



# Introduction to Autism Spectrum Disorders

Presented by

Victorian Dual Disability Service

Better and  
fairer care.  
**Always.**

# Acknowledgement of Country

The Victorian Dual Disability Service would like to recognise the traditional owners of the country where we live, work and meet. We recognise and celebrate the diversity of Indigenous people and their enduring cultures and connections to the land and waters of Victoria. We pay our respects to elders; past and present, and recognise the Indigenous people that contribute immensely to mental health and disabilities services.



Artwork by Mandy Nicholson

# Acknowledgement of Lived Experience

We would also like to acknowledge the immeasurable contributions of people with a lived and living experience of mental illness, psychological distress, alcohol and other drugs, and disability, as well as those who love, have loved and care for them.

We acknowledge that each person's experience is unique and valued. We recognise their adverse experience of stigma, but also their strength and resilience. We respect and value their generous contributions which teach us, and guide us to continually shape, reflect upon and deliver quality care, from a lived experience perspective.



Artwork by Zeva Mirankar

# Victorian Dual Disability Service (VDDS)

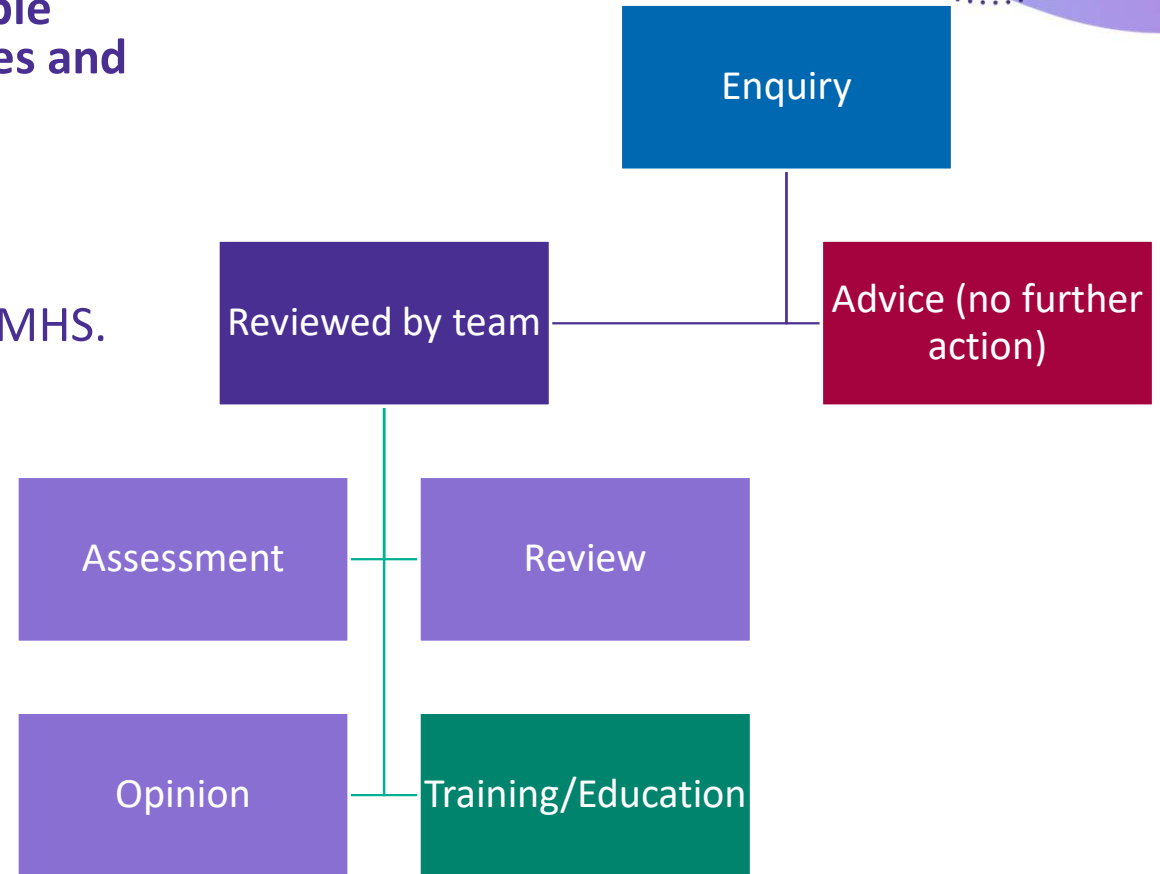
State-wide mental health service for people with co-occurring mental health challenges and a developmental disability.

## What does VDDS do?

- Telephone consultation to anyone.
- Assessment & consultation for public AMHS.
- Assessment & consultation for NDIS participants
- Education & Training
- Service Development

## How to make a referral or request training:

- *Telephone Referral: (03) 9231 1988*
- *Email: [vdds@svha.org.au](mailto:vdds@svha.org.au)*



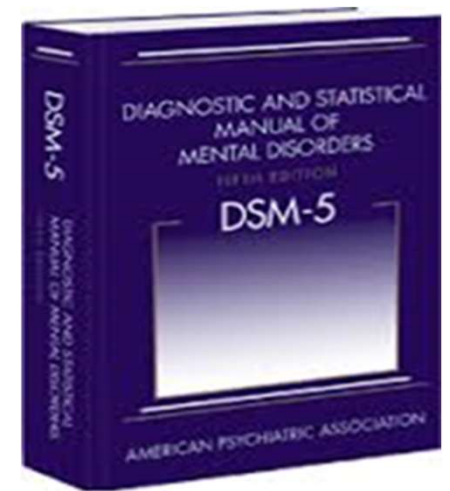


# OBJECTIVES

1. Prevalence, nature & impact of Autism
2. Understand the core features of Autism
3. How these influence experiences & behaviour
4. Autism screening and assessment
5. Introduction to comorbid health issues

# Autism Spectrum Disorder (ASD): DSM-5 Criteria

1. Persistent deficits in social communication & interaction across multiple contexts.
2. Restricted, repetitive patterns of behavior, interests or activities.
3. Must be present in the early developmental period.
4. Cause significant impairment in functioning.
5. Not better explained by intellectual disability.



# Autism Spectrum Disorder

Level 1	Level 2	Level 3
Requiring support	Requiring substantial support	Requiring very substantial support
Difficulty with social interaction	Marked deficits in social interaction	Severe deficits with social interaction and communication
Inflexible behaviour	Inflexible behaviour	Inflexible behaviour
Difficulty with organization	Distress with change to routine	Extreme difficulty with change
Difficulty switching between activities	Repetitive behaviours are frequent	Repetitive behaviours that markedly interfere with function.

# Prevalence

First Survey (*Lotter, 1966*)

4.5 : 10,000

ASD (*Wing & Gould, 1979*)

20 : 10,000

UK (*NAS, 2004*)

1 : 100

Australia (*ABS, 2012*)

1 : 150

Victoria, Australia

1 : 150

Globally (*Baxter et al., 2014*)

52 million people

Adults in the UK (*Brugha, 2012*)

1 : 100

Males 4-5 x more than females



# Why is Prevalence of Autism Increasing?

## Apparent Prevalence

- Awareness, screening programs
- Decreased stigma
- Access to services
- Diagnostic substitution
- Expansion of concept

## Real Prevalence

- Parental age
- Social influences?
- Geographic clustering

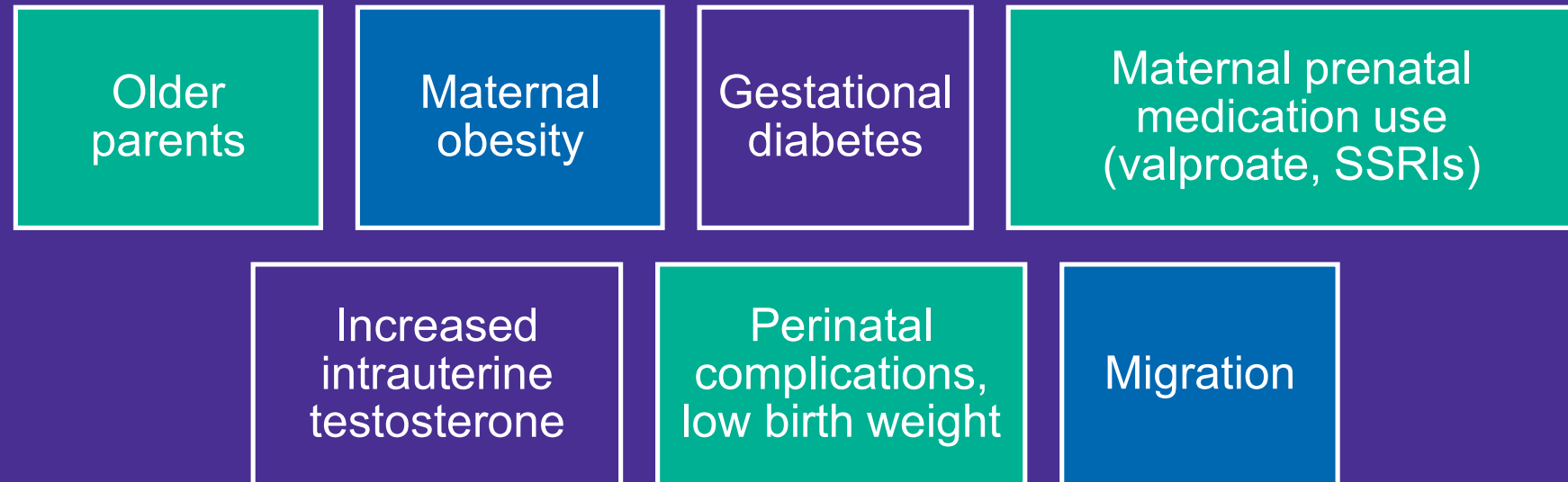


# What Causes Autism?



- Multiple causes (still unknown)
- Gene / environment interaction (multiple genes)
- Exposure to toxins
- Immune dysfunction
- GI dysfunction
- Neurological damage
- Persistent myths e.g MMR

# Risk Factors for Autism



(James, W. H. (2012). A potential explanation of some established major risk factors for autism. *Developmental Medicine & Child Neurology*, 54(4), 301-305.)



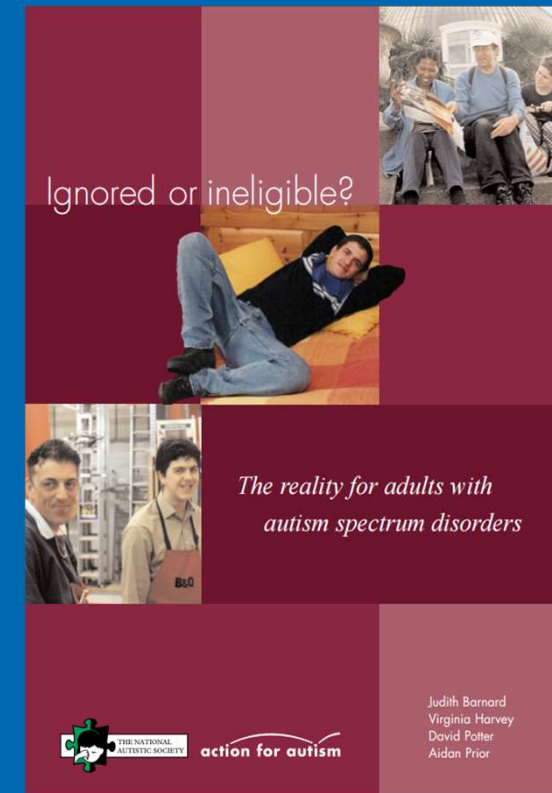
# Impact of Autism in Children



- One of the major causes of disability
- Personal, carer distress & family burden  
*(Karst & Van Hecke 2012)*
- Rapidly increasing numbers  
*1:68 (CDC 2014)*
- 70% have mental health problems  
*(Australian Advisory Board on Autism 2012)*
- 46% used a MH service in the last year  
*(Narendorf et al 2011)*

# Impact of Autism in Adults

- Lifelong disorder  
*(Baxter 2013)*
- There are more adults with ASD
- Poor socioeconomic outcomes
- Poor mental health  
*(Joshi 2013)*
- Limited research  
*(Howlin 2015)*
- Struggle to access services



# Impact of ASD



- Outcome related to IQ and language
- Core features remain evident in adulthood
- 60% poor outcome
- Few live alone and unlikely to marry
- Dependent on family/services
- High unemployment



# Core Features of Autism

# Social Communication

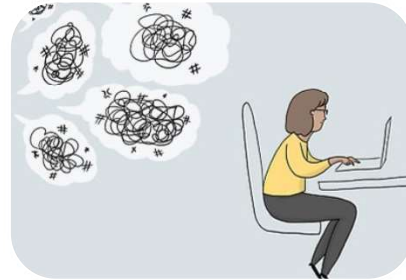


## What skills are needed for conversation?

- Listen/hear
- Understanding
- Knowledge of grammar & syntax
- Desire to communicate
- Ability to generate new sentences
- Shared vocabulary
- Able to remember
- Ability to process (what is relevant)
- Articulate response
- Understanding of social rules



# Social Communication



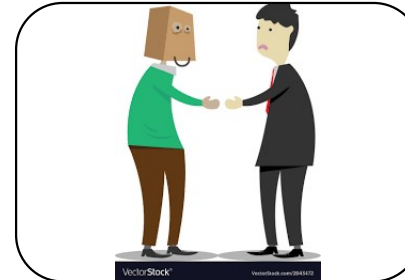
Aloof



Passive



Active, but cold



Overly formal

# Social Communication

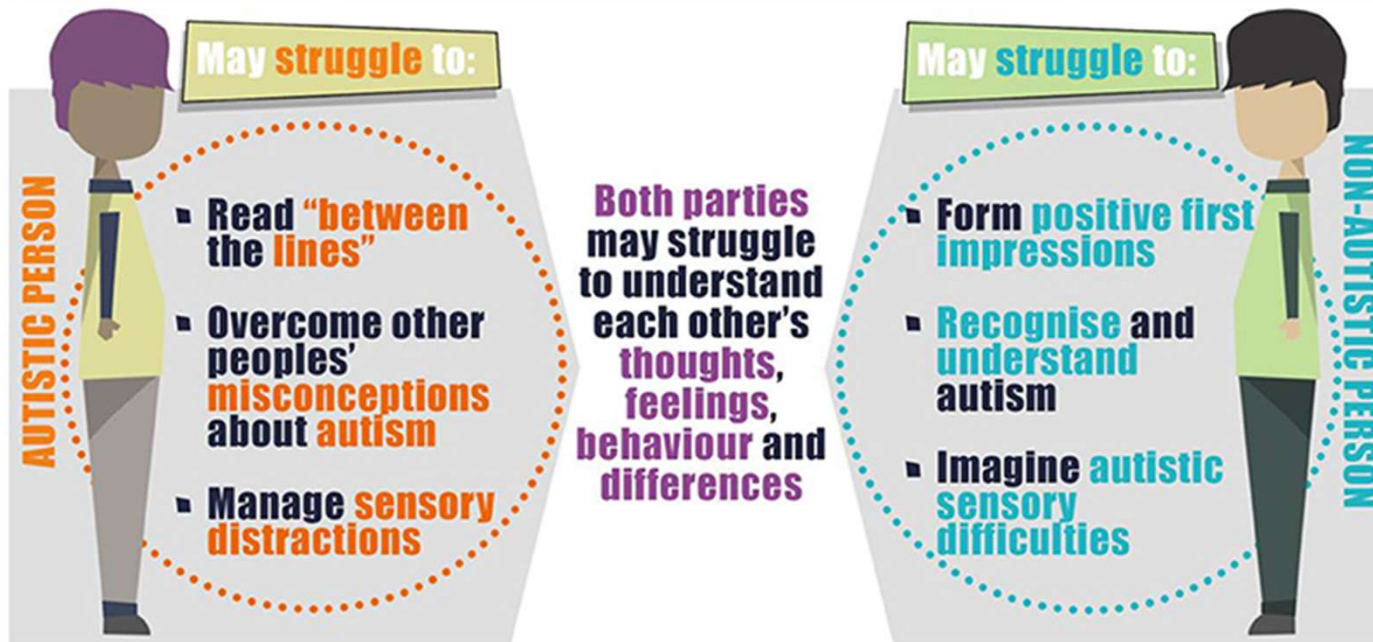


## Difficulties in:

- Reciprocal social interaction.
- Non-verbal elements of communication.
- Initiating & maintaining relationships (friendships)
- Sociable with 1 person – problems with groups.
- Understanding beliefs, desires, intentions & emotions of self and others (social imagination).

# Double Empathy Problem

## THE DOUBLE EMPATHY PROBLEM



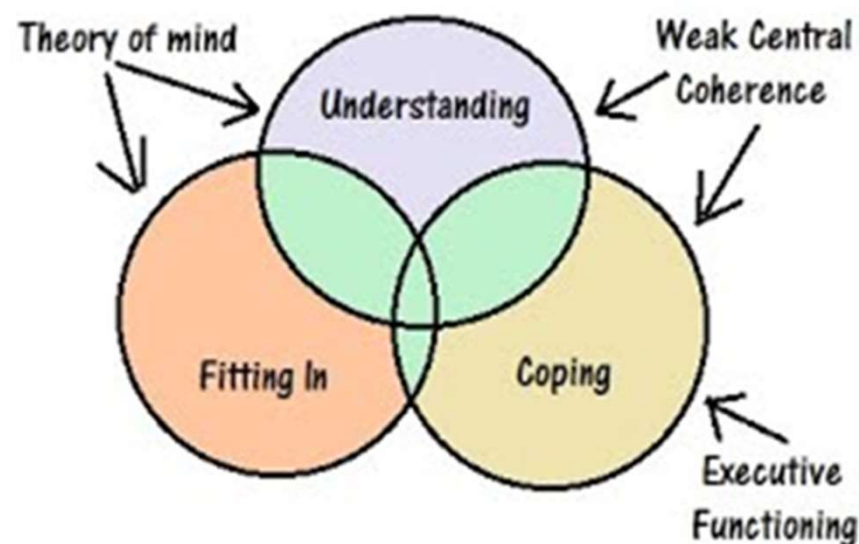
# Restricted, Repetitive Patterns of Behavior, Interests or Activities

- Desire for sameness & predictability
- Rigid adherence to routines, inflexible
- Aids in reducing anxiety.
- Difficulty in tolerating change.
- Excessive interest in highly specific topics.



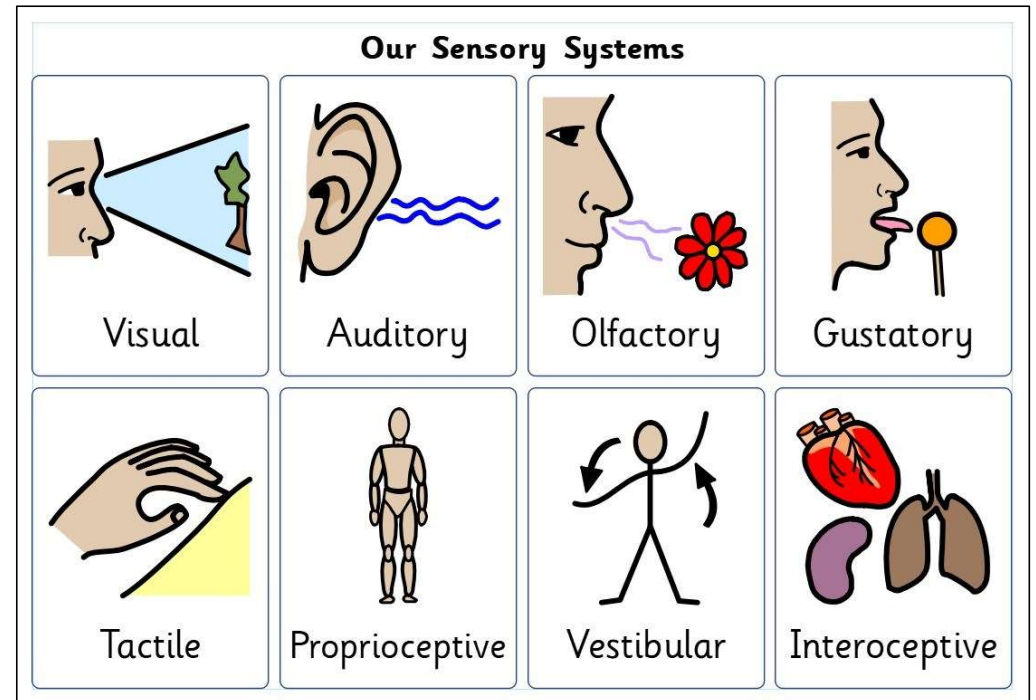
# Associated Challenges

- Concrete thinking, rules based, explicit learning.
- Focus on detail (weak central coherence).
- Inability to prioritise the relevance of details.
- Sticky attention / Distractibility.
- Difficulty combining ideas.
- Problems organising or sequencing.
- Difficulty generalizing.



# Sensory Sensitivities: Registration and Response

- Everyone has sensory preferences.
- Many Autistic people experience sensory sensitivities.
- This may affect them in a variety of different ways, from being distracted, unable to concentrate and having mild discomfort, to symptoms of acute 'pain' and deterioration in functioning.
- Consider the environment & make adjustments



*“Neurodivergent people are more sensitive to the things that bother everyone”  
- Autistic mental health consumer*

## Sensory Sensitivities: Registration and Response – Hyper / Hypo

Sensory domain	Arousing	Calming
Visual	Florescent lighting Clutter Colour Eye contact	Natural light Empty space Colour
Vestibular	Sudden movements	Rhythmic motion
Touch/Proprioception	Slopes, Stairs, light touch	Flat surfaces, pressure, hugging, water
Odour	Perfume, paint, petrol	Vanilla, banana
Auditory	Loud sudden, chatter	Music, soft voices
Temperature	Sudden changes	Natural warmth

# Associated Problems

Sleep

Activity levels

Food intake

Emotional  
dysregulation

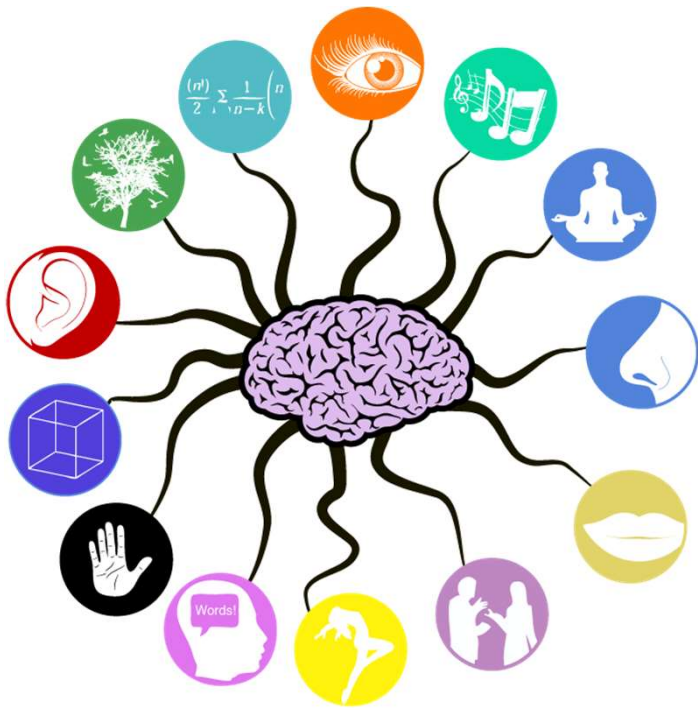
Epilepsy

Anxiety,  
meltdowns  
(overwhelmed)



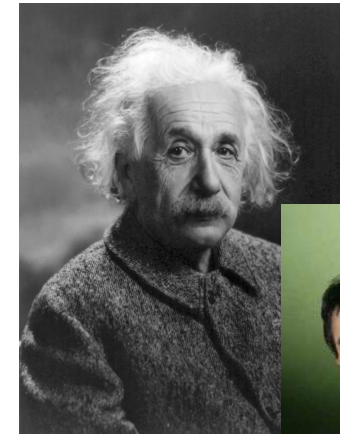
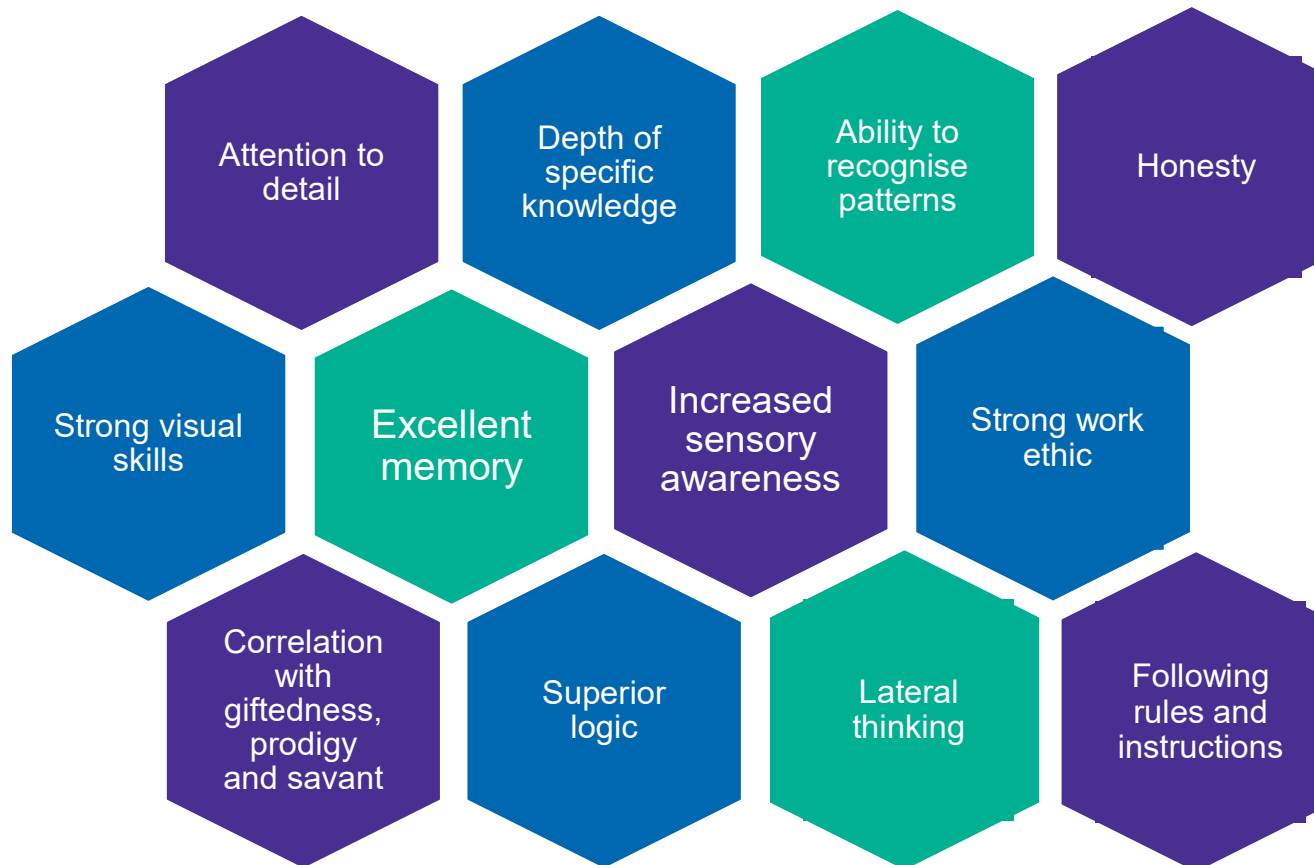


# Summary of Core Features



- To varying degrees, have difficulty working out **social interactions**.
- Benefit from being informed clearly in advance (with careful explanations) if plans are changed.
- Difficulties caused by over sensitivity to various kinds of **sensory** input are very common.

# COMMON STRENGTHS



# The Autism SPECTRUM



Pragmatic Language	Social Awareness	Monotropic Mindset	Information Processing	Sensory Processing	Repetitive Behaviors	Neuro-Motor Differences
Social communication including body language, eye contact, small talk, and turn-taking in conversation.	Ability to pick up on etiquette, social norms, taboos. Ability to form and maintain relationships.	Narrow but intense ability to focus, resulting in "obsessive" interests and difficulty task-switching.	Ability to assimilate and apply new information quickly or to adapt to new environments or situations.	Challenges interpreting sensory information, hypersensitivity or hyposensitivity to stimuli.	Tendency to "stim" in response to varying emotions. Can be beneficial or harmful in nature.	Ability to control body movements. Ranges from clumsiness to complete loss of ability to move with intention.

[www.theaspergian.com](http://www.theaspergian.com)



# Autism Screening and Assessment

# Why Assess for ASD?

1. Understanding of strengths, challenges & a possible explanation for lifelong struggles
2. Understanding & support from others
3. Informs therapies or services
4. Better outcomes
5. Determines service eligibility



*“It explained a lot about why I couldn’t get on with others but it was really too late to do any good.”*

# Delayed Diagnosis of ASD

- Delayed diagnosis is common, self-diagnosis is increasing.
- Significant barriers to diagnosis include:

Cost – lack of public funded assessment in VIC

Limited access to Adult ASD Specialists

Camouflaging “spent decades pretending to be normal” – increased risk of depression

Anxiety – telling life story to a stranger, not being believed / listened to.

Inability to describe symptoms “I suck at recognizing feelings”

No one to provide collateral info or developmental history

Mistrust of professionals – misdiagnosis, being blamed, bounced around

Stigma – association with ID, media perception of ASD “not Rainman again!”

(Amaze 2019, Foran Lewis 2017)

# Identifying Autism

- No biological markers
- Based on developmental history & behaviour
- Can be detected as early as 18 months
- CDC's "*Learn the Signs. Act Early.*" program provides free resources to help monitor developmental milestones & recognise signs of developmental concerns.
- Developmental screening
- Loss of previously acquired skills



# Look for Risk Factors

## Family History:

- ASD
- Broader Autism Phenotype (reclusive, eccentric)

## Genetic Disorders:

- Tuberous sclerosis
- Fragile X
- NF
- PKU

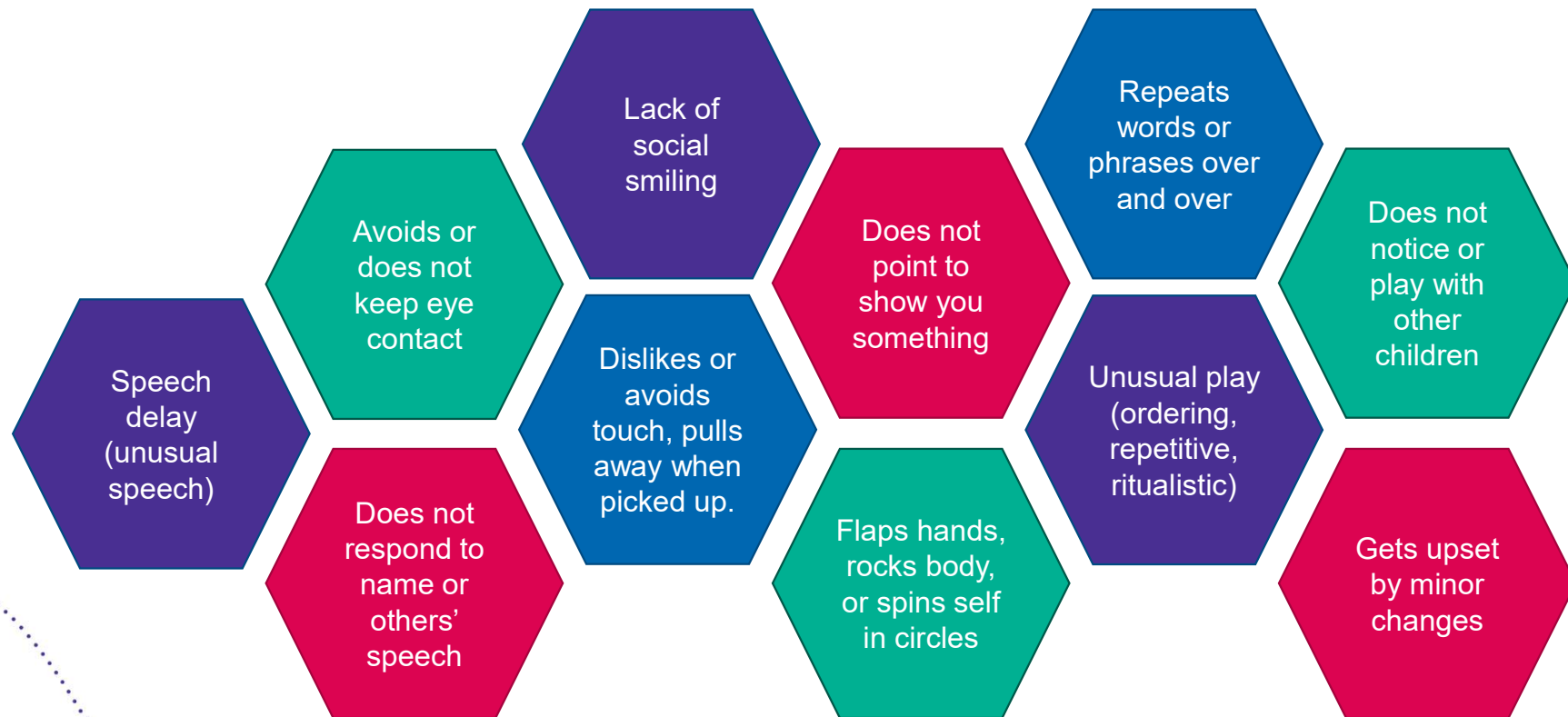
## Non-genetic risk factors for ASD:

- Older parents
- Prenatal infection and drug exposure
- Epilepsy
- GI disorders
- Early childhood infection, febrile convulsions





# Look for these signs:



# Early Developmental History

*"He crib rocked. He was never cuddly and would become stiff and hard to hold when I picked him up. He would never prepare himself to get picked up and would get angry if I interrupted his activity. He never sought affection."*

*"Ideal baby", Lack of eye contact, lack of interest in others*

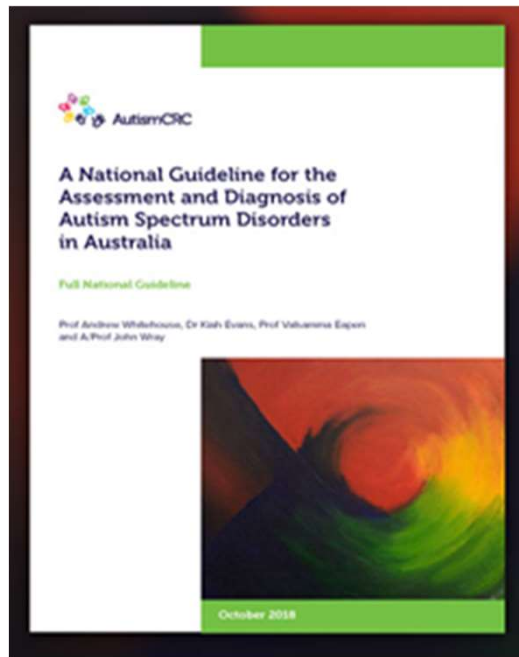
*"Never had any friends"*

*"Would line all his toys up in order of size and get upset if people moved them"*

*"...limited range of interests and in psychotherapy he would explain complex arithmetical problems or crosswords and would only write in Roman characters"*

*"Had to have things on his terms, unable to see how his behaviour affected others, over familiar with strangers, no friends, private talks in public"*

# ASD Assessment Guidelines



- Rise in Autism prevalence – now 1:68 (CDC 2014)
- Increased demand for ASD assessments
- Various guidelines (Autism CRC, NICE, BAP, RCPsch, AAP, SIGN, NZ)
- Little evaluation of ASD diagnostic guidelines quality
- Significant variation, especially regarding screening & diagnostic tools
- Paucity of robust evidence, limited applicability .

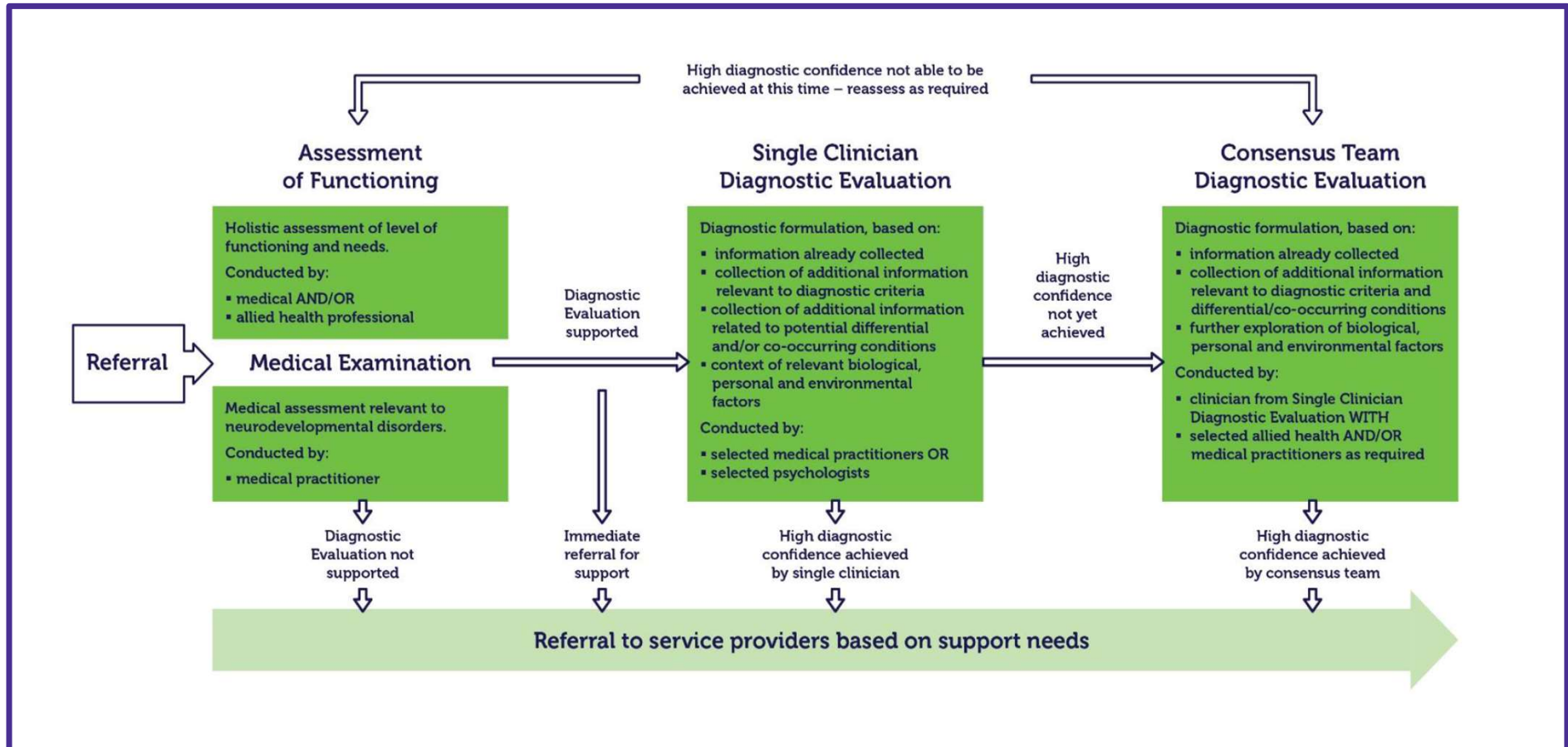
# National Guideline for Assessment & Diagnosis of ASD in Australia

- Diagnosis based on DSM or ICD criteria
- Assessment individual, holistic & strengths focused
- Longitudinal lifespan perspective
- Comprehensive needs assessment
- Diagnostic Evaluation
- Coordinated by a nominated clinician
- All clinicians involved should be trained in developmental assessment/ ASD

(Whitehouse et al. 2018)



# Assessment Process



# Screening for Autism: NICE GUIDELINES

Consider assessment for possible Autism when a person has:

➤ One or more of the following:

- Persistent, lifelong difficulties in social interaction (never had friends)
- Persistent lifelong difficulties in social communication (always 'awkward')
- Stereotypic (rigid and repetitive) behaviours, resistance to change or restricted interests

**AND**

➤ One or more of the following:

- Problems in obtaining or sustaining employment or education
- Difficulties in initiating or sustaining social relationships
- A history of neurodevelopmental condition (including ID & ADHD)

*Onset in adulthood suggests illness, lifelong problems suggests a developmental disorder*

# NICE Assessment & Diagnosis



1. For adults with possible autism who do not have ID

- AQ10  $\geq 6$  & developmental evidence = refer for comprehensive ax

2. For adults with ID

- Brief ax & informant information against criteria for ASD – refer for comp ax if 2 or more symptoms present.

3. Comprehensive Assessment

- Expert MDT (NICE recognizes the limitations of formal Ax tools)
- Developmental history & direct observation in multiple settings
- Explore core ASD features (social communication, sensory, RRIB)
- Behaviour and functioning assessment

# Instruments & Diagnostic Tools



- **Self report questionnaires**
  - Recommended by NICE & ACRC to inform assessment.
- **Many tools developed (e.g. AQ, EQ, DISCO, SCQ, RAADS, ADI, ADOS & co.).**
  - Can be useful, but only as an aid to diagnostic decision-making.
  - Help structure inquiry, collect data & systematically match to criteria.
  - However, limited compatibility with diagnostic criteria.
  - Limited or inconsistent psychometric properties.
- **Limited evidence for ASD screening in adults especially. with co-occurring conditions.**
- **Particular problems differentiating ASD from Schizophrenia & PD.**



# NICE Complex Assessment for Adults

## Tools for people without a Learning Disability

- Adult Asperger Assessment (AAA; Autism Quotient [AQ 50] & Empathy Quotient [EQ])
- Autism Diagnostic Interview – Revised (ADI-R)
- Autism Diagnostic Observation Schedule – Generic (ADOS)
- Asperger Syndrome (and high-functioning autism) Diagnostic Interview (ASDI)
- Ritvo Autism Asperger Diagnostic Scale – Revised (RAADS-R)
- Diagnostic Interview for Social and Communication Disorders (DISCO)

## Tools for anyone

- ADOS
- ADI-R
- DISCO

# Diagnosis of Autism in Adulthood



## 1. Comprehensive developmental history

- By trained professionals
- Info from multiple sources (family, carers)
- Existing reports - Speech, sensory & cognitive assessment, medical & school reports

## 2. At least one face-to-face assessment

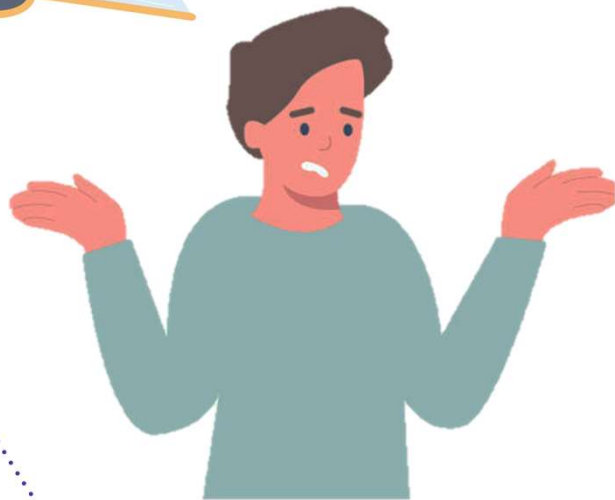
## 3. Ideally observation in an unstructured setting

## 4. Assessment of functioning / strengths

## 5. Medical evaluation

Filipek 2000, Howlin et al 2012, Wolf & Ventola 2014, Mandy et al 2015

# Diagnosis of Autism in Adulthood



**Aim to identify persistent deficits in three Autism domains:**

- *Social: Joint attention, friendships, social interest, play, rules*
  - *Communication: Language delay, speech problems, muteness, unusual speech*
  - *Restrictive repetitive speech, interest, behaviour: Fixations, obsessions, play, topics*
  - *Sensory*
  - *Repertoire of behaviours increases with age and IQ*
- 
- **Expect significant (frank) Autism to already be identified**
  - **Clear onset of problems after childhood indicative of other illness**

The background features a dark purple field on the left, transitioning into a white field on the right. A large, flowing shape in shades of purple and blue curves across the middle. Dotted lines in purple and blue follow the contours of these shapes.

# Co-occurring Health Conditions

# Differential Diagnosis and Co-occurring Conditions

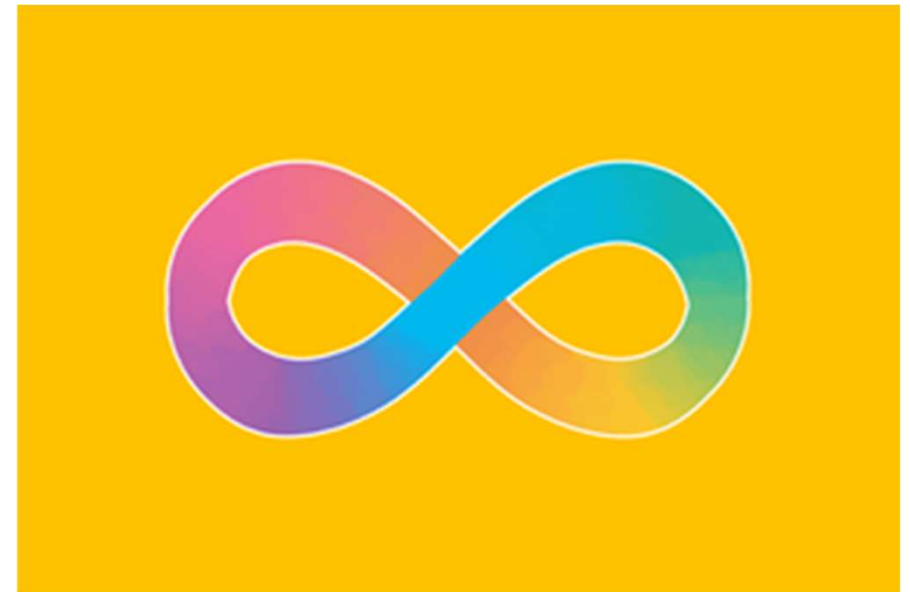
- Social communication impairment occurs in many conditions
- Significant overlap with many mental disorders
- ASD is not protective against any other mental disorder
- Higher risk of all disorders found in neurotypical population
- Expert diagnostic evaluation required for differential
- **ASD-specific assessments are not a substitute for clinical judgement**



# Autism and Co-occurring Conditions

## Neurodevelopmental Disorders

- People with Autism have high rates of other neurodevelopmental disorders.
- **25% to 40%** of people with ID have Autism, **40% to 70%** of people with Autism have ID (borderline IQ also common).
- **40%** of children with ASD have ADHD and **22%** of children with ADHD have ASD.
- Specific learning disorders increased.
- Each neurodevelopmental disorder increases the risk of psychopathology.



# Autism and Co-occurring Conditions

## Mental Health Disorders

Autistic individuals experience the full range of co-morbidity

**Anxiety disorders:** 40 to 50 % in clinical settings.

**Problem Behaviours:** The lower the IQ ,the higher the risk (higher IQ can make specific diagnosis).

**Catatonia:** 15-20 % people with ASD affected.

**Psychosis:** Prevalence unclear but higher rates than general population

**Mood disorders:** Depression ~20%, BPAD 1 to 2%

**Personality disorders:** Overlap in symptoms and prevalence unclear

*Can increase severity of ASD impairments – diagnostic overshadowing*



# Autism and Co-occurring Conditions

## Physical Health

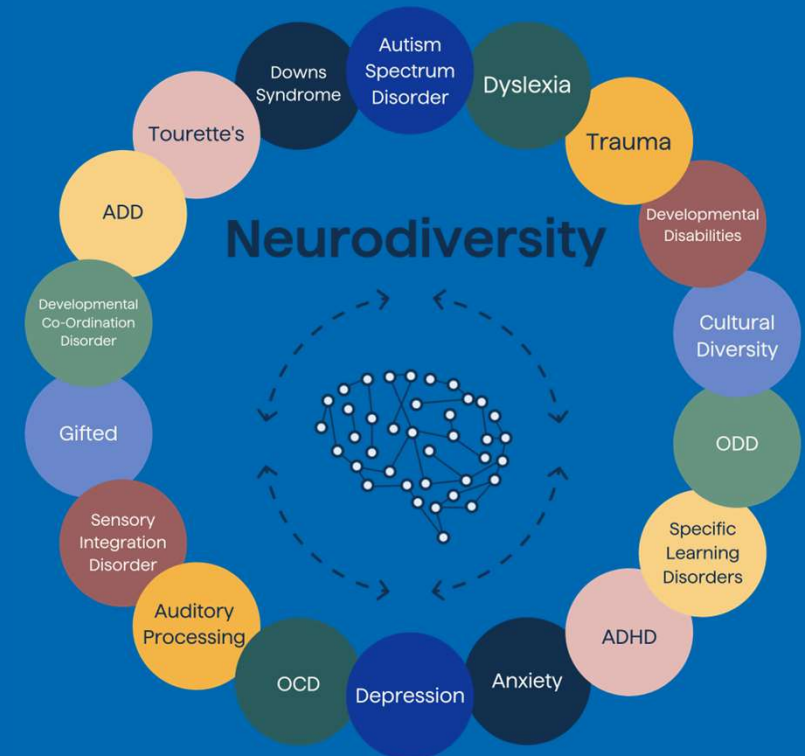
- High rates of some disorders (epilepsy/GIT)
- High/altered pain threshold
- Inability to communicate pain or discomfort (even those who appear articulate)
- Prior bad experience of medical intervention
- Often do not understand what is being asked or the information provided about symptoms
- High rates of medication use





# Summary

- Autism is a relatively common form of neurodiversity.
- ASD is associated with a variety of mental health, social and physical health challenges.
- Correctly identifying and diagnosing ASD can result in both more appropriate supports, but also increased stigma.
- Assessment and screening should be thorough, and completed by an appropriately skills clinician.



# Thank you

For a copy of these slides, please email  
[vdds@svha.org.au](mailto:vdds@svha.org.au) with subject header  
*"Please send Screening Intro to ASD slides"*

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