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Assessment and Treatment of Mental Illness in People with an Intellectual Disability

Victorian Dual Disability Service

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)

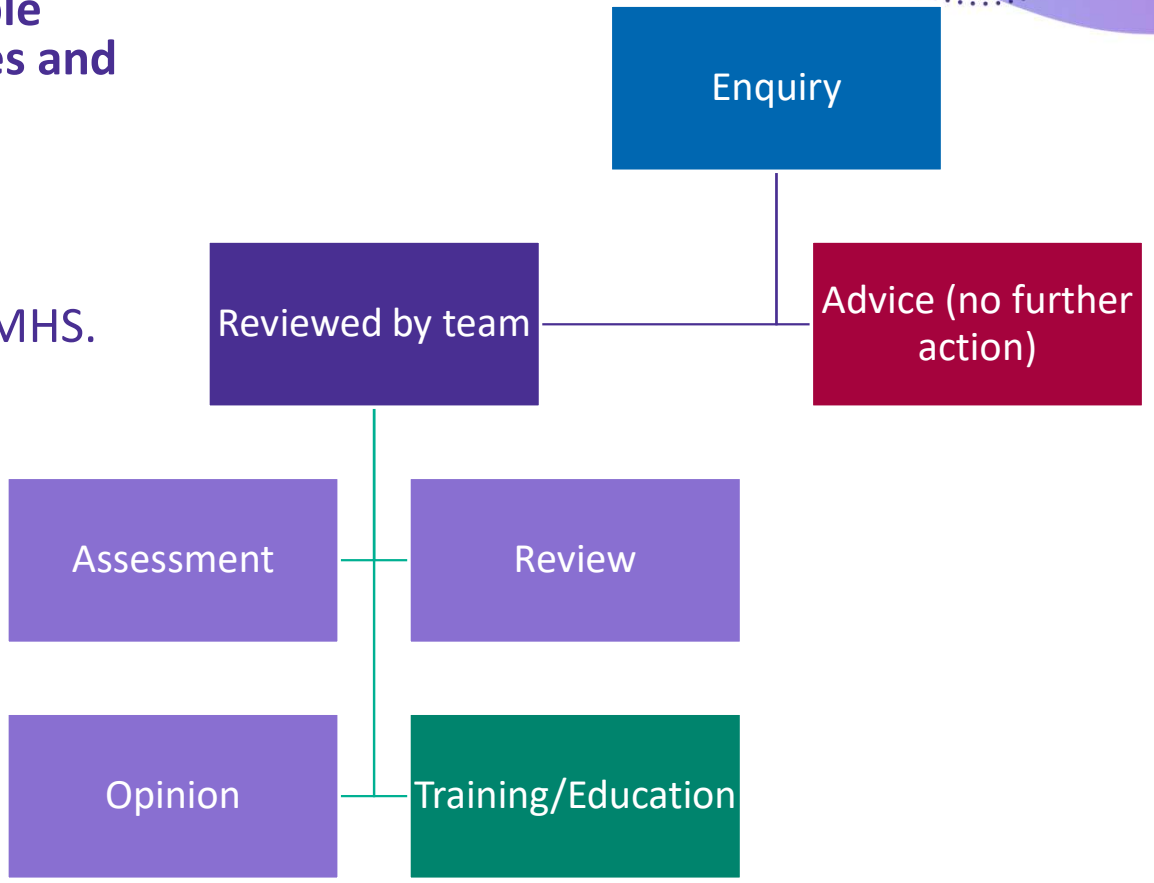
State-wide mental health service for people with co-occurring mental health challenges and a developmental disability.

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:

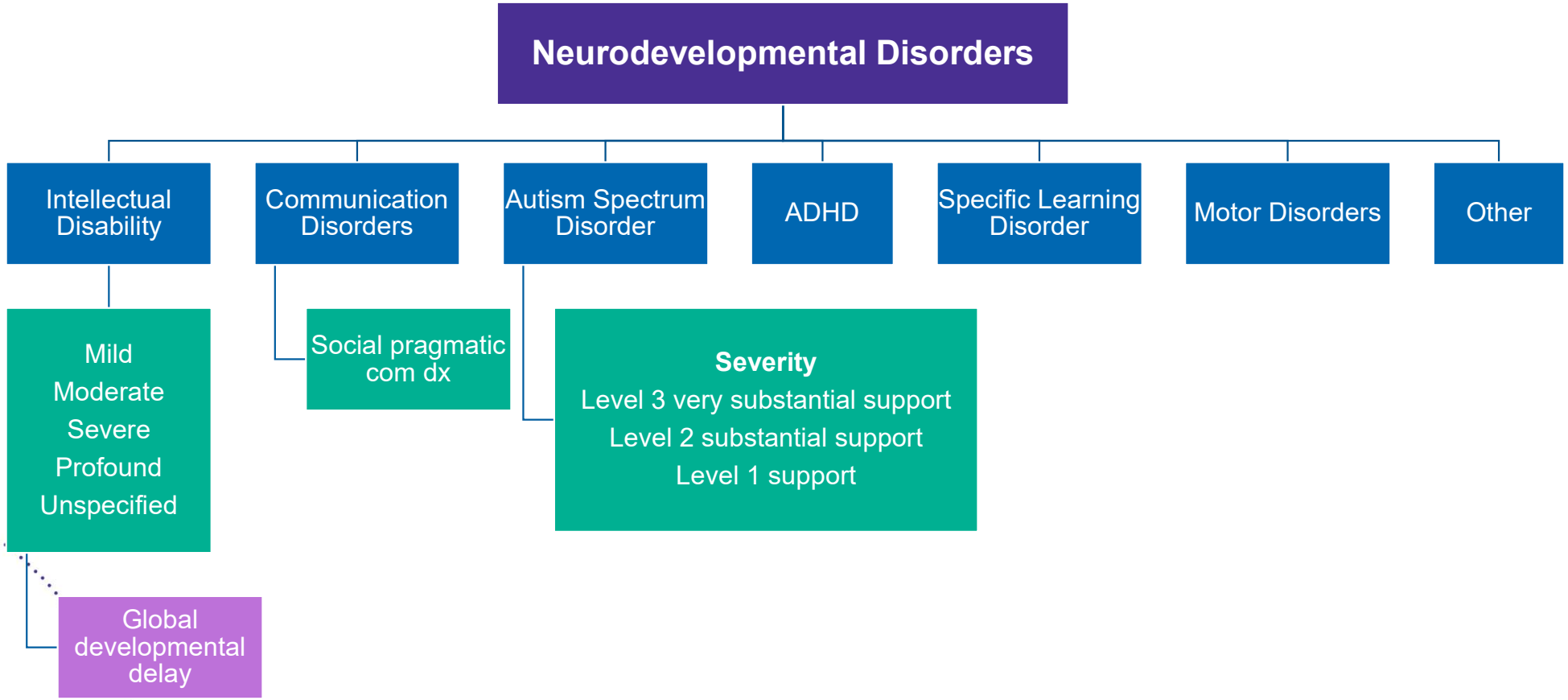
- *Telephone Referral: (03) 9231 1988*
- *Email: vdds@svha.org.au*



Outline

1. What is “Intellectual Disability”?
2. Assessment
3. Clinical Interviews and Mental State Examinations

DSM-5: Neurodevelopmental Disorders



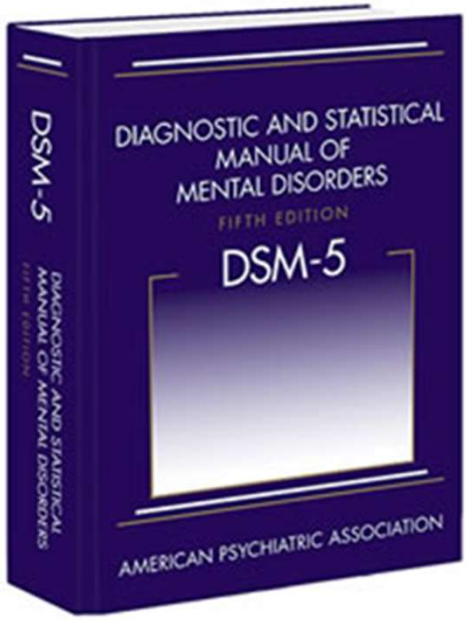
What is an Intellectual Disability: DSM-5

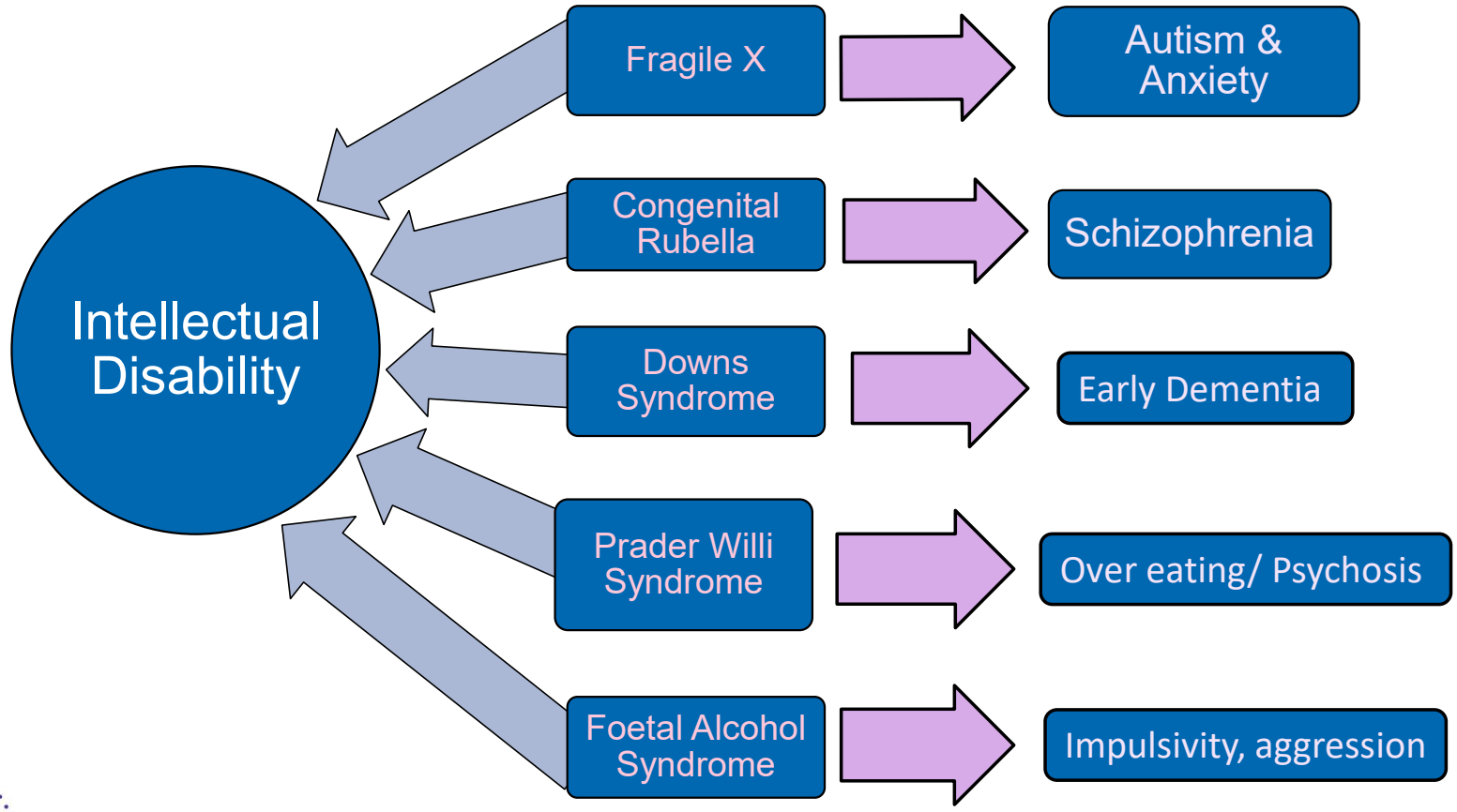
Intellectual Disability = Intellectual Developmental Disorder

- Deficits in intellectual function (Both clinical and IQ testing)
- Deficits in adaptive function (failure to meet expected standards)
- Onset during developmental period (0-18):

➢ Mild, moderate, severe and profound determined on basis of function NOT IQ

➢ Function considered in 3 domains being conceptual, social and practical




Intellectual Disability
Fragile X
Autism & Anxiety
Congenital Rubella
Schizophrenia
Downs Syndrome
Early Dementia
Prader Willi Syndrome
Over eating/ Psychosis
Foetal Alcohol Syndrome
Impulsivity, aggression

Intellectual Disability

- **NOT** a diagnosis (aetiology, prognosis, treatment) or explanation of his behaviour
- ID cannot determine treatment or prognosis
- ID is a bureaucratic category determining eligibility for services.
- A person has an ID when they need additional supports to live (independently) because of cognitive impairment.
- **NDIS List A** - moderate, severe or profound
- **NDIS List B** – mild (needs further evidence)
- In 2012 there were around 668,100 Australians (**2.9%**) with Intellectual Disability.
- **60%** have severe communication impairment.
- **57%** also have psychiatric disability.
- High levels of unmet need.

Intellectual Disability and Mental Health

- People with ID experience the same **range** of mental disorders
- There is increased risk due to multiple vulnerabilities
- Mental disorders **30%** – **40%** (**60%** in prison populations)
- Schizophrenia **2-4 times more prevalent**
- Access to mental healthcare is limited
- Barriers at a personal, professional and service levels

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Assessment

Assessment

- The principles of assessment are similar to those in general psychiatry:

Determine the presence and severity of symptoms	Classification of psychopathology into diagnostic groups	Determine the likely aetiology

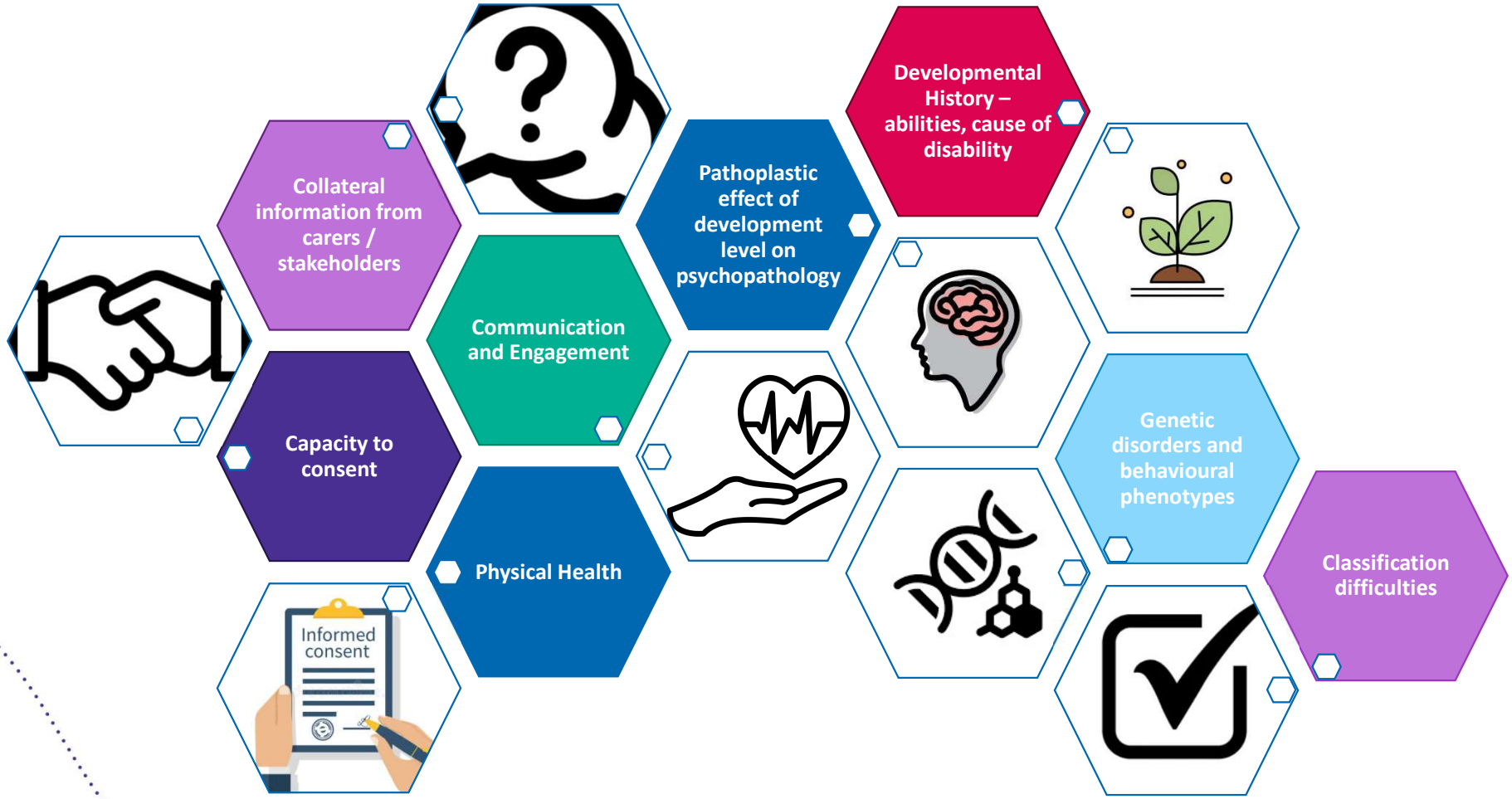
- Information is obtained via client interview, informant interview, observation and records.

- Modification depends on the severity of cognitive and communication impairment.

Common Difficulties in Assessment

1. • Attributing problems to the disability
2. • Labelling problem as “behavioural”
3. • Lack of clarity about service roles and “service gap”
4. • Lack of policy and service models
5. • Discrimination and stigma
6. • Assume lack of skills (lack of training)
7. • Limited resources

Special Considerations



Consent

- Test Capacity – who is providing consent?
- Medical Treatment Planning and Decisions Act 2016
- Guardianship and Administration Act 2019
- Office of the Public Advocate https://www.publicadvocate.vic.gov.au/
- The person may want to know what's happening even if they can't consent, and a guardian is now bound to make decisions that reflect the person's will and preferences, unless this would cause serious harm to the person.

Communication

- How much do they understand?
  - Check understanding & retention
  - Speak to family & carers about receptive communication
- How do they usually communicate?
- Do they need support?
- Allow plenty of time
- Consider the environment (sensory impairments or sensitivities, distractions, acquiescence to authority figures)
- Verbal – clear simple (age appropriate) language, repetition
- Non-verbal – visual (pictures, signing)

Collateral History

- Identify key stakeholders
- Obtain information from multiple informants (? bias)
- Seek information on usual level of functioning:
  - Adaptive (e.g., level of independence in daily activities)
  - Cognitive (e.g., previous psychological testing, verbal & performance IQ)
  - Communication (e.g., receptive and expressive language)
  - Social (e.g., presence of autism/PDD)
  - Level of supports provided or required in residential & day setting
- Measure all psychopathology, not just that volunteered by carers
- Previous assessments, diagnoses & interventions

Engagement: Optimising the Clinical Encounter

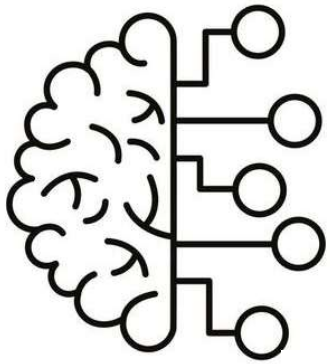
- Plan and Prepare

- Consider the environment & how they got there.
- Explain time frames and stick to them.
- If possible spend time with the person on their own.

Pathoplastic Factors

- **Diagnostic / behavioural overshadowing**
  - Attributing problems to known diagnosis or *'its behavioural'.*
- **Psychosocial masking**
  - Symptoms not identified because of different reference points for PWID due to impoverished experiences.
- **Cognitive disintegration**
  - Inability to think clearly under stress due to limited reserves (can appear psychotic like).
- **Baseline exaggeration**
  - Severe ID and lack of ability to express self so only see change in frequency or severity.

Pathoplastic factors



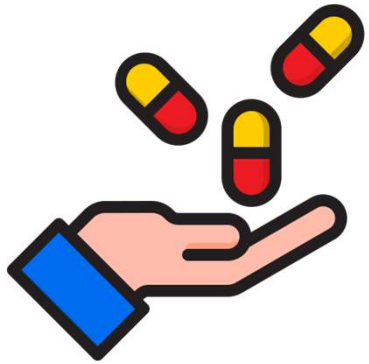
- **Cognitive distortion**
  - Inability to understand and express symptoms
- **Cloak of normality**
  - Desire to appear normal affects behaviour & responses
- **Acquiescence vs demand avoidance**
  - Attempt to give the *'right'* answer vs resistance to requests
- **Developmental issues**
  - Talking to self, imaginary friends, sexual behaviour
- **The disappearing problem**
  - Behaviour not apparent in structured settings e.g. hospital

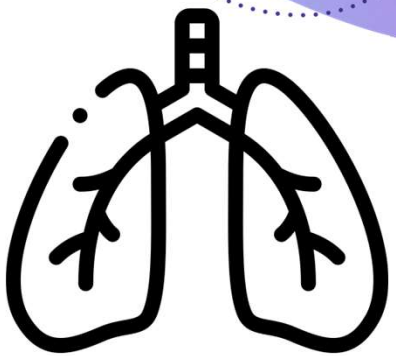
Developmental History

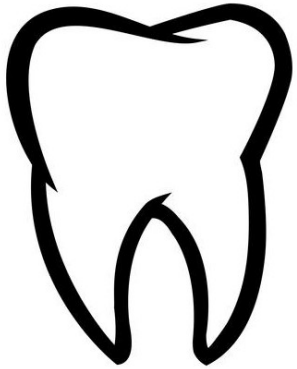
- Measurement of developmental level enables appropriate interpretation of psychopathology.
- Determining usual pattern of behaviours & skills is essential to distinguish symptoms of mental ill-health from long-standing traits.
- Diagnosis requires developmental history.
- A good understanding of development reduces the likelihood of *'diagnostic overshadowing'.*
- Understanding the aetiology of problem behaviours.
- Developmentally appropriate interventions.
- Genetic causes.

Physical Assessment

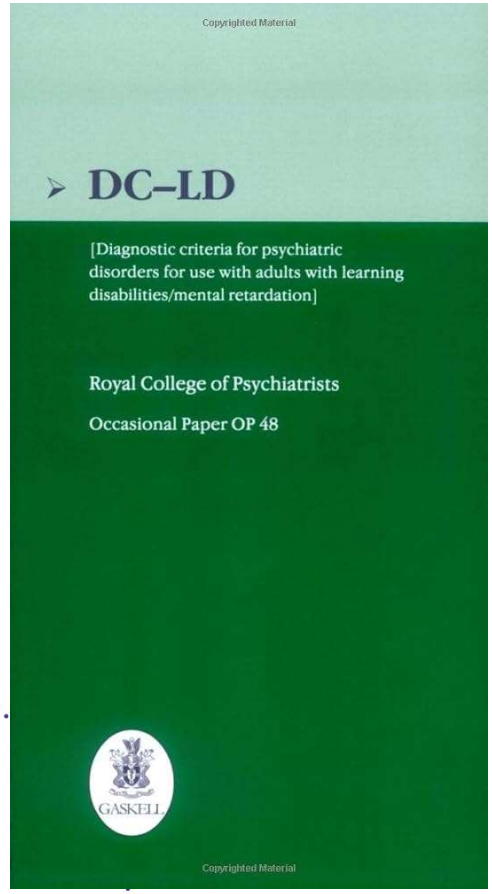
- Respiratory conditions (most common cause of death)
- Sensory impairments / sensitivities
- Epilepsy is very common
- Drug interactions & adverse reactions
- Obesity
- Endocrine problems (thyroid, osteoporosis)
- Gastrointestinal (constipation, GORD, H Pylori)
- Dental
- Dementia (esp. Down Syndrome)
- Delirium (less cognitive reserve)







Assessment Structure



- Severity of Intellectual Disability (cognitive testing & adaptive behaviour.)
- Cause of Intellectual Disability (genetic testing - e.g. 22q11ds)
- Developmental Disorders (ASD, ADHD)
- Psychiatric Illness
  - Delirium
  - Dementia (especially Down Syndrome)
  - Psychosis
  - Affective disorders
  - Anxiety & OCD
- Personality Disorders (not before 21 years old)
- Problem Behaviours (aggression, SIB, pica); due to psych illness
- Other Disorders (eating, sexual, sleep etc)

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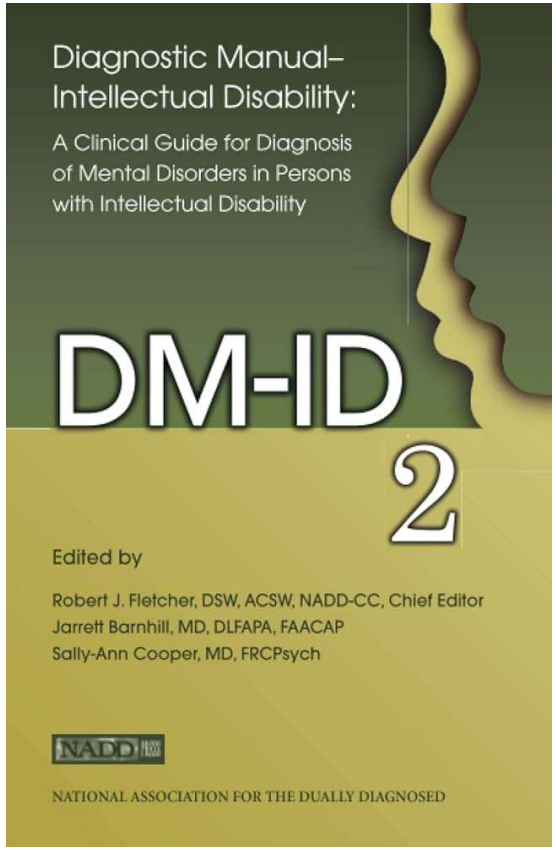
Classification Difficulties

- DSM and ICD based on “normal” population.
- Does not include psychopathology specific to ID (pica, self injurious behaviour, stereotypies).
- Identification of symptoms relies on verbal skills & cognitive capacity.
- Relationship between behaviour & syndrome not specified.
- Modified presentation of illness
  - Adults with mild ID & reasonable verbal skills: similar presentation to adults without ID.
  - Adults with moderate-severe ID, ID & autism, or limited verbal skills: changes in behaviour, including disturbed or regressed behaviour.



Interview and MSE

Speak directly to the person with intellectual disability, not just to their support person.

The Interview

- **The rules of good interviewing apply even more than the general population**

Keep language as simple as possible
Allow time for process and response
Low tolerance and attention - ? several shorter sessions
Avoid leading questions (tendency for acquiescence)
Ask for examples
May need to use multiple choice (are you happy or sad?) and/or reframe questions

The Interview

Check ability to answer simple questions
Does the person understand? - vocabulary, abstract concepts, time?
Check understanding of concepts and probe “yes” or “sometimes” responses
Establish “Anchor” events
Ask the same question in different ways.

Mental State Examination (MSE)

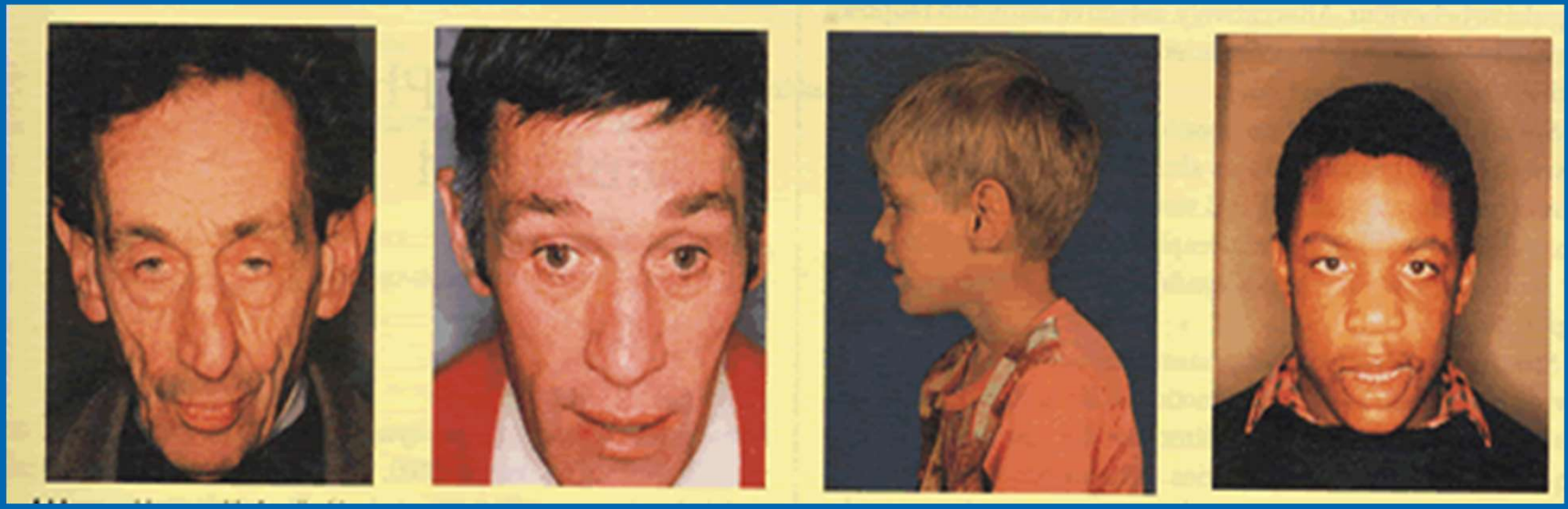
- **MSE *may* have to be modified but <u>should always be attempted</u>.**
  - ➢ Same format
  - ➢ Increase emphasis on observation
  - ➢ May not be able to access mood or thought
  - ➢ Consider risk
- *'Often diagnosis of a person with ID, particularly when this is severe or profound, is made without the clinician making a systematic observation of the patient, or in some cases without the clinician even seeing the patient (a dangerous and unethical practice).'* (Levitas et al 2001)

Appearance

- Self neglect? - Quality of care, increased need for support
- Lack of choice in clothes
- Autism - may be very particular about appearance
- Syndromal appearance, facial dysmorphia
- Scarring
- Use of aids (wheelchair, hearing aid, teeth)

Examples of Syndromal Appearance

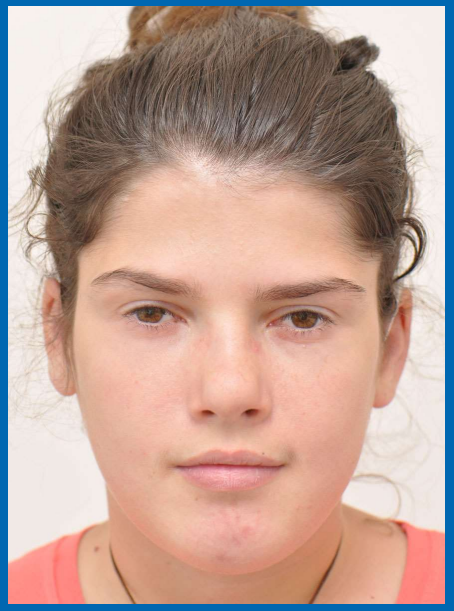
Fragile X Syndrome (FXS)

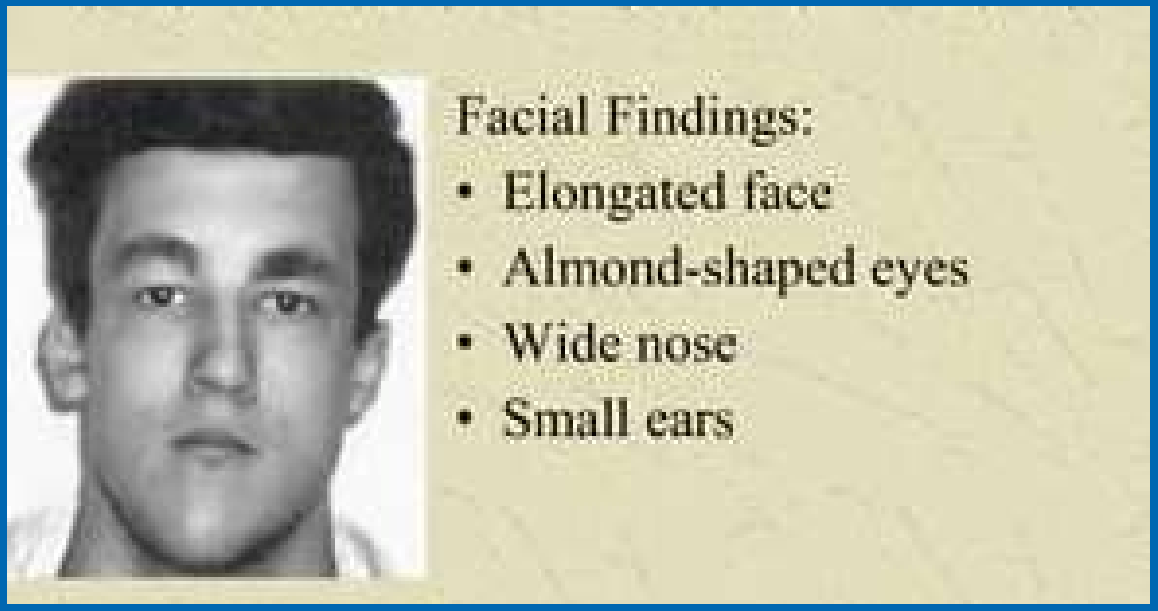


Multiple anxiety symptoms

Examples of Syndromal Appearance

22q11. 2 deletion syndrome
Velocardiofacial Syndrome (VCFS) – DiGeorge Syndrome

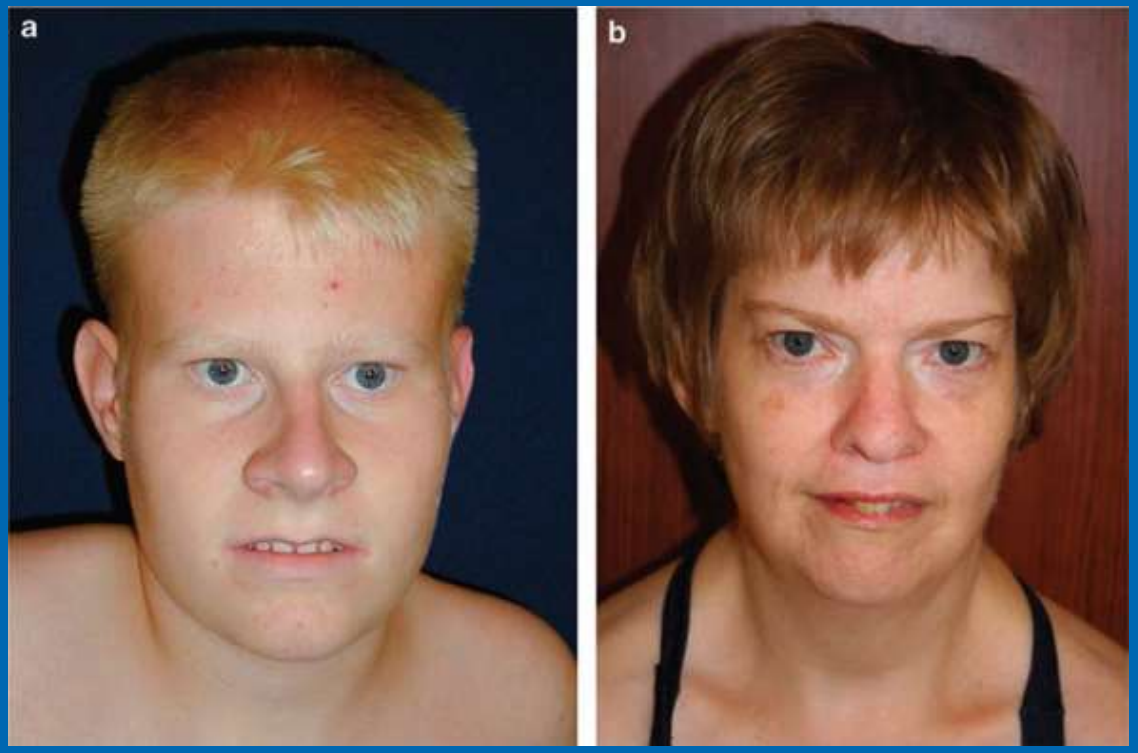


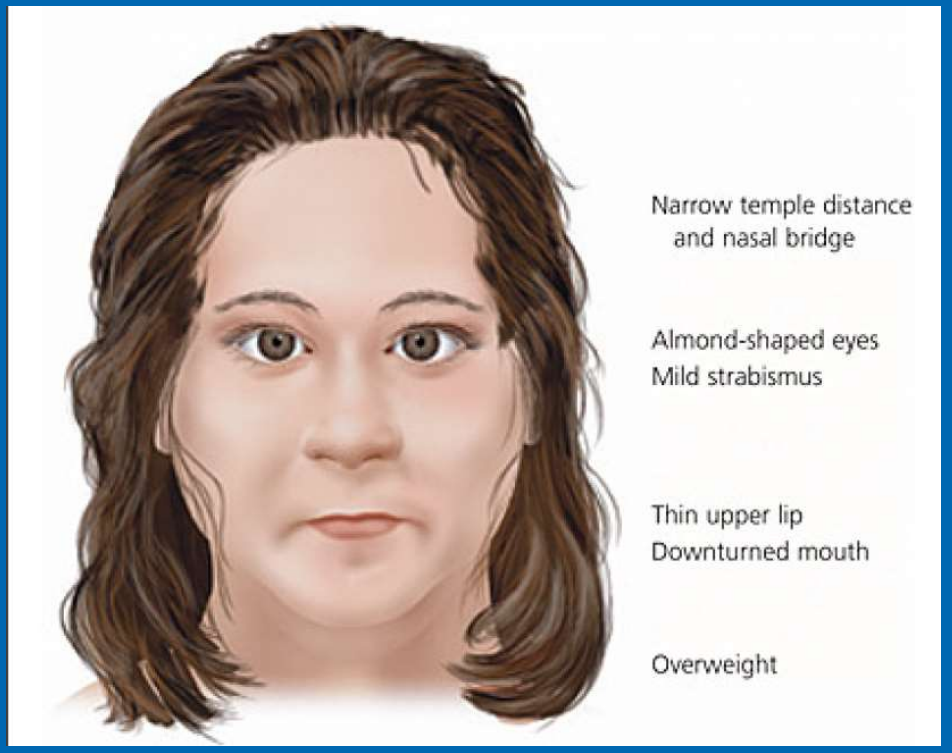


High risk of Psychosis!

Examples of Syndromal Appearance

Prader Willi Syndrome





Hyperphagia, Affective Psychosis

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Manner / Behaviour

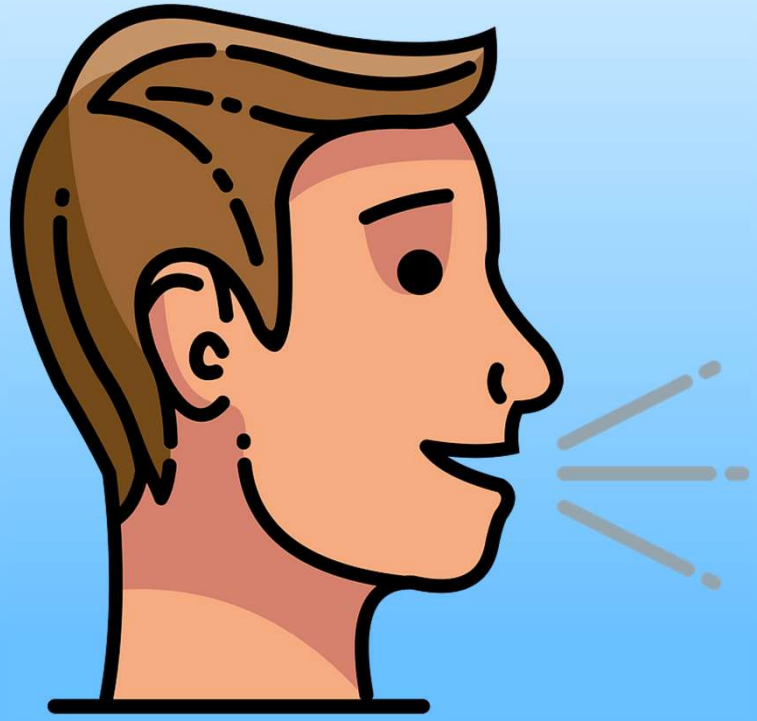
- Purpose of interview
- How do they relate to familiar / unfamiliar people?
- Over-familiar to uninterested
- Social greeting (aloof, passive, irritable rejection)
- Gaze and touch avoidant (e.g. in ASD)
- Odd idiosyncratic greeting, reciprocal interaction
- Don’t know responses
- Beware experienced interviewees

Motor

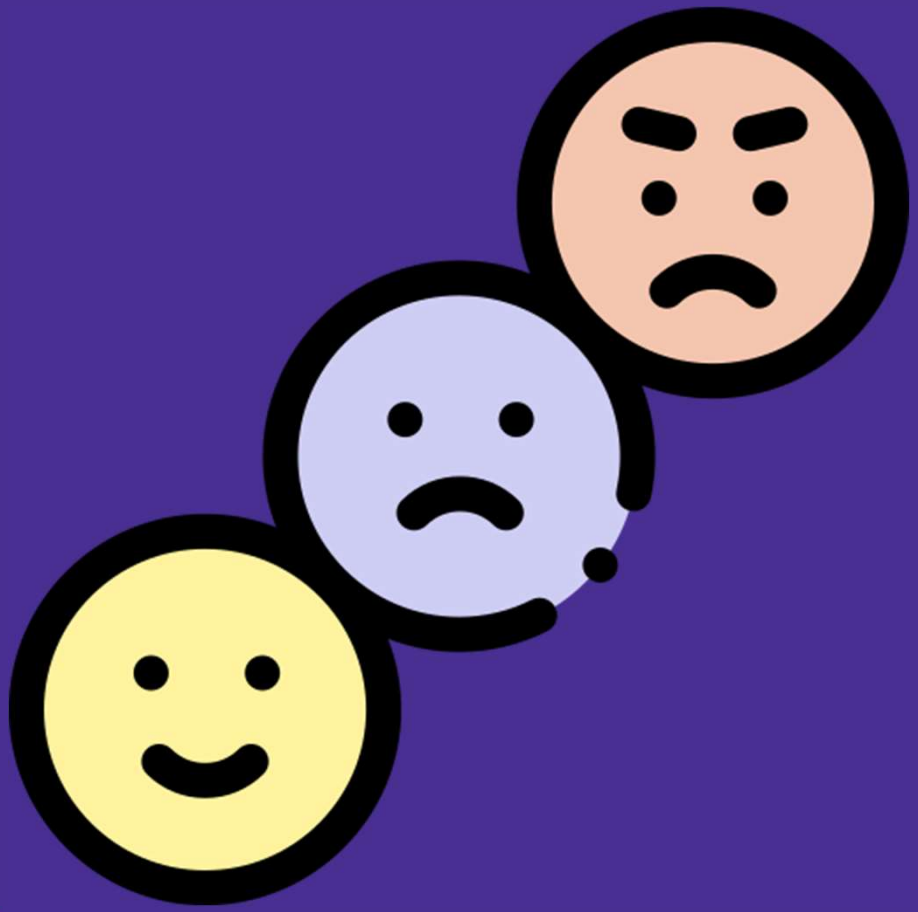
- Posture, gait, movements, activity levels
- Caregivers can confirm whether the observed state is typical or atypical
- People with autism can have changes in activity level and catatonia
- May be associated with underlying neurological damage (CP, epilepsy)
- Tourette's
- Autism (flicking, hand rubbing, spinning)
- EPSE from medication

Speech (Production)

- How do they usually communicate?
- May have dysarthria
- Abnormal prosody as part of lifelong pattern
- Lack of intonation and odd manneristic speech
- Echolalia common
- Social chatter e.g. in Williams syndrome



Mood



- Capacity (global delay or specific inability)
- Check with simple drawings and stories
- Lability / Instability
- Emotional activation, recognition and expression (anxiety often = aggression)
- May not want to express negative emotions in front of carers
- Blunted

Thinking and Perception

- Self talk may be developmentally appropriate
- Fantasy world
- Concrete thinking
- Tangentiality and circumstantiality may reflect impaired cognitive capacity
- Failure to provide context (Built the house)

Thinking and Perception

- Grandiosity (psychosocial masking)
- Persecutory experiences
- Obsessions or obsessive interests
- Hallucinations or thoughts
- ‘Auditorisation’ of thoughts
- Epileptic aura

Cognition

- Orientation may be impaired
- Delirium common (infection, medication)
- Look for change from base line
- Informal approach

Insight & Judgement

- May be accessible in some with mild ID
- Question about everyday issues (eg. “What do you need to do to get a job, a house, a partner” etc.)
- Do you have a problem or need help?
- Do you know what medication you are taking?
- Look for change from normal for that person
- Loss of abilities

Severe Disability

MSE for people with severe Intellectual Disabilities

- Observational
- Baseline Exaggeration
- Response to care givers and strangers
- Ability to engage
- Physical examination

Assessment tools

- Limited evidence base or availability
- Hampered by heterogeneity of ID
- Adjunct to clinical opinion
- Moss-PAS Diag (ICD-11 & DSM5)

https://moss-pas.com/video_player.php?hBdcjIfMfgaj

Link to a list of assessment tools suitable for assessing people with intellectual disability
https://idmhconnect.health/sites/default/files/media-document/assessment-tools_1.pdf

Barriers to good assessment

Consent

Overmedication

Assuming care is NDIS / Disability responsibility

Assumption that consumers are lacking skills

Stigma, discrimination

Clinician lack of knowledge

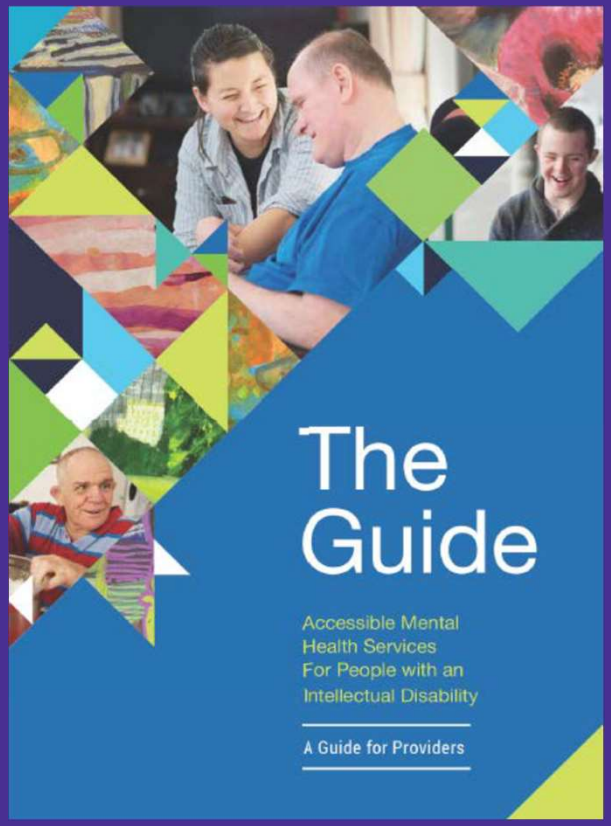
Lack of policy (*role and responsibilities of services unclear*)

Lack of resources (*rationing of services*)

Lack of service models (*inpatient models, therapeutic models*)

Diagnostic overshadowing & behaviour attribution (it's behavioural, its due to the ID)

Accessible Mental Health Services for People with Intellectual Disability: A Guide for Providers



- National framework
- Principles of service delivery
- Adapting clinical approach
- Improved access
- Integration of services
- Training
- Data collection
- Inclusion in policy

3dn.unsw.edu.au

Summary

- ✓ Standard psychiatric history and MSE (+ modifications)
- ✓ Formulation = Bio-Psycho-Social-Developmental
- ✓ Adapt your assessment / management process according to the needs
- ✓ Cope with uncertainty

Thank you

For a copy of these slides, please email vdds@svha.org.au with subject header *“Please send ID Assessment webinar slides”*

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