Multidisciplinary Approaches to Deprescribing

SA Intellectual Disability Health Service

Government of South Australia

Health
Northern Adelaide
Local Health Network

Acknowledgement of Country

SAIDHS recognises the Kaurna people as the traditional custodians of the land where we proudly work to deliver health and wellbeing services.

We also honour Kaurna Elders past, present and emerging. We recognise Aboriginal cultural authority, and their ongoing spiritual connection to country.

Presenters

Stephanie Searle – Snr Service Manager

Paul Jones – Nurse Consultant

June Buxton – Snr Pharmacist

Dr Bahman Zarrabi - Psychiatrist

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Session Outline

- Role of MDT in understanding the person and what's going on
- Importance of deprescribing
- Strategies for successful deprescribing
- Case Studies
- Q&A

We acknowledge people with lived experience of Intellectual disability and their families and carers and recognise their valuable contributions to Australian and global society.

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Check your assumptions…

- Personal beliefs, cultural & religious beliefs
- Past experiences
- Functional ability (can be different to chronological age)
- Social expectations
- Spiky profiles
- Understanding your own role in any interaction

Case Study - Dan

Reason for referral

"Dan is on a palliative pathway for recurrent bowel obstructions. Current medical treatment does not seem to be helping. Dan is continuing to have significant behavioural issues, including self harm, hitting and biting himself. Both mum and carers are feeling out of their depth with current management. Dan is on the NDIS and has support from local Palliative care nurse. Dan is non-verbal. He has presented to the Royal Adelaide Hospital a number of times. His mum is finding his care increasingly stressful and we would appreciate specialist assistance"

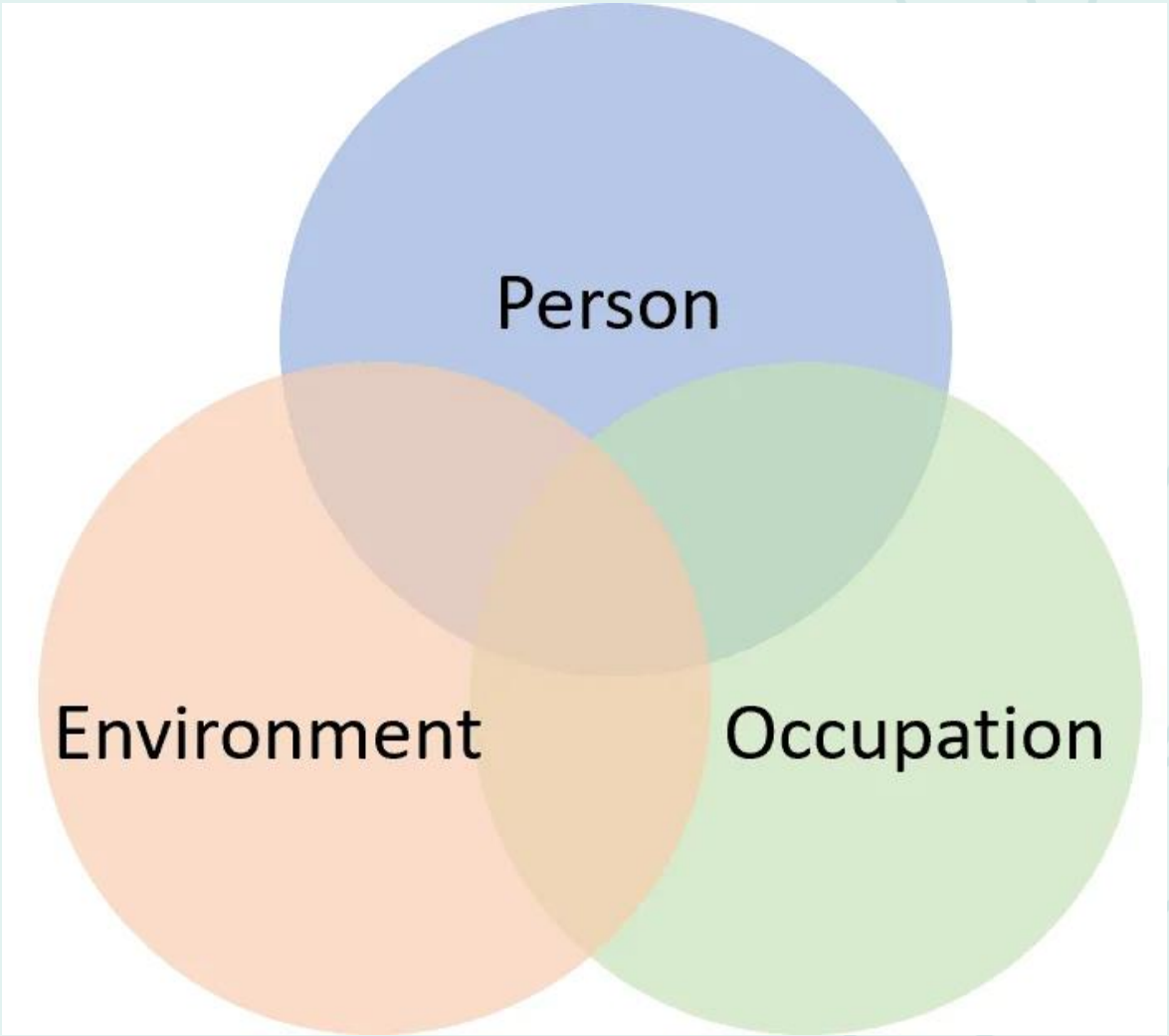
Case Study - Dan

- 21 year old male
- Born at 27 weeks premature – chromosome 8 inversion with intellectual impairment
- Lived with parents in regional area who are main carers
- Autism, Global Developmental Delay, chronic constipation, small bowel obstruction 12 y/y, scoliosis
- Behaviour:
- - Agitation/aggressive outbursts
- - More frequent outbursts, hit his head and bite his hands
- Used to enjoy swing, would clap and have happy vocalisations, now appearing sad and not enjoying things
- Current prescribed medications have limited effect and mum does not want any life prolonging measures that increases his suffering
- Weighs 35kg

Understanding the person and the situation

Role of multidisciplinary teams

Occupational Therapy



Case Study - Dan

- Sensory seeking
- Limited engagement in activity outside of home
- Equipment – paediatric, sourced by mum
- Pressure care
- NDIS funding available for therapy, not currently using

Social Work

- Psychosocial factors
  - NDIS supports
  - Carer burnout
  - Financial stressors
  - Living arrangements
- Legal guardianship
- Assessing for abuse/neglect concerns
- Perspectives of primary caregiver
- Case coordination

Case Study - Dan

- Cheryl and husband supporting Dan with severe ID and complex medical hx at home for 20 years
- Limited support, geographically isolated
- Carer burnout
- Limited education and support from clinicans.
- Mum states ‘they saved a baby at 27 weeks that perhaps shouldn’t have been saved?’

Case Study - Dan

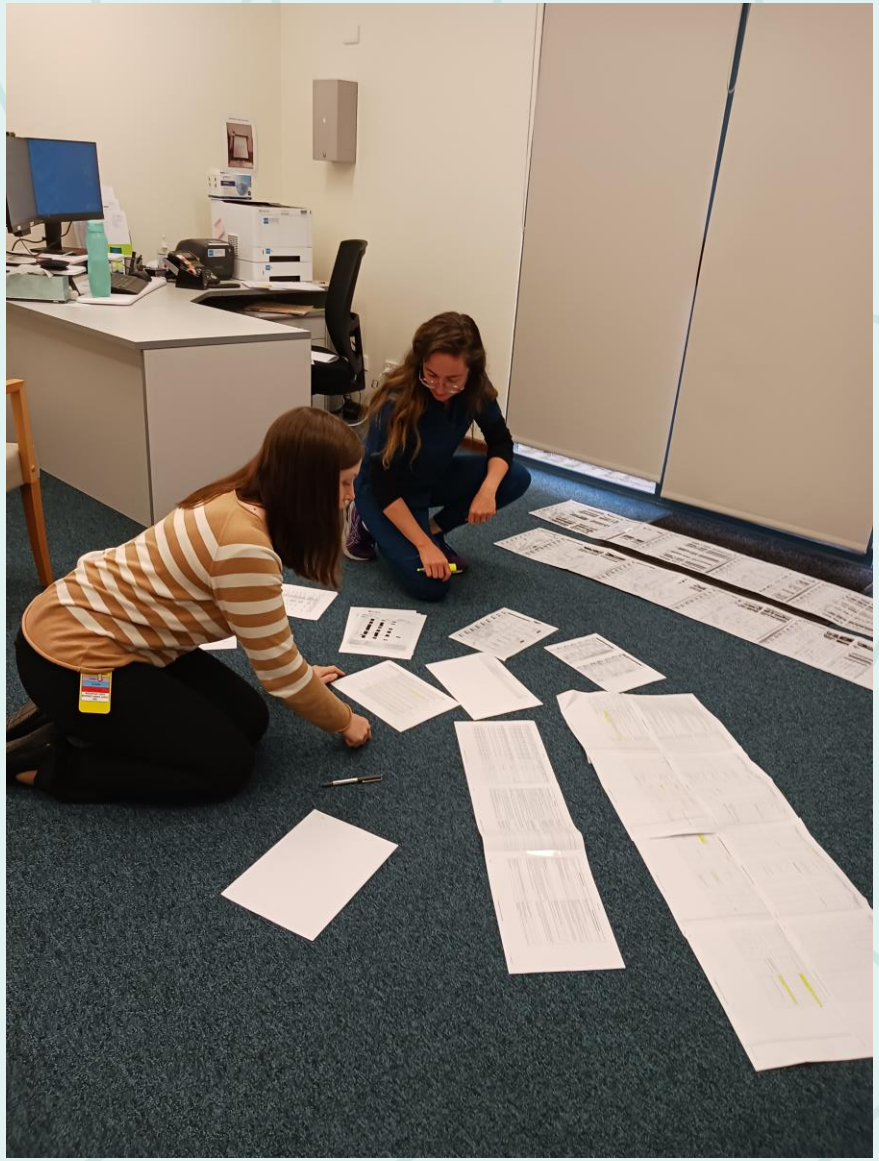
- ASU report filed for suspicion of neglect
- Team meeting with ASU including rehab physician, SAIDHS OT, SAIDHS Pharmacist, Clinical Care Coordinator
- Multi D home visit to investigate – to explore medication storage, diet, carer burnout
- Dietitian referral and review – recommended Fortisip to supplement caloric requirements

Communication

- *Everyone* uses behaviour to communicate
- Most people are actually quite skilled at hypothesising what a behaviour might be communicating
- When it comes to considering what behaviour is communicating in a disability context, things often break down

Understanding the behaviour

- Are these concerns longstanding or new? When did the change occur?
- Are there any patterns to the behaviour?
- Any changes in environmental factors?
- Is there an unmet need?



Physical Health & Nursing

Figure 14.21 Commonly missed causes of challenging behaviour in people with developmental disability

- abuse and trauma
- constipation
- dental pain and gum disease
- gastro-oesophageal reflux disease (GORD) and Helicobacter pylori infection
- hunger and poor nutrition
- infection—consider immunisation status
- medication adverse effects (see Medication reviews)
- poor physical activity
- psychiatric disorder (eg anxiety, depression)
- sensory deterioration or loss (eg vision, hearing)
- sleep problems
- social or environmental changes, including irregular contact, or loss of contact with a trusted carer or friend (eg change of staff or co-residents, death of a family member)
- thyroid disease
- unrecognised or poorly controlled neurological condition (eg epilepsy)
- unrecognised physical injury (eg fracture)

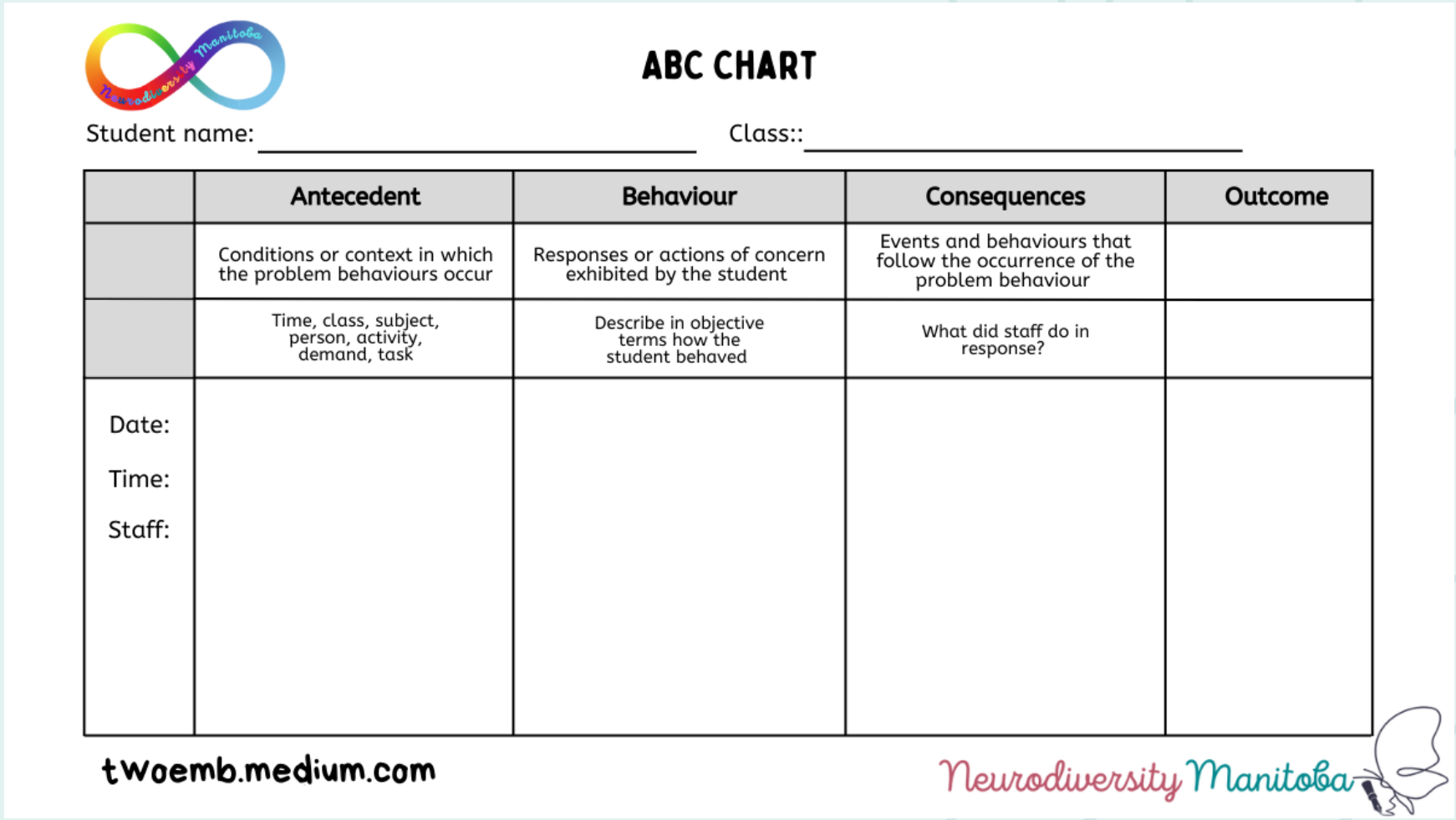
Challenging behaviour in a person with developmental disability [published Mar 2021]. In: Therapeutic Guidelines. Melbourne: Therapeutic Guidelines Limited; accessed 06/10/23. https://www.tg.org.au

Physical Health & Nursing

- ABC Charts

- Antecedents (A): what happened directly before the behaviour occurred.
- Behaviour (B): the specific action(s) or behaviour of interest.
- Consequences (C): what happened directly after the behaviour occurred.
- In high prevalence of behaviours. It would benefit the MDT if there was at least a weeks' worth of charts made available so we can try and identify patterns.

ABC chart



ABC CHART

Student name: _____ Class:: _____

	Antecedent	Behaviour	Consequences	Outcome
	Conditions or context in which the problem behaviours occur	Responses or actions of concern exhibited by the student	Events and behaviours that follow the occurrence of the problem behaviour	
	Time, class, subject, person, activity, demand, task	Describe in objective terms how the student behaved	What did staff do in response?	
Date: Time: Staff:				

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Neurodiversity Manitoba

Bowel action and Charting

- It has been identified that bowel discomfort can be a trigger for behaviours for our cohort. The inability to express discomfort and pain can lead to frustration and aggression towards themselves , parents or carers. Monitoring bowel movement is a key component to identify when and why a behaviour is occurring.
- Ensuring staff complete bowel charts will help provide the MDT the evidence to support the right course of action/treatment for the patient.

Bowel chart

BOWEL MOVEMENT RECORD

Name: ..... CHI: ..... Date Commenced: ...../...../.....

Date	Time	Comments i.e. volume, blood, mucous S – small M – medium L – large	Type 1 Separate hard lumps like nuts (hard to pass)	Type 2 Sausage shaped but lumpy	Type 3 Like a sausage but with cracks on surface	Type 4 Like a sausage or snake, smooth and soft	Type 5 Soft blobs with clear-cut edges (passed easily)	Type 6 Fluffy pieces with ragged edges, a mushy stool	Type 7 Watery, no solid pieces (entirely liquid)	Staff Initials

Case Study - Dan

- Periciazine + benztropine may contribute to constipation
- Benztropine contraindicated in bowel obstruction
- Periciazine prescribed with no primary psychiatric diagnosis (considered chemical restraint)
- ? Constipation causing pain

Case Study – Dan
At present during the first pharmacy review (late June):

- Benztropine 2mg mane
- Periciazine 2.5mg nocte
- Buprenorphine 15microg/hr patch
- Movicol sachets daily
- Morphine 5mg/mL – 1-2mL (5-10mg) prn – used approx. 4 doses x 5 mg/24 hours)
- Clonazepam oral drops 2.5mg/mL - 5 drops mane and midi and 7 drops at night
- Fleet enema – 1 enema daily prn
- Pantoprazole granules 40mg midi

Subcut medications recently prescribed (stopped abruptly – not weaned)

- Hyoscine butylbromide 20mg/mL inj – 20mg SC q2h prn for secretions
- Metoclopramide 10mg/2mL inj – 10mg q8h prn for N + V
- Midazolam 5mg/mL inj – 2.5mg SC prn
- Morphine 10mg/mL inj – 2.5mg SC hourly for pain

Case Study – Dan

Medical history

- Multiple admissions to hospital for bowel obstruction with complications including being managed with NGT - developed COVID-19 between the time of 2017-2022
- In an admission in October 2022, mum had approached clinicians for options regarding medically assisted death for Dan -> referred to Palliative care, reviewed via telehealth
- Behaviours of concern

- Screaming and punching self in the head (noted when interrupted from his favourite activity, watching TV to shower or change incontinence pads. Dan no longer seems happy

Case Study - Dan

- Concerns regarding restrictive practice using chemical restraints
- High doses of opioids and benzodiazepines with significant changes overtime
- High risk of death due to respiratory depression on the background of low body weight. BMI est 12-13. Although this might have been acceptable had he been receiving EOLC, there is no clear indication that he was actively dying at that moment
- Significant change in behaviours last week after stopping in SC meds due to withdrawal rather and inability to absorb medications orally or inadequate doses

Early July

- Subcut line reinserted as Dan's behaviour escalated following removal of the line-> identified due to withdrawal of medications. Midazolam and morphine subcut injections reinstated

Joint home visit – Early August

- Medication history

– discuss options for iron supplementation

- Recommended tapering plan under direction of rehab physician

- discuss how tapering SC meds will need to complete prior to moving Dan to 1 in 4 weeks respite care

- PBSP to identify and approve current restrictive practices

- Counselling on plan if Dan does not tolerate the reduction of medication

Pharmacy

- Medication history
- Recent changes to medications
- Previously tried medications
- Investigations of behaviours of concern & pain management
- Bowel management discussed – including deprescribing benztropine and periciazine
- Monitoring recommendation for screening nutritional deficiencies
- Oral intake – only drinks about 500mL of liquid per day – limited oral intake potentially trigger BOC -> dietitian referral
- Internal referral for OT and speech pathologist to optimise environment and communication
- Opioid tapering dose discussed (once strategies in place to support behaviours and absence of clear identification of pain)
- Education and advice

Deprescribing and quality of life

Psychiatry

Effective Prescribing & De-prescribing

RPU presentation

Dr Bahman Zarrabi

Psychiatrist- SA Intellectual Disability Health Service (SAIDHS)

12 April 2025

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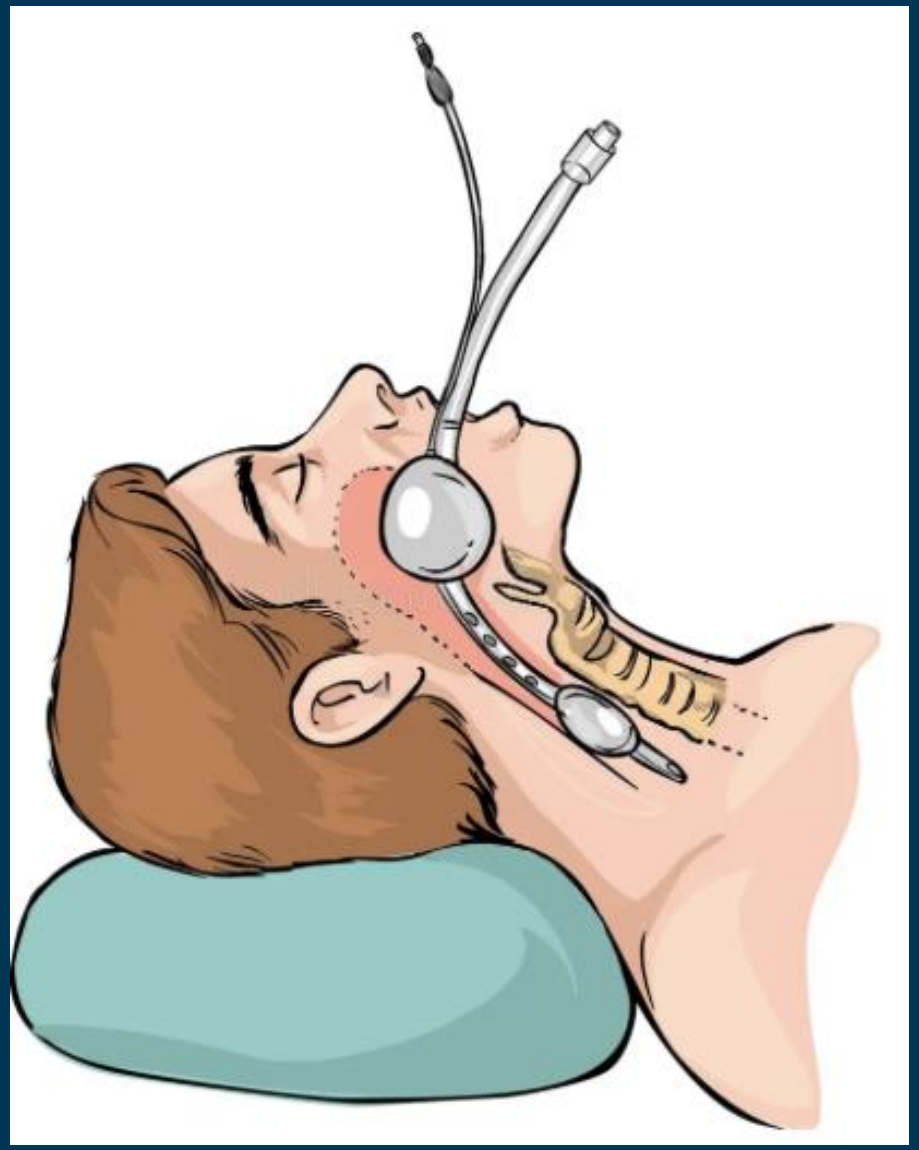
Jake

21 yo, ASD (L3) and ID (moderate), non-verbal. Generally settled but more recently randomly goes to foetal position and clutches his tummy. Can occur anywhere. This time in car, when carer didn't stop, he attacked the carer. Then lied down in the road. Mum took him to hospital. Agitated in ED > code black > ICU intubated purely for sedation



Ben

19 yo, severe autism and ID. On risperidone by paediatrician for behaviours. Gained significant weight, in wheelchair. Significant aggression when taken to day option and when returns home, mainly targeting mum. She is at her wits end, pushing for additional medication

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44 yo man, ID, lives in shared SIL. Forensic hx: inappropriate behaviour towards minors, required constant supervision. In a complex same sex relationship with another resident, difficult to establish if consensual. Frequent episodes of aggression.

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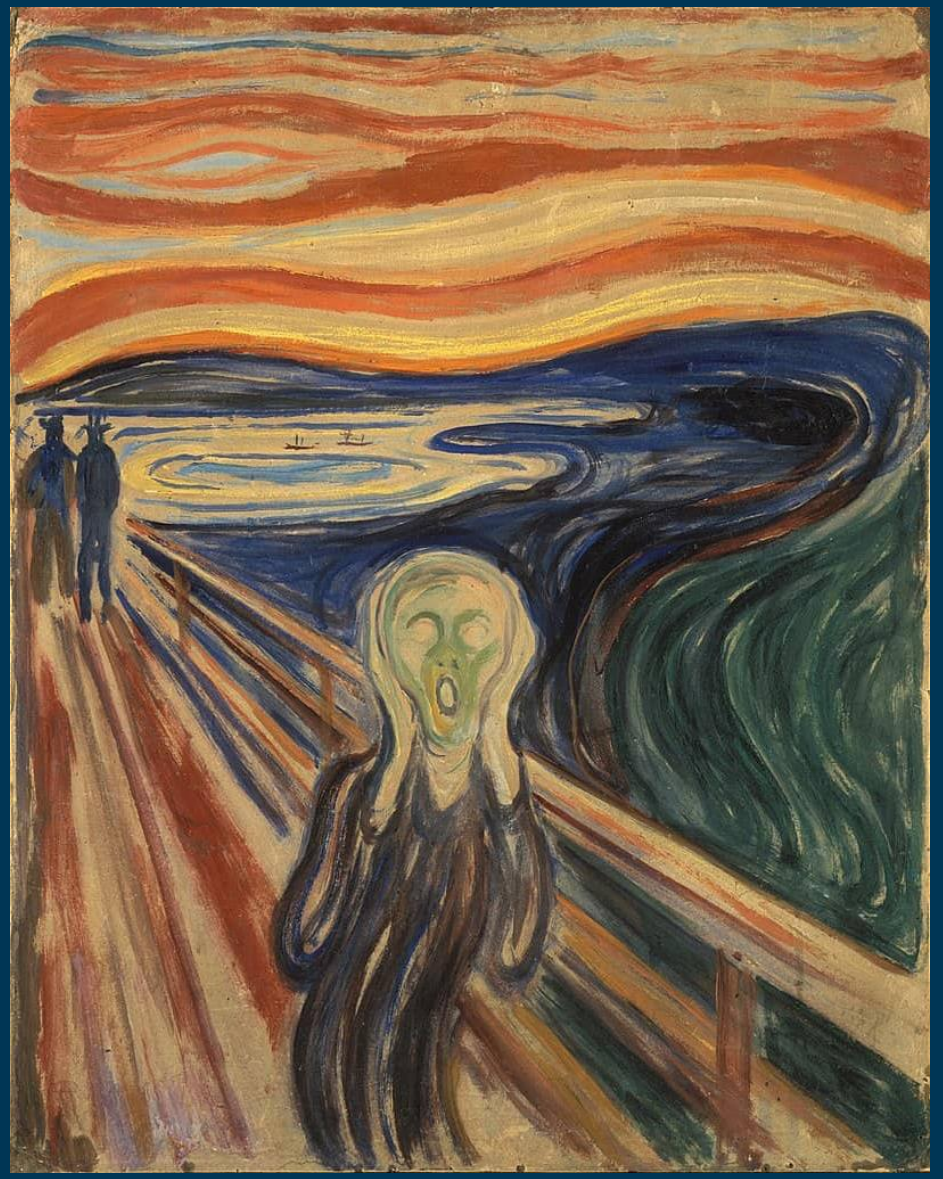


Evidence Base

- In the psychiatry of ID, the evidence base for the use of psychotropic medications is extremely limited
- Reasons:
  - Very few well-designed randomised controlled trials (RCTs)
  - Adults with ID frequently have additional health problems that preclude them from being recruited into studies.
  - Measurement tools for symptoms and outcomes vary, not standardised, and prone to rater bias
  - Mixed results
- On the basis of current evidence, the use of psychotropics could neither be supported nor be refuted

Aggressive Behaviour

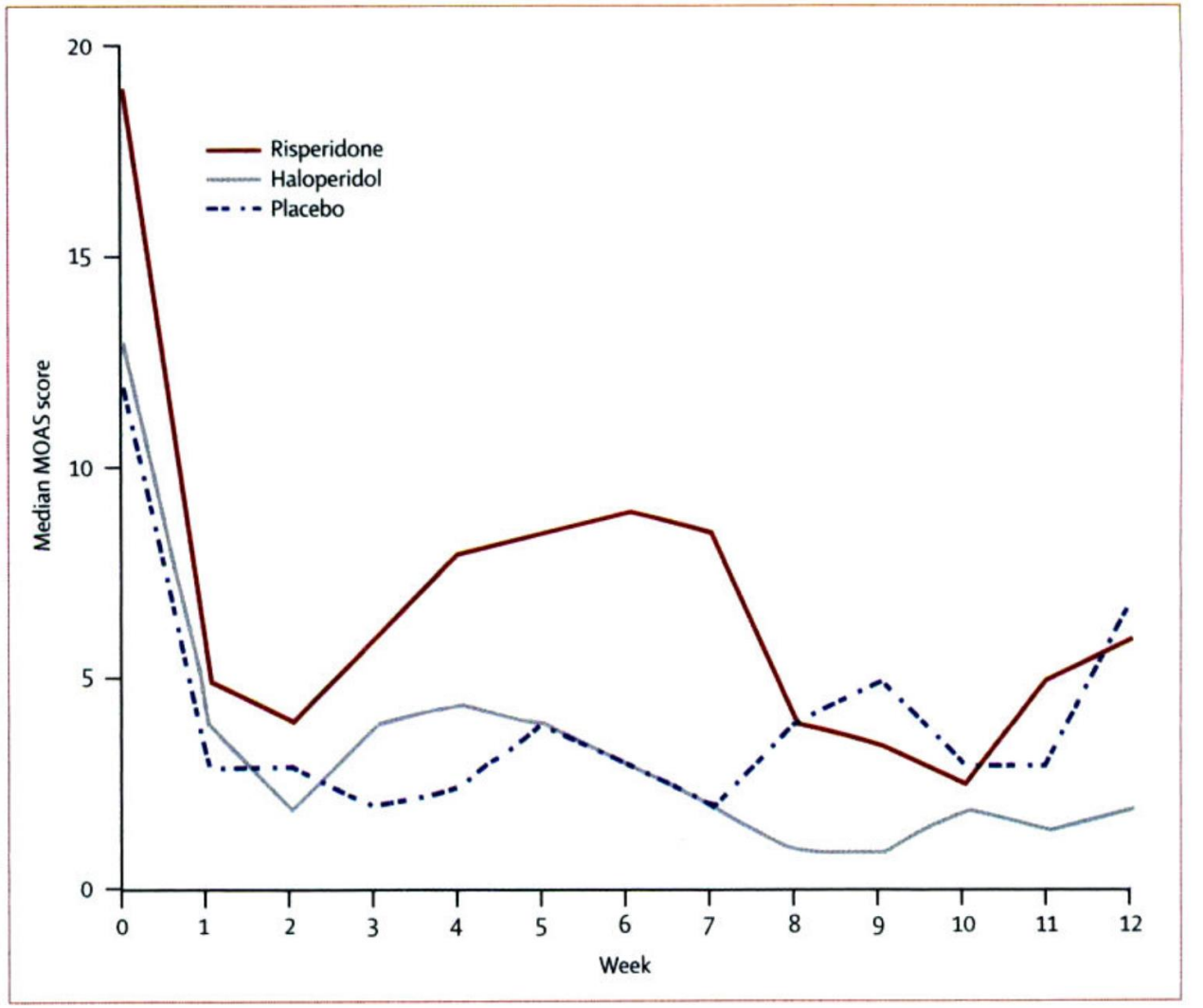


Figure 2: **Median aggression scores on the modified overt agression scale (MOAS) during the first 12 weeks of the trial**

Tyrer P, Oliver-Africano PC, Ahmed Z, Bouras N, Cooray S, Deb S, et al. Risperidone, haloperidol, and placebo in the treatment of aggressive challenging behaviour in patients with intellectual disability: a randomised controlled trial. The Lancet (British edition). 2008;371(9606):57–63

Does this data inform the practice of prescribing psychotropics for people with ID?

- 32%-85% of the ID population are prescribed antipsychotics for behavioural disturbances
- UK primary care data 1999-2013 : 49% prescribed, only 21% had a psychiatric diagnosis
- Off-label prescription for problem behaviour
- Polypharmacy and using high dose is common

Why?

- Pressure from professionals/care givers for immediate resolution of a problem
- Limited resources available for changing the environment
- Lack of appropriately training for care givers
- Shortfall of psychiatrists
- Lack of input from clinical psychologists, behavioural specialists, occupational therapist, clinical pharmacists, speech therapists, etc.

Antipsychotic	Dose	DDD effective dose eq.	Current
Risperidone	6mg	120 %	Ceased
Olanzapine	20mg	200 %	15mg (150%)
Aripiprazole	30mg	200 %	Ceased
Ziprasidone	160mg twice-a-day	400 %	Ceased
		920 %	

Assessment

Challenges in assessment

- Cognitive and communication impairments: Difficult to achieve understanding of subjective experience
- Difficult to ascertain degree of subjective distress and impairment in function necessary for defining a psychiatric disorder
- Baseline exaggeration
- Characteristic symptomatology can be significantly altered by the nature of ID syndrome, e.g. neurovegetative symptoms, interpersonal relationships, etc. (Diagnostic overshadowing)
- Intellectual distortion
- Developmental biases: mismatch between chronological age and developmental stages
- Psychosocial masking
- Expression of psychopathological symptoms as behavioural equivalent

Assessment- Environment

- Big space
- Not too medicalised, not childish
- Safety issues
- Sensory tools
- Communication tools

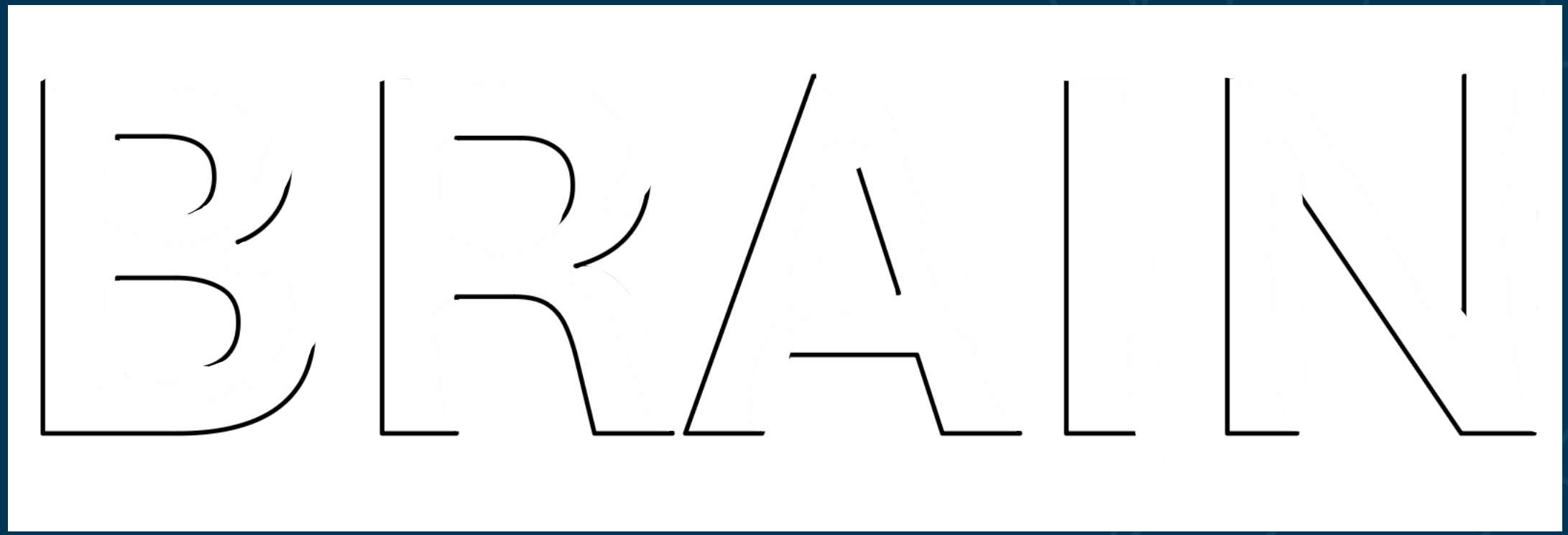
Assessment- Assessor

- Do your research first
- Allocate adequate time
- Collateral information
- Tailor your communication
- Explain the process
- Be flexible with the format
- Pay attention to patient through the review
- Note the affect/body language and decide about direct approach or talking to informant first
- Frequently provide positive feedback and remind them they are not in trouble

Assessment- Team

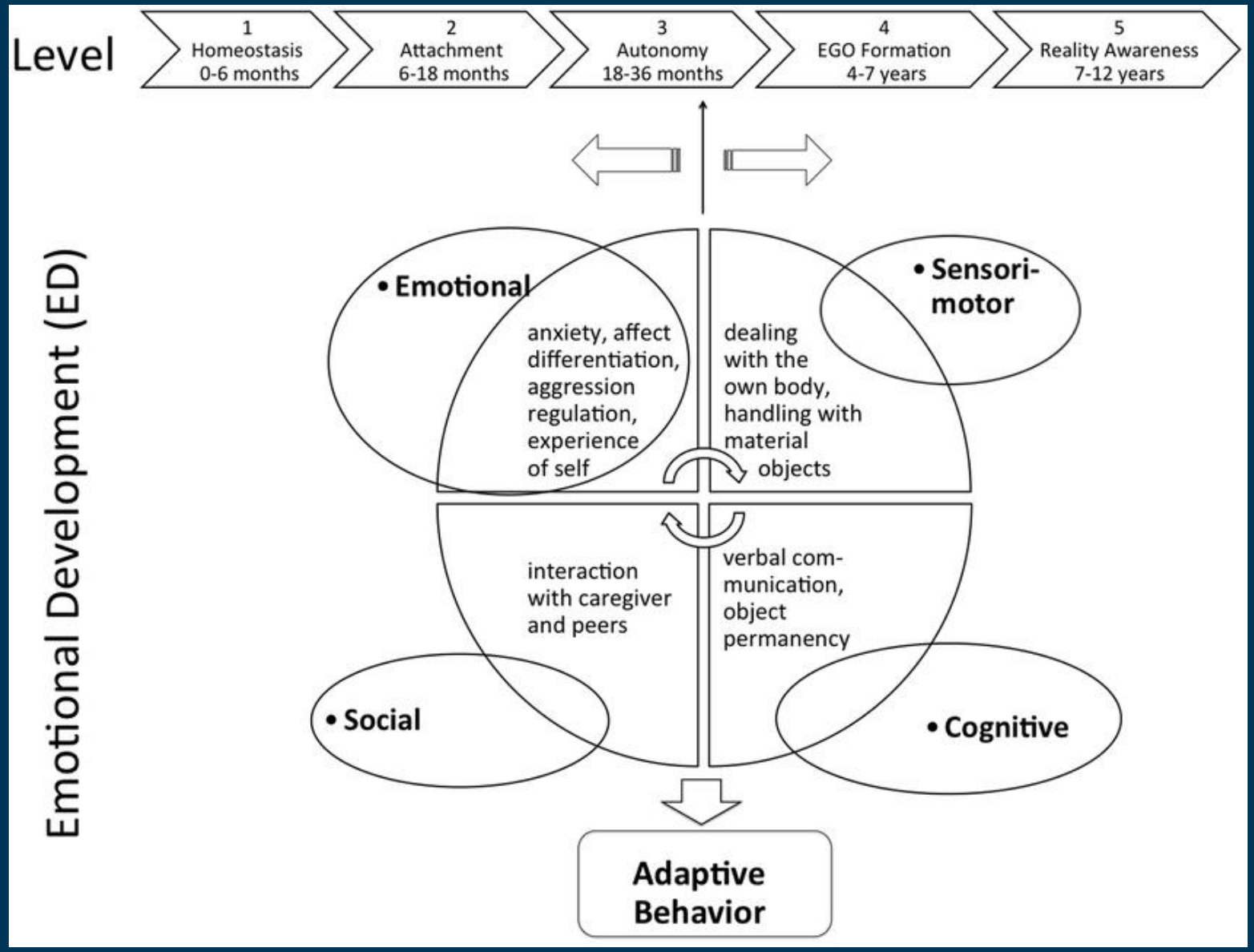
A multi-professional, person centred, integrated, bio-psycho-social approach is needed. Done by different professionals working together to build up a shared project with person, their family and care givers, looking at:

- ID assessment (cognitive and adaptive behaviour)
- Medical and personal Hx
- Language (communication assessment profile: CASP)
- Physical/ functional assessment
- Psychiatric and Mental state assessment
- Assessment of problem behaviour (ABC, ABA, CATS)
- Assessment of support needs (Support Intensity Scale: SIS)
- Assessment of quality of life, should be the main outcome measure, (QoL)
- Emotional development (Scheme of Appraisal of Emotional Development: SAED, SED-R, SED-R2, SED-S)



Emotional Development

- Prof. Anton Dosen (1939-2023)
- Cognitive and emotional brain functions are located in different brain regions
- The stages of emotional development may differ from the cognitive reference age



The emotional development approach includes affective, cognitive, sensorimotor and social aspects relevant to development

SED-S

Domains

1. Relating to own body
2. Relating to significant others
3. Dealing with change
4. Differentiating emotions
5. Relating to peers
6. Engaging with the material world
7. Communicating with others
8. Regulating affect

Developamnetal Stages

1. Adaptation (0-6 months)
2. Socialisation (7-18 months)
3. First Individuation (1.5-3 years)
4. Identification (4-7 years)
5. Reality Awareness (8-12 years)
6. Social Individuation (13-17 years)

SED-S

Overall Emotional development phase:

- **Phase 2 (equivalent to 7-18 months in typically developing children)**

Profile of Emotional Development, for [redacted] aged 59yrs, 4months

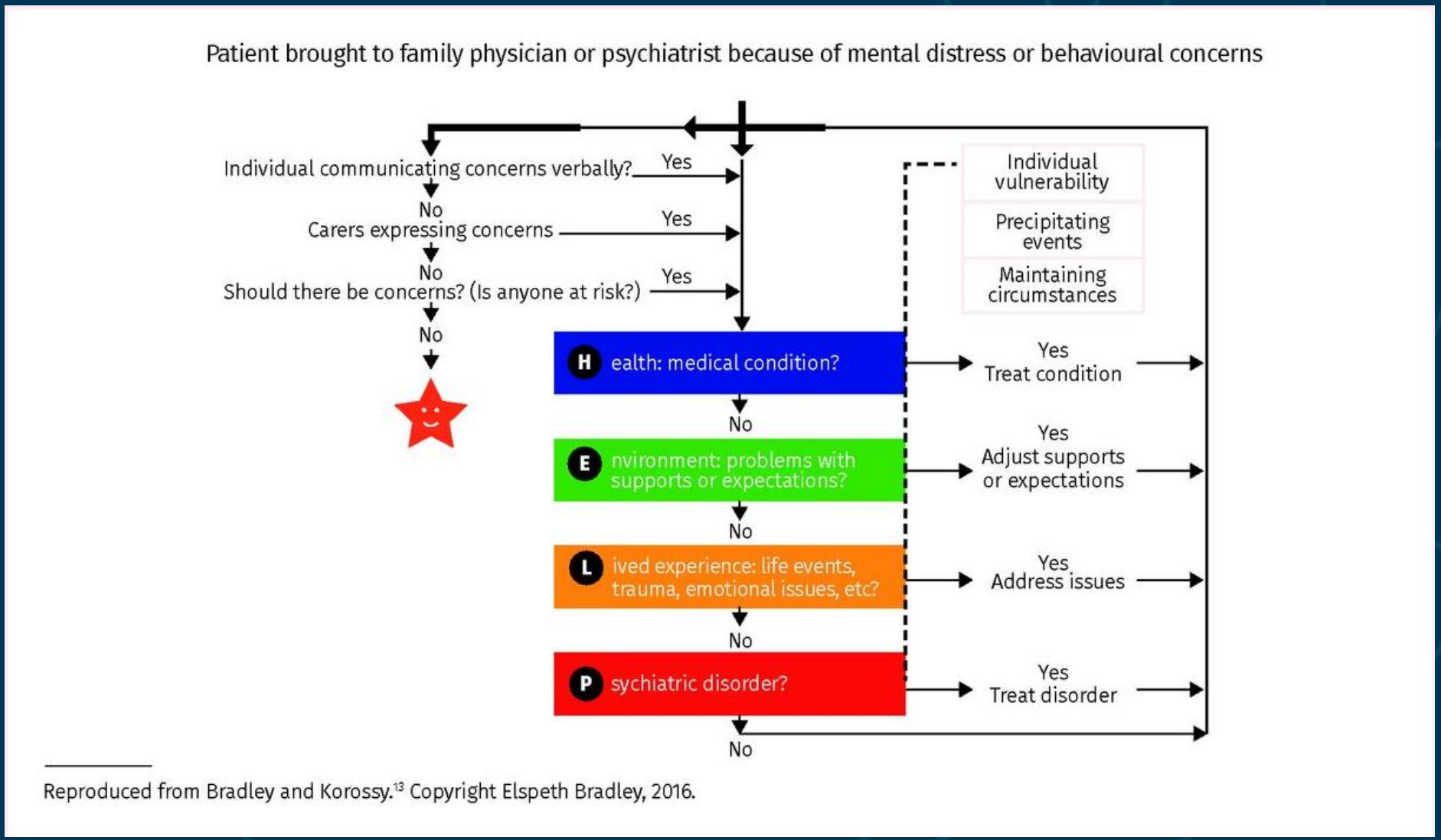
Legend: White Box = skills not achieved, Blue Box = skills achieved, Yellow Box = skills emerging

Phase	Emotional Development Domains							
5. Reality Awareness (8-12 years)								
4. Identification (4-7 years)								
3. First Individuation (1.5-3 years)								
2. Socialisation (7-18 mths)								
1. Adaptation (0-6mths)								
	1	2	3	4	5	6	7	8

SED-S

Domain	Key Emotional Development Milestones
1. Relating to own body	*Phase 2:* Developing a mental map of his body, managing physical sensations *Phase 3:* Sees own body as centre of the world and deliberately uses it to communicate and get what he wants, developing fine motor skills.
2. Relating to significant others	*Phase 2:* extremely dependent on others *Phase 3;* Asserts will and independence, long separations from caregivers is hard. Balancing growing need for independence with emotional need for closeness.
3. Dealing with change	*Phase 2:* Developing his understanding of material object permanence.
4. Differentiating emotions	*Phase 2:* Expressing pleasure and displeasure, enjoying contact with significant others, developing attachment with significant others. *Phase 3:* Experiences pride, jealousy, sadness and fear (fear of physical injury, loss of autonomy)
5. Relating to peers	*Phase 1:* Peers are not recognised, seen as objects.
6. Engaging with the material world	*Phase 2:* Manipulates things within reach, explores materials without a form. *Phase 3:* Focused, deliberate investigation of materials, more interested in the process than the final result.
7. Communicating with others	*Phase 2:* Communication directed to others,uses small number of words, imitates what he sees and hears. *Phase 3:* begins to use language specifically to relate to others, uses 'I', expresses opposition 'no'. Communication focused on immediate needs, feelings, wants & trying to provoke reactions in others.
8. Regulating affect	*Phase 2*: Requires significant others for maintaining emotional control *Phase 3;* Starting to manage emotions on own by satisfying physical or emotional needs, begins to show the ability to compromise, aggression is directed at the source of frustration (eg; objects or people imposing limits on own will.

Assessment

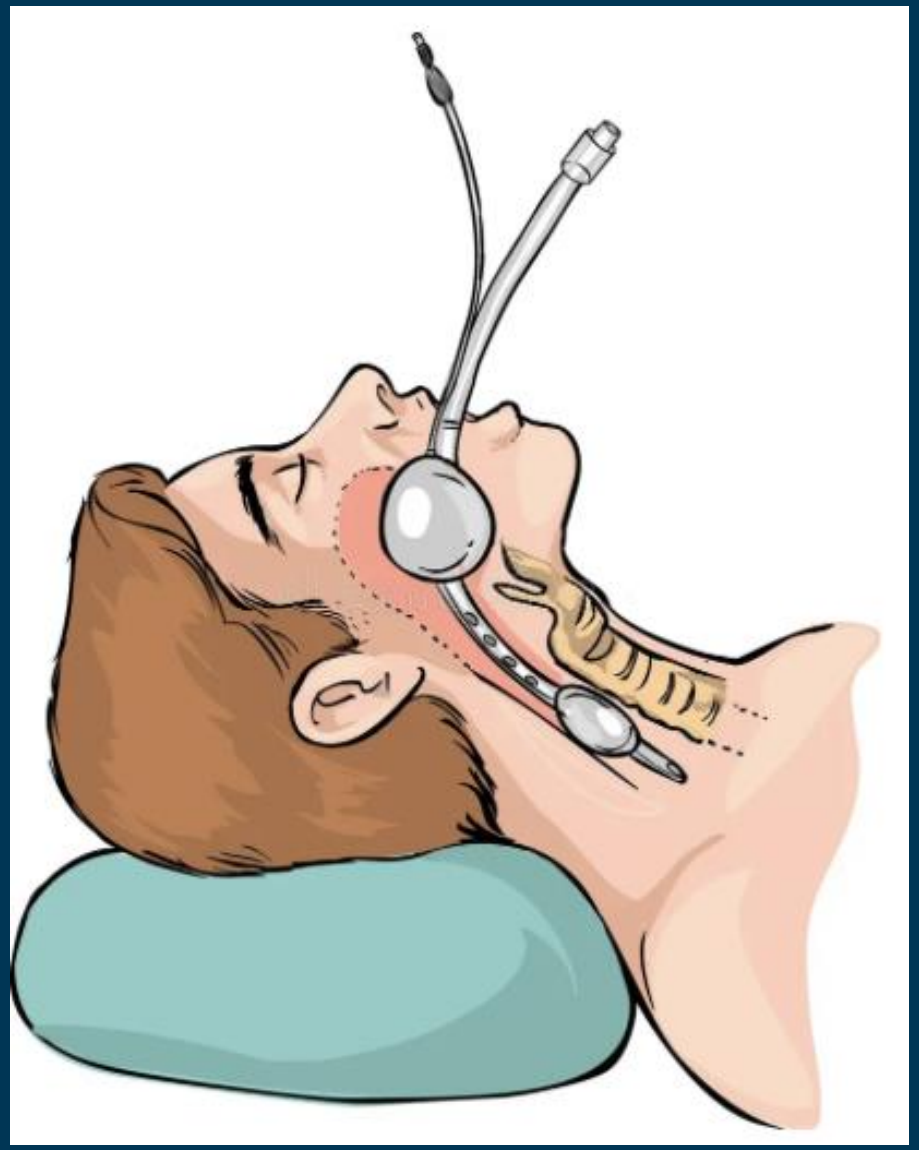


Reproduced from Bradley and Korossy.[13] Copyright Elspeth Bradley, 2016.

Jake

21 yo, ASD (L3) and ID (moderate), non-verbal. Generally settled but more recently randomly goes to foetal position and clutches his tummy. Can occur anywhere. This time in car, when carer didn't stop, he attacked the carer. Then lied down in the road. Mum took him to hospital. Agitated in ED > code black > ICU intubated purely for sedation

Gluten sensitivity: Health



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Punishment: Environment

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44 yo man, ID, lives in shared SIL. Forensic hx: perpetrator of sexualised behaviour towards minors: required constant supervision. In a complex same sex relationship with another resident, difficult to establish if consensual. Frequent episodes of aggression.

Previous Trauma: Lived Experience

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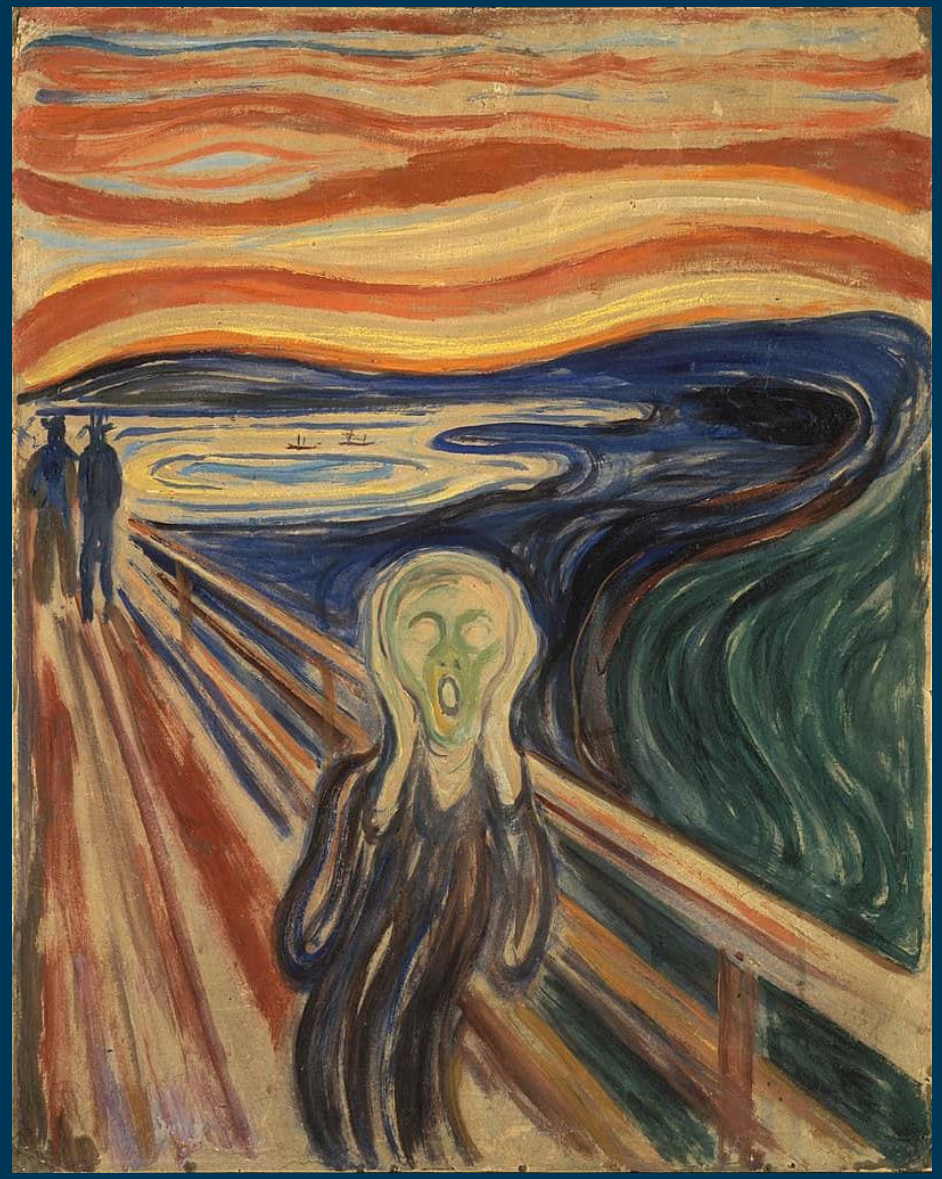
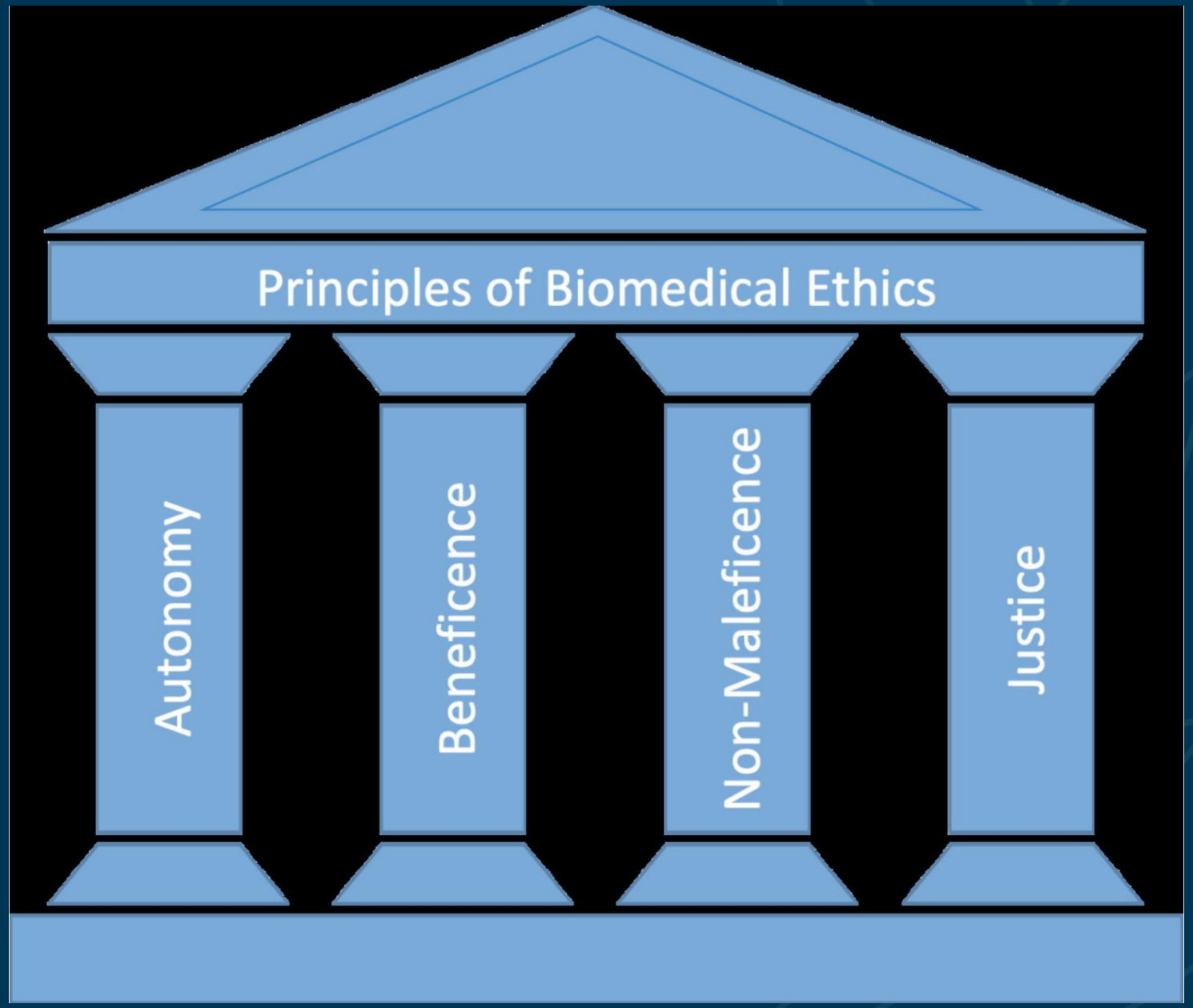
Bipolar Disorder: Psychiatric



Striking the Balance



- Balance of:
  - Duty to provide care to patient and protect him/her from harm
  - Duty to protect others from harm
  - Respect for autonomy and wishes
  - Avoid causing harm

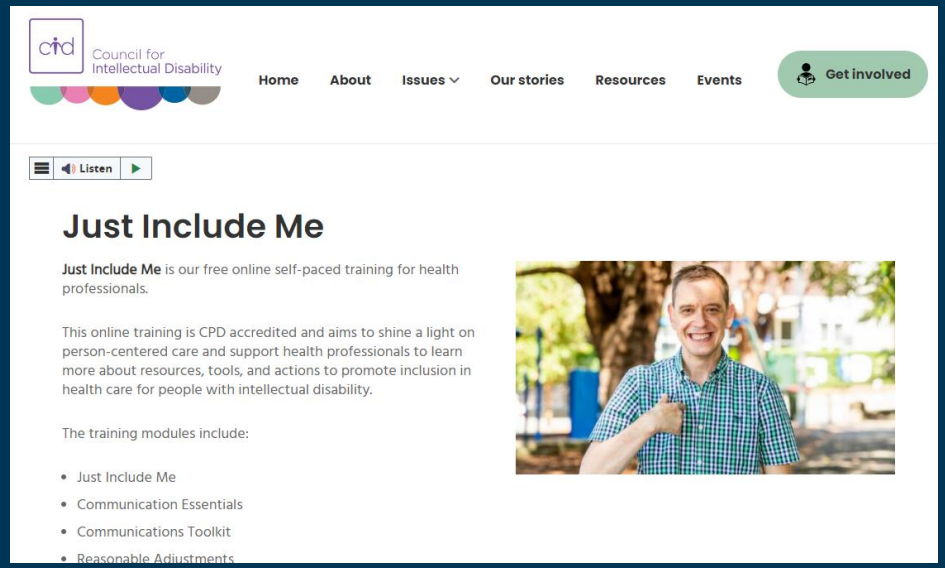
- Drinking excessively, sodium 121 (135-145), NO fluid restriction
- Running into traffic, damaging cars: NO physical restraint
- Eating excessively, significant weight gain and T2DM, NO lock on fridge

Other areas to focus:

- Advocacy and better allocation of resources
- Hospitals and inpatient wards
- Prisons and justice system

Questions

Resources



SA Intellectual Disability Health Service (SAIDHS)

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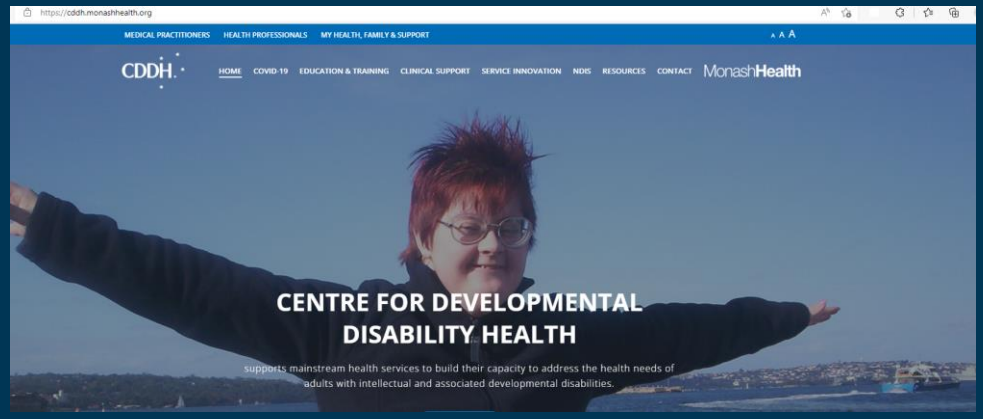

EVERYONE HAS A STORY. MATTERS. CONTRIBUTES. GROWS.

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