific screening or comprehensive assessment: ADOS11 Brief screening: SDQ Impact Supplement*, WHODAS* More specific screening or comprehensive assessment: VABS1, ABAS1 Brief screening: SDQ1*, ASEBA*, Inter-NDA*, ABC1, Conners, ECI, CSI, MINI*, ACE-Q* More specific screening or comprehensive assessment: PAPA, CAPA, K-SADS*, SCID1 See medical evaluation section
Diagnostic formulation • Integrate all available information • Evaluate the diagnostic criteria for ASD and severity of manifestations • Exclude differential diagnoses • Consider all diagnostic specifiers, including co-occurring diagnoses	



A National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorders in Australia

Full National Guidelines
Prof Andrew Whitbourne, Dr Kath Evans, Prof Valammas Eapen and A/Prof Jane Wiley

The Lancet Commission on the future of care and clinical research in autism
Lancet 2022; 399: 271–334

Girls and women with ASD

- Diagnosed 4x > M:F – ? subtler manifestation of social and communication difficulties
- "Girls often present differently to boys, and are often mis-diagnosed, mis-understood, or missed completely."

Are you concerned your daughter isn't coping socially or emotionally?

Does she have anxiety or sensitivities to food, clothes or noise? Have you considered *autism*?

Girls often present differently to boys, and are often mis-diagnosed, mis-understood, or missed completely. But with better understanding we can change this. Learn more about the common traits in girls below:

Common traits in girls

- She may display **extreme focus** on her special interest (commonly animals, nature, books, art)
- She may be described as being either '**extremely shy**' or **not aware of 'social boundaries'**
- She may **withhold her anxiety** in public but then **melt-down** or **shut-down** once home
- She may be **overly dependent or reliant** on one friend and have trouble coping without them
- She may be extremely **interested in socialising, but unsure** how to approach making connections
- She may have **sensory sensitivities** (eg. noise, clothing, temperature)
- She may exhibit **extreme reactions**, compared to the size of the problem
- She may **interpret language literally**
- She may be more **fluid in her gender identity** (eg. prefers less 'girly' clothes or be extremely 'girly')
- She may be **extremely empathetic, nurturing and sensitive**

Find a clinician that understands the female presentation of autism.
Go to www.yellowladybugs.com.au for more information.



Yellow Ladybugs is a volunteer community group who proudly create social events, similar to birthday parties, where autistic girls can come together and have the opportunity to meet and bond over their similar journey. Our vision is to foster a strong bond, which will ultimately create a network of friends outside of school.

For more information, or to register your interest for future events go to:

www.yellowladybugs.com.au



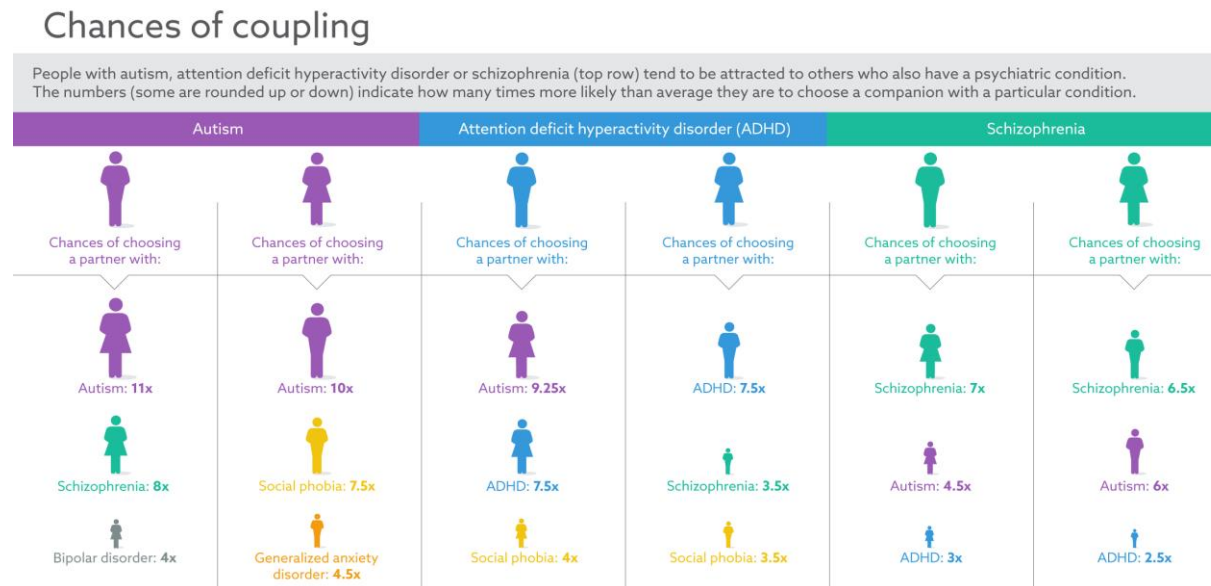
- [GQ-ASC \(Girls Questionnaire for Autism Spectrum Condition\) - Adult-Women version](#)
 - [Autism-in-Girls-checklist](#)
 - [Autistic Checklist by Samantha Craft](#)
- (Latter two not formally validated by research)

Other correlations

LGBTQIA+ (lesbian, gay, bisexual, transgender, queer, intersex, and asexual individuals)

- Gay, lesbian, or bisexual: 15-35 % (2-3x higher) among autistic people who do not have intellectual disability
- ↑ likelihood of being transgender or gender nonconforming (6-40%) compared with non-autistic people
- up to 18% of men and 43% of women may be sexual minorities
- Higher rates of substance use (>2x % use of illicit drugs and ≤2x risk of substance use disorder) – discrimination and social/family stigma, loneliness

“People with autism prefer partners on the spectrum”



Patterns of Nonrandom Mating Within and Across 11 Major Psychiatric Disorders

JAMA Psychiatry 2016 Apr;73(4):354-61. doi: 10.1001/jamapsychiatry.2015.3192.

<https://www.spectrumnews.org/news/people-with-autism-prefer-partners-on-the-spectrum/>

Prevalence and Risk Factors

- USA: 1 in 58 (1.7%); Australia: 1 in 70 (1.4%)
- Diagnosed 4x > M:F (? subtler manifestation of social and communication difficulties)
- Children >> Adults [many adults were not identified as autistic when they were children]
↑ rate: diagnostic criteria, increased awareness, differences in study methodology, or a true increase in the frequency of autism spectrum disorder. [DSM-5-TR]

Genetic factors

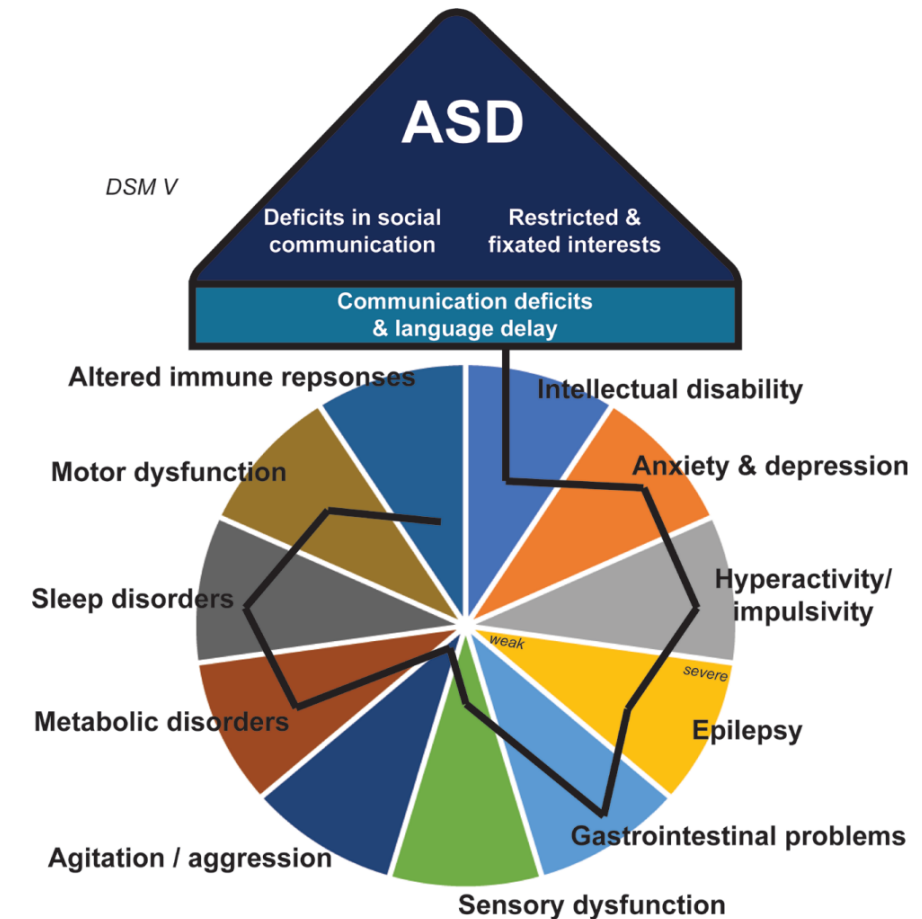
- ASD is a multifactorial disorder with high heritability (37-90-%)
- Concordance rates: identical twins 70–90%; fraternal twins 0–10%
- Familial clustering: younger siblings of family members with an ASD diagnosis face an increased risk for ASD, esp'ly younger male siblings
- Up to 40% of cases of ASD in children have a genetic cause (e.g., fragile X syndrome, Rett syndrome, tuberous sclerosis)

Environmental factors

- ↑ parental age, maternal nutritional and metabolic status, infection during pregnancy, prenatal stress, exposure to certain toxins, heavy metals, or drugs (valproate); low birth weight

Comorbidity of ASD

- ~70% have one comorbid mental disorder; 40% may have ≥ 2 comorbid mental disorders)
- **ADHD** 28% (95%CI 25-32%) [30-80%]
- **PTSD** 32-45%
- **Epilepsy** 20-30% [Seizures more in children <5 & teenagers (esp. mod. to severe ID, neurological conditions (e.g. cerebral palsy), or children who show regression in their skills]
- **Intellectual disability** (IQ ≤ 70) 20-30%
- **Borderline intellectual functioning** (IQ 71-85) 20-25%
- **Anxiety disorders** 20% (17-23%) [40-60%; Social anxiety disorder]
- **Sleep-wake disorders** 13% (9-17%)
- **Disruptive/impulse-control/conduct disorders** 12% (10-15%)
- **Depressive disorders** 11% (9-13%)
- **Obsessive-compulsive disorder** 9% (7-10%)
- **Tic disorder** 9-12%; **Tourette disorder** 5% (esp. mod. to severe ID)
- **Borderline personality disorder** 4%
- **Hoarding behavior** 4%; **excessive acquisition**
- **Bipolar disorders** 5% (3-6%)
- **Schizophrenia spectrum disorders** 4% (3-5%)
- **Eating disorders** [Anorexia nervosa, Avoidant restrictive food intake disorder] 20-30% of adults with EDs have ASD; >15 times higher
- **Problematic Internet Use** and **Gaming Disorder**
- **Pathological demand avoidance (PDA)** / **Extreme demand avoidance (EDA)**



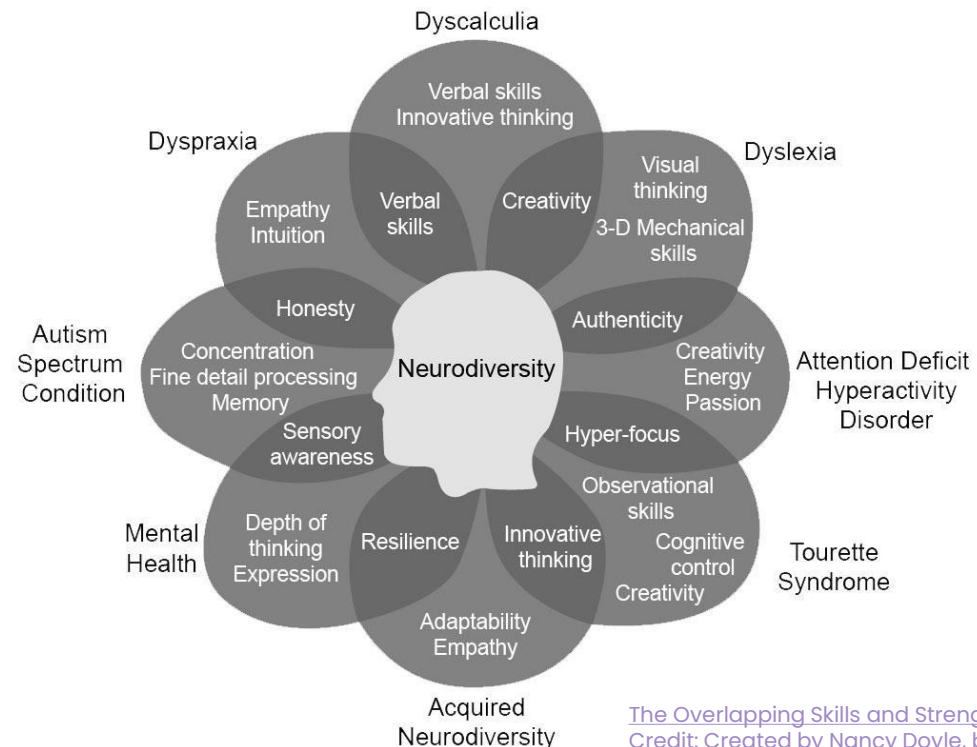
Neurodiversity

“Neurodiversity refers to the virtually infinite **neuro-cognitive variability** within Earth’s human population. It points to the fact that every human has a unique nervous system with a unique combination of abilities and needs.”

<https://www.neurodiversityhub.org/what-is-neurodiversity>

Neurodiversity describes the idea that people experience and interact with the world around them in many different ways; there is no one "right" way of thinking, learning, and behaving, and differences are not viewed as deficits.

<https://www.health.harvard.edu/blog/what-is-neurodiversity-202111232645#>



[The Overlapping Skills and Strengths of Neurodiversity](#)
Credit: Created by Nancy Doyle, based on work by Mary Colley.

ASD and Trauma

Video clip: <https://youtu.be/CaRdPYvWt48?t=211>

Rates of probable PTSD in autistic people (32-45%) – cf. general population (4-4.5%)

Potentially traumatising events:

- abandonment by/loss of a loved one (for example a family member, pet or support staff)
- sensory experiences (for example fire alarms)
- transitions and change (for example school transitions, routine changes with the seasons, unpredictability)
- social difficulties and confusion (for example difficulties interpreting social cues, misunderstandings and conflict)
- events related to one's own mental health difficulties (for example psychotic experiences).

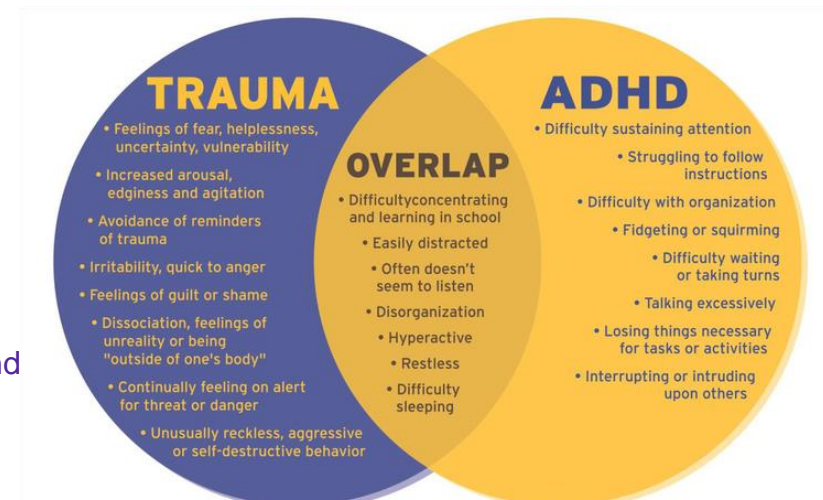
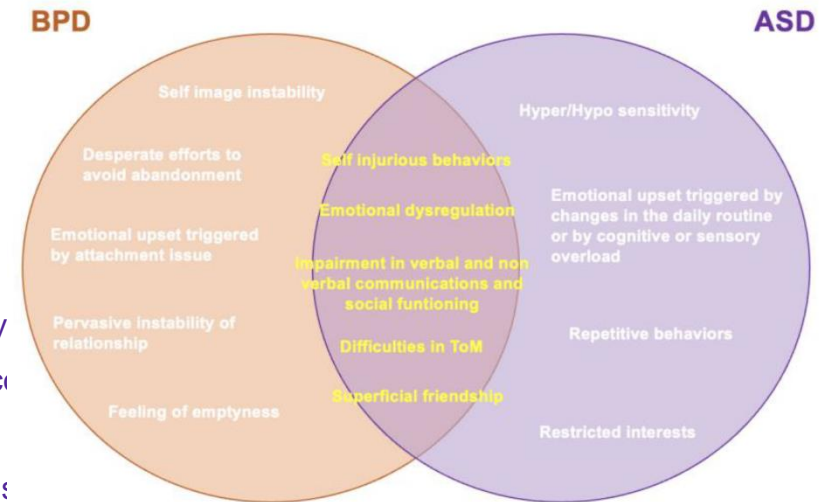
Autistic people may also be **more likely to find these experiences traumatic** due to autistic characteristics :

- sensory sensitivities
- communication and social interaction differences
- distress around changes to routines
- distress if prevented from taking part in repetitive and restricted behaviours such as stimming.

Some theories suggest that other factors associated with being autistic, may mean an **increased risk of developing or maintaining PTSD symptoms**, such as:

- neurological and genetic factors
- detailed focused processing (in other words a tendency to focus on the details of a situation)
- increased rumination (unable to stop thinking about negative feelings and thoughts), inflexible thinking and
- emotion regulation difficulties.

<https://www.autism.org.uk/advice-and-guidance/professional-practice/ptsd-autism>



ASD and Substance use disorders

Why might autistic people develop addictions?

- struggling to cope with everyday life
- family also acopic, conflictual, critical, dysfunctional, substance-using, etc.
- use of substances to mask their autistic traits to help socialise/‘fit in’
- to help manage emotions, e.g. generalised anxiety
- to help with sleep

“The chief aspect of [being autistic] which resulted in extremely heavy use of alcohol to cope was a near constant sense of anxiety. I also was socially awkward and discovered alcohol turned me into a much more relaxed person.”

Matthew Tinsley (2016)

ASD as a protective factor for SUDs

Autistic individuals might be less likely to report engaging in substance misuse. Those who do, report using drugs to self-medicate.

Lancet Psychiatry 2021; 8: 673–85

Understanding the substance use of autistic adolescents and adults: a mixed-methods approach

Elizabeth Weir, Carrie Allison, Simon Baron-Cohen

Case vignettes

25 yo man presenting for Dx and Rx for ADHD

Referred via psychologist seeing him for PTSD and GAD

Later Dx with ASD

Family: parents, 2 older brothers with significant substance use disorders – Negative role models

37 yo man with schizoaffective disorder

Later Dx with ASD

Family: parents, siblings with schizophrenia and substance use disorders – Negative role models

Case vignettes: 31yo male with ASD and ADHD

Barkley Deficits in Executive Functioning Scale (abbrev'd)

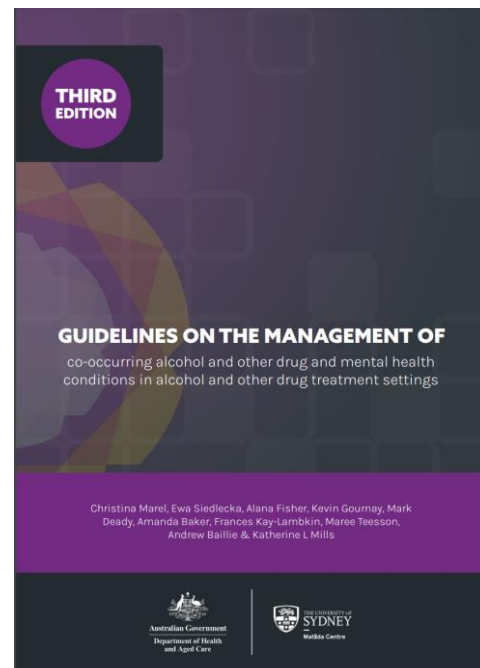
34yo male with bipolar disorder, ADHD, methamphetamine and cannabis use disorders. Dx with ASD

	Mark if you agree
Forget to do things I am supposed to do	True
Can't seem to accomplish the goals I set out for myself	
Can't seem to hold in mind things I need to remember to do	
Having difficulty judging how much time it will take to do something or get somewhere	
Having difficulty motivating myself to stick with my work and get it done	
Have trouble completing one activity before starting into a new one	
Having difficulty arranging or doing my work by its priority or importance; can't "prioritize" well	
Find it hard to get started or get going on things I need to get done	
I have trouble organizing my thoughts	
Easily distracted by irrelevant events or thoughts when I must concentrate on something	
Not able to comprehend what I read as well as I should be able to do; have to reread material to get its meaning	
Cannot focus my attention on tasks or work as well as others	
Easily confused	
Can't seem to sustain my concentration on reading, paperwork, lectures, or work	
Procrastinates or puts things off until the last minute	
Have trouble planning ahead or preparing for upcoming events	
Having difficulty motivating myself to stick with my work and get it done	
Having trouble completing one activity before starting into a new one	
I have trouble organizing my thoughts	
Having difficulty stopping my activities or behavior when I should do so	
Having difficulty changing my behaviors when I am given feedback about my mistakes	
Not aware of things I say or do	
More likely to drive a motor vehicle much faster than others	
Likely to take short cuts in my work and not do all that I am supposed to do	
Have to depend of others to help me get my work done	

	Mark if you agree
Forget to do things I am supposed to do	
Can't seem to accomplish the goals I set out for myself	
Can't seem to hold in mind things I need to remember to do	
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Clinical relevance of Dx/Mx comorbid ASD

- Help with recovery – dealing with underlying ASD issues, finding alternative coping mechanisms
- Engaging with ASD peer-support groups, online forums
- Screening for conditions comorbid with ASD that may impact on risk of relapse, QoL, etc. via clinically significant distress, impaired functioning, etc.
- Family inclusive practice (broader autism phenotype)
- Neuroaffirming / ASD-friendly service delivery (e.g. appointment reminders, sensory friendly waiting rooms)



Further reading / Resources

ASD Resources

- Autism Spectrum Australia (Aspect): autismspectrum.org.au
- Autism Victoria (Amaze): amaze.org.au
- Asperger's Victoria: www.aspergersvic.org.au
- <http://www.autismawareness.com.au/>
- <http://www.autismcrc.com.au/>
- <https://reframingautism.com.au>
- [Others \(1\)](#); [Others \(2\)](#); [Others \(3\)](#)

Miscellaneous resources

https://www.youtube.com/results?search_query=asd

<https://www.reddit.com/r/AutisticAdults/>

<https://www.reddit.com/r/asd/>

<https://www.reddit.com/r/autism/>

<https://www.meetup.com/en-AU/Aspie-Rebels/>

https://twitter.com/search?q=autism&src=typed_query

@AutismTalkAspie, @autismspeaks, @Autism, @AutismSociety, @thinkingautism, @AutismTips, @NationalAutism, @theautismnews, @Spectrum, @AmbitiousAutism

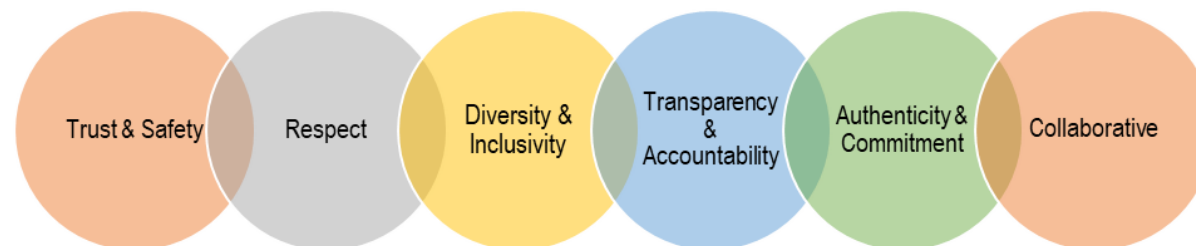
<https://www.facebook.com/search/top/?q=autism>

Stakeholder group	National peak body
Individuals on the autism spectrum	Autistic Self Advocacy Network of Australia and New Zealand
Individuals with an Aboriginal or Torres Strait Islander background	First Peoples Disability Network Australia
Individuals and service providers living in a rural or remote area	National Rural Health Alliance
ASD-specific service providers	Australian Autism Alliance
Parents and caregivers	Autism Awareness
General practitioners	Royal Australian College of General Practitioners
Occupational therapists	Occupational Therapy Australia
Nurses	Australian Primary Health Care Nurses Association
Paediatricians	The Royal Australasian College of Physicians – Paediatrics & Child Health Division
Psychiatrists	Royal Australian and New Zealand College of Psychiatrists
Psychologists	Australian Psychological Society
Speech pathologists	Speech Pathology Australia
Teachers	Australian Professional Teachers Association

Acknowledgement of Lived/Living Experience

We recognise and value the knowledge and wisdom of people with lived/living experience, their supporters and the practitioners who work with them.

We celebrate their strengths and acknowledge the important contribution that they make to the development and delivery of health and community services.





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