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Multidisciplinary Approaches for Reducing Chemical Restraint in Practice

SA Intellectual Disability Health Service

March 2024

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We acknowledge this land that we meet on today is the traditional lands for the Kaurna people and that we respect their spiritual relationship with their country.

We also acknowledge the Kaurna people as the custodians of the Adelaide region and that their cultural and heritage beliefs are still as important to the living Kaurna people today.

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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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Session Outline

- Five important principles for reviewing chemical restraint prescribed for people with Intellectual Disability
  - Multidisciplinary focus
  - Case studies

1. All behaviour is a form of communication

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Consider these scenarios

- Putting the bins out onto the kerb is a job you typically manage. However, you've had a huge argument with your partner so you decide that you're not going to do so this week.
- You've organised to catch up with an old friend 3 times but they've cancelled on the day each time.
- You're inconsistent putting your dishes in the dishwasher, tending to just leave them in the sink. Your housemate has been placing your dirty dishes that you left on the sink by your bedroom door.

Behaviour is a form of 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

Disability and behaviour

- Behaviours might be hard to relate to – this makes the message it is communicating harder to receive
- Just because the behaviour doesn't make sense to you, doesn't mean there isn't a message there
- It's easier to dismiss a behaviour as meaningless when you can't understand what it's saying or it seems illogical

Trial and error

- It's okay to not know the message
- Make a long list of potential messages the person might be communicating
- Pick a hypothesis and test it – be brave!
- Examine the response to your test – does the behaviour change? How does it change?
- Try and try again!

Always consider…

- Safety/fear (does the person feel safe?)
- Regulation (does the person have ways to experience regulation?)
- Pain (is the person in pain?)
- Boredom (does the person have sufficient stimulation?)
- Relationships/connection (is the person feeling isolated?)

Real life examples of behaviour and their messages

Behaviour	Message
Self-harming (scratching and biting self, head banging) when toileting	I'm in pain due to constipation and I don't know how to tell you or manage this pain. When I hurt myself a different way, you usually help me achieve relief which incidentally helps my constipation pain.
Not eating or drinking once arriving to hospital	I've never had the opportunity to choose my own food, I don't even know how to make this kind of decision. If the food is there, I'll eat it.
Eating non-food items (tissues, bark, plastic)	I hate this puree diet you've made me eat. I want to feel something different in my mouth. I need texture and variation! You won't let me have real food so I'll eat what's available.
Collecting/hoarding food, but not eating it	I believe this food is poisoned and I'm trying to prevent others from eating it and getting sick.

Are you open to hearing the message?

- Is it just that you don't like the message that is being communicated?
- We don't have the right to stop a behaviour just because we would prefer it to be something else
- Everyone has the right to communicate whatever they want
- *How* we communicate what we want has parameters:
  - Safety
  - Social 'acceptability'*

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2. Chemical restraint should be part of a bigger picture approach to supporting an individual and their care team.

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When a flower doesn't bloom, you fix the environment in which it grows, not the flower.

Alexander den Heijer

The bigger picture – Speech pathology and behaviour

- Many people struggle to understand how a speech pathologist relates to behaviour support

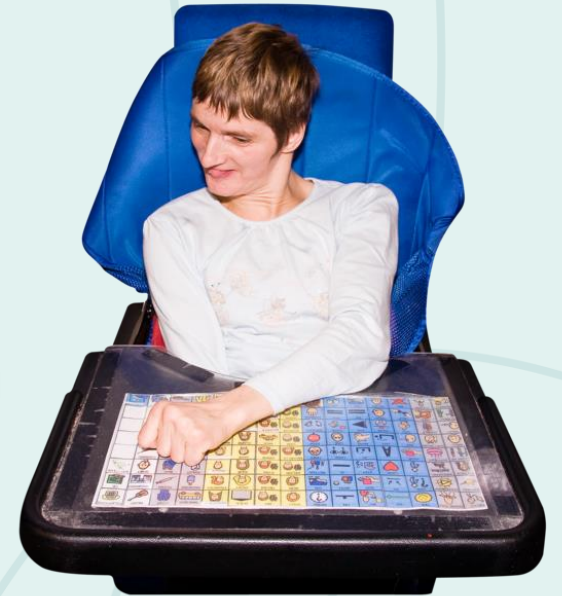
- Behaviour and communication are intimately related

The SP’s focus:

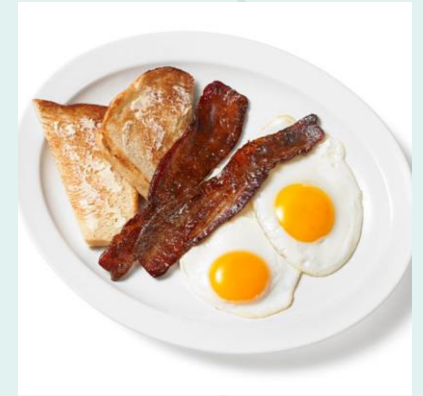
- What is the underlying message behind the behaviour?
- What is an accessible means of communicating for this person?
- How can I support this person to learn a new “language?”
- How can I upskill this person’s support team to learn a new “language?”
- How can I change the environment to support communication access?
- How can we make communicating fun, motivating, easy and worthwhile?

Having a voice

- AAC is not a quick fix
- Being heard and understood is incredibly powerful
- Having a voice can “solve” many behaviours of concern
- We use the easiest option available to us to communicate – behaviours of concern are often easy, effective and achieve the desired outcome



Are we actually creating the behaviour?



CASE EXAMPLES

- Sam’s carers constantly prompt her to use a knife and fork when she is eating her bacon and eggs. Sam prefers to use her fingers. Breakfast is a “battle” for everyone and usually ends in tears.
- Lisa’s Mum won’t take her to the shops anymore because every time they go she has to purchase a ball of wool. If she can’t, it causes a “meltdown”, often involving property damage.
- Frank loves rearranging the pantry at day options. He would do it all day if he could. He doesn’t eat the food, just organises it. Day options aren’t sure they can support him anymore, because when they try and involve him in other activities, he displays verbal aggression towards others.

3. Not all behaviours meet the legal threshold for chemical restraint

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Behaviours

"Behaviours of concern"

"Challenging Behaviour"

"Disturbed behaviours"

"Complex behaviours"

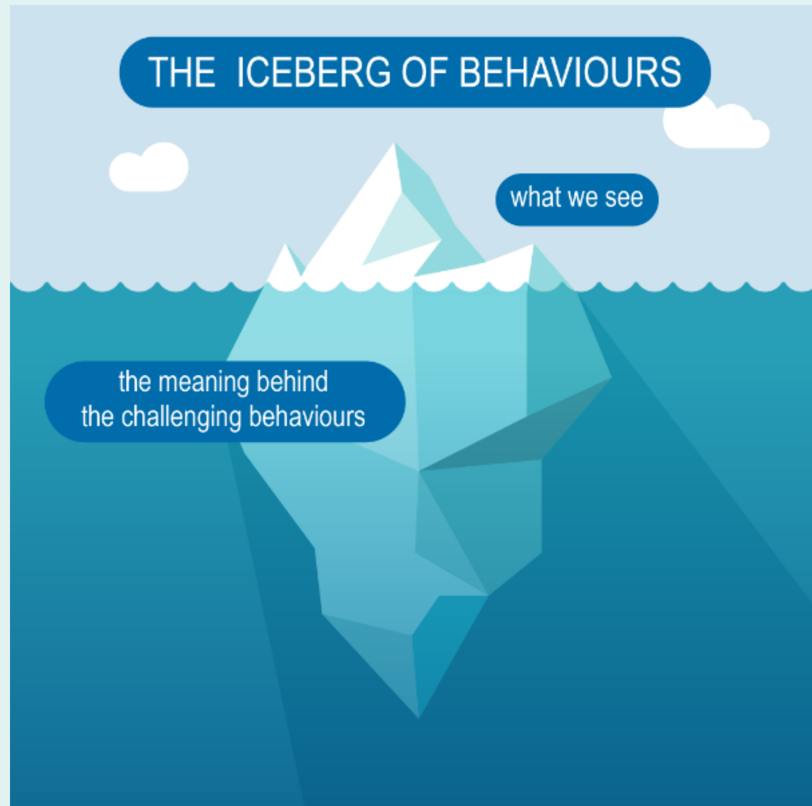
- Restrictive practices may only be authorised where it is required to minimise and prevent harm, and no other strategies are sufficient to address the risk.

Restrictive Practices Authorisation

The legislation defines behaviours of concern that create a risk of harm as:

- the use of force against another person
- self-harm
- behaviour that substantially increases the likelihood of physical or mental harm
- property damage
- spreading biological matter.

Behaviour is a form of communication



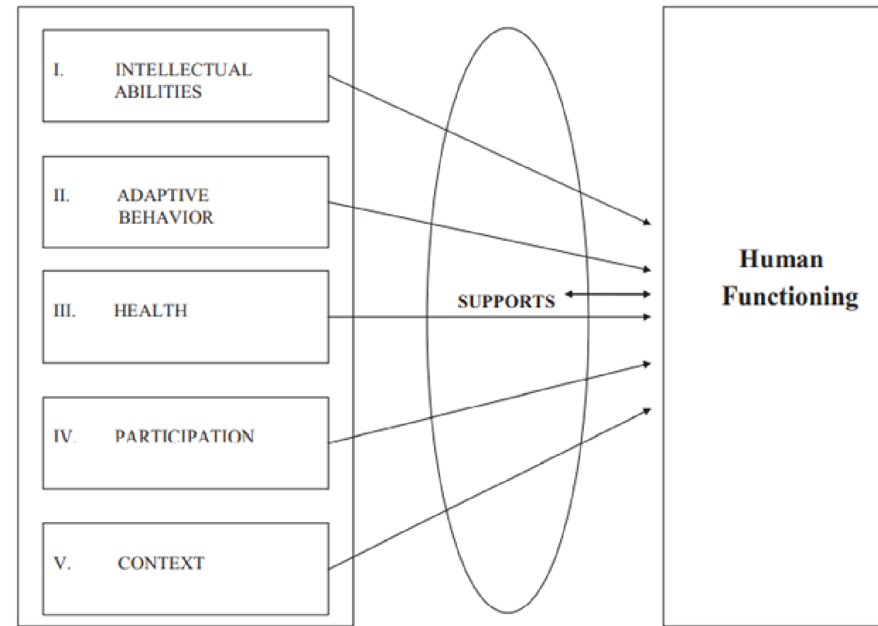
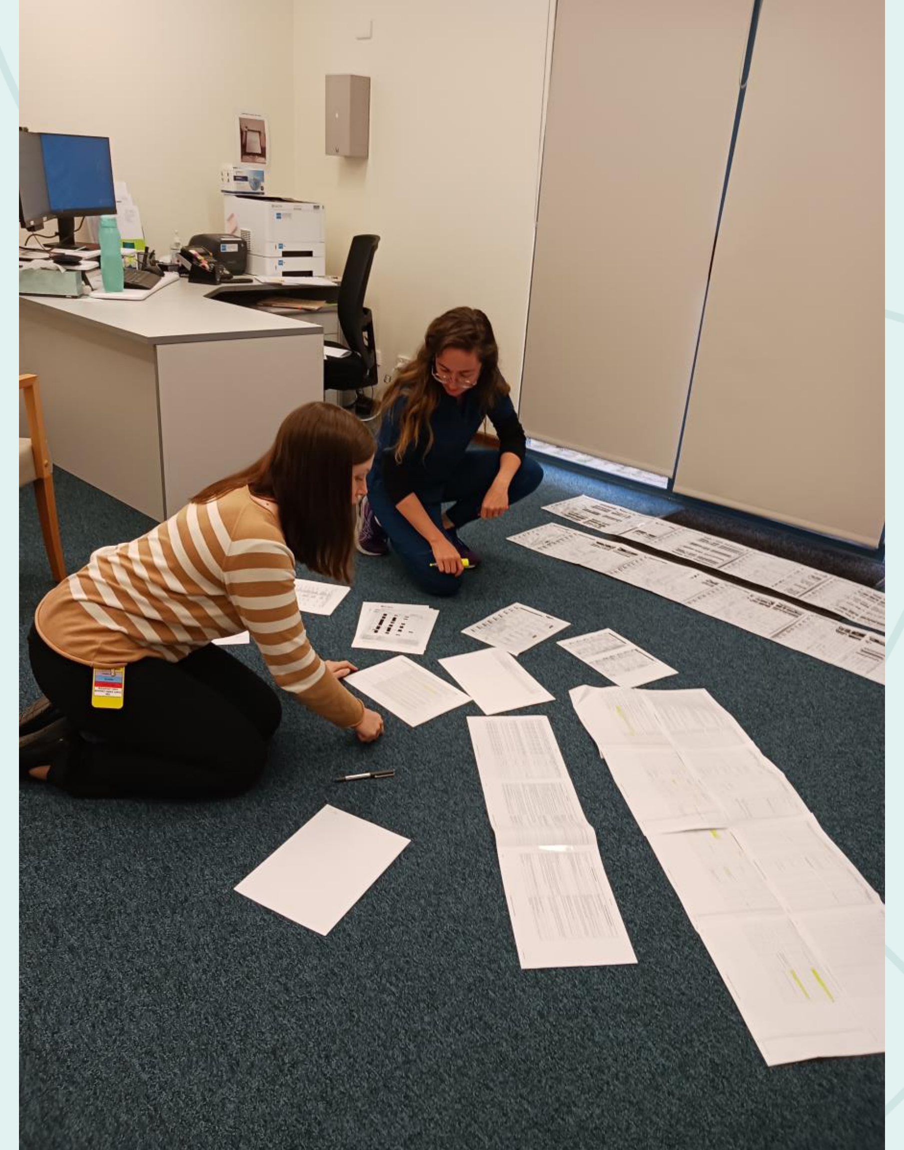


FIGURE 2

American Association on Intellectual and Development Disabilities conceptual framework for human functioning (Schalock et al., 2010).

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?



Causes of behaviours – Physical health

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

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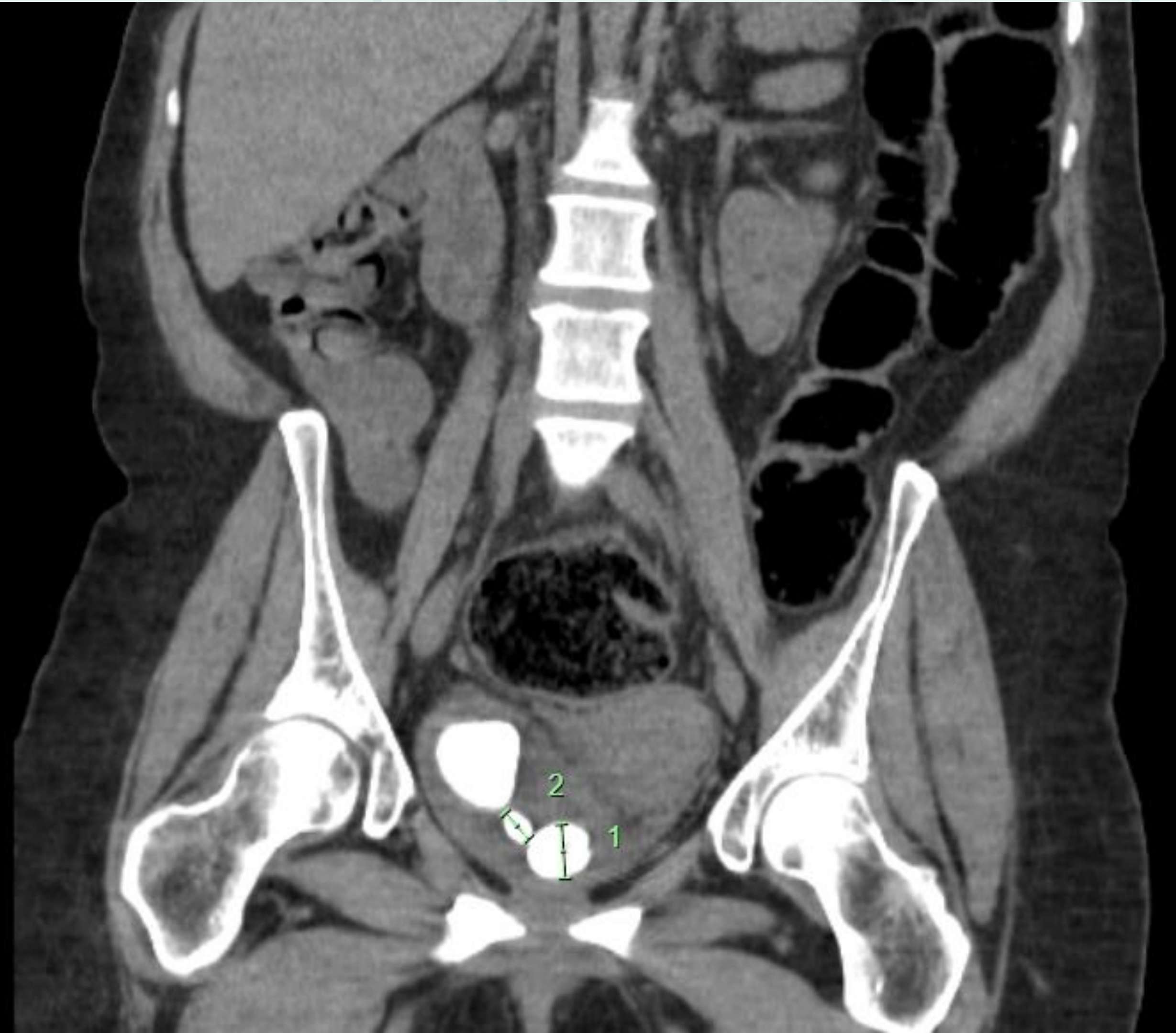

(1) Length: 1.84 cm
(2) Length: 1.17 cm, Ratio1/2: 1.57

Causes of behaviours – Mental health

- People with ID have significantly higher rates of mental illness than people without ID.
  - At any one time between 20% and 40% of people with intellectual disability will have a mental health disorder. Schizophrenia is 2-4 times more prevalent than in the general population.
  - Despite this, people with ID, as well as their families and carers, often report difficulties in accessing mental health services.
  - Barriers to accurate diagnosis include atypical presentations and difficulties describing symptoms due to cognitive and/or communication difficulties.

RANZCP (2022)Position statement: Intellectual disabilities: Addressing the mental health needs of People with ID, Available https://www.ranzcp.org/clinical-guidelines-publications/clinical-guidelines-publications-library/intellectual-disabilities-id-addressing-the-mental-health-needs-of-people-with-id (Accessed 01/03/24)

NSW CID (2013) National Roundtable on the Mental Heath of People with Intellectual Disability, Available https://cid.org.au/wp-content/uploads/2014/05/roundtable-mental-health-intellecutal-disability-2013-background.pdf, (Accessed 01/03/24)

4. Chemical restraint needs to be judicious, appropriate, and regularly monitored and reviewed.

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Chemical restraint

- Section 6 (b) of the NDIS (Restrictive Practices and Behaviour Support) Rules 2018 defines chemical restraint as:

  'the use of medication or chemical substance for the primary purpose of influencing a person's behaviour. It does not include the use of medication prescribed by a medical practitioner for the treatment of, or to enable treatment of, a diagnosed mental disorder, a physical illness or a physical condition'.

- Important to identify the purpose of the medication to allow effective review

RISK
BENEFIT

Chemical restraint

- Antipsychotics have a range of effects on physical health
  - EPSE (tremor, rigidity, parkinsonism)
  - Morbid obesity (increases appetite which can lead to new behaviours)
  - Obstructive sleep apnoea
  - Hyperprolactinemia
  - Diabetes
  - Increased cardiovascular risk/stroke/arrhythmia
  - Sedation/respiratory depression
  - Anticholinergic burden – dry mouth (dental), urinary retention, constipation, headache, GI upset
- It can be more difficult to monitor the effects of these medicines in people with ID
- They are also more likely to experience uncommon or atypical side effects

Case Study – Bethany

46yo lady with Turner Syndrome and subsequent Intellectual Disability. Lives in supported accommodation with 3 other clients with 24/7 support.

Past Medical History:

Turner Syndrome, Epilepsy, Hearing impairment (bilat aids),Diabetes,

HTN, hyperlipidaemia, probable TIA (2009), hypothyroidism, R) femur # (2019), IHD, Aortic Stenosis, schizoaffective disorder, ?early onset dementia

Medications:

Metformin 1000mg BD
Aspirin 100mg
Lamotrigine 75mg BD
Escitalopram 20mg
Ralovera 5mg
Saxagliptin 5mg

Gliclazide 60mg MR
Atorvastatin 40mg
Paracetamol 1000mg BD
Progynova 1mg mane
Valproate 1000mg BD
Risperidone 2mg TDS

Calcium carbonate 500mg
Vitamin D 1000U
Pantoprazole 20mg
Thyroxine 50mcg

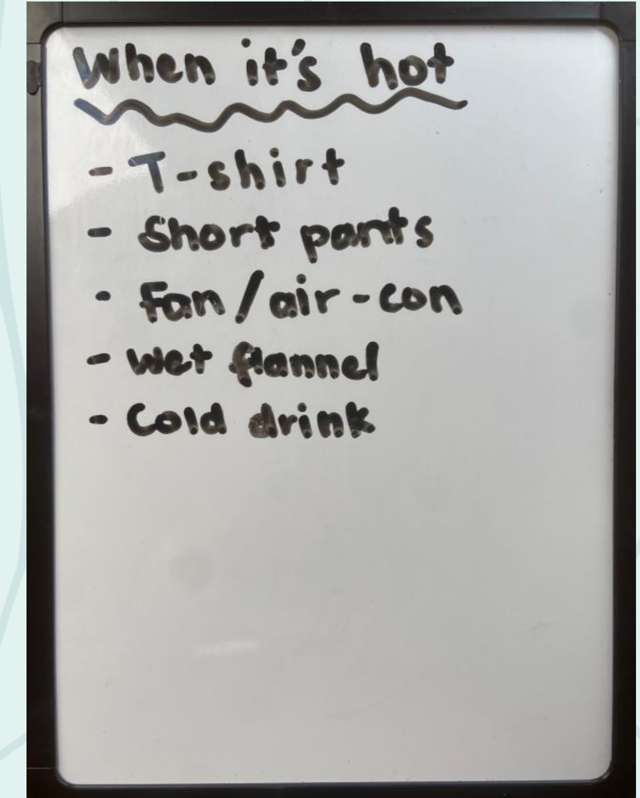
GP referral:

"Bethany is on multiple medications for schizoaffective disorder and epilepsy. Can you please provide psychiatry review of her medications?"

Carers describe demanding behaviours, including repeatedly wanting drinks and to go to the toilet. Over the past 6 months she has also started taking all her clothes off in inappropriate settings.

Pharmacy, Speech Pathologist and Physical Health (GP) review as well as Psychiatry

- Poor diabetic control, leading to excessive thirst and frequent urination
  - Referral to Endocrine/diabetes education
- Stripping found to be due to feeling 'hot'
  - Alternative strategies discussed
  - Investigating cause - ?Cardiac medicines
- Psychiatry review scheduled
  - Bethany is currently taking the highest recommended dose of risperidone
  - Side effects noted – EPS, Metabolic



Consumer story – Cassie

29 yo living with her parents

Past Medical History:

ID (unknown cause), Dyspraxia, Irregular PV bleeding, Iron deficiency, Eczema

Current Medications:

Diazepam 2mg tablet – 2mg daily prn

Paracetamol 500mg tablet - 1g qid prn

Mefenamic acid 250mg capsule – 1 capsule bd prn

Risperidone 0.5mg po bd *Recently commenced

Cassie has limited verbal communication and attends Bedford day options 5 days per week. She is dependent on family to assist with all activities of daily living and has double incontinence. She currently has NDIS funded support for Psychology and Speech pathology.

GP referral:

"In the recent 12months she has developed quite difficult to manage behaviours. She has very high and low moods with tearfulness and florid mood swings. More recently and of concern to her parents is that she has begun to self harm."

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Collateral history from Cassie's mother

- Behaviours of concern and they were closely linked with menstruation

Examination and fasting bloods

Abdominal x-ray showed extensive faecal loading which was likely contributing to her distress

- Noted to have increased appetite and changes to her bowel habits since starting risperidone

- Laxatives prescribed
- GP to commence a trial of Oral Contraceptive Pill
- Occupational Therapy for sensory profiling
- Psychologist for ASD assessment
- Psychiatry review at SAIDHS
  - PBSP
  - Independent living options
  - Review of medications – wean risperidone once period pain managed effectively

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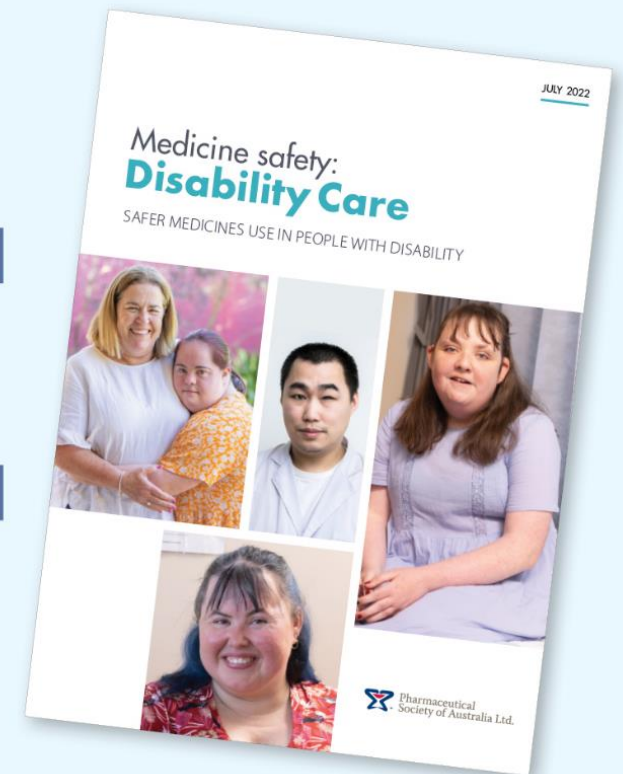
Home medicines review

There is a need for better promotion of pharmacist-led medication reviews for people with ID

- A MBS funded health assessment can assist identifying patients who may benefit from a pharmacist-led medication review
- People with cognitive difficulties eligible (Item 900)

Medicine safety: disability care report

> We need a greater focus on medicine safety to address the health and life expentancy gap for people with disability.



Home medicines review

- Home medicines review easy read document now available
  https://www.countrysaphn.com.au/wp-content/uploads/2022/10/Medicines-Review_Easy-Read_FINAL.pdf

- Pharmacists Optimising Medicines in People with Intellectual Disability and Autism (POMPIDA)
  - Contact Pharmaceutical Society of Australia sa.branch@psa.org.au to be linked with a POMPIDA accredited pharmacist

5. Just because someone needed chemical restraint in one season of their lives does not mean they will always need it

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Case study - Hannah

Hannah is a 31yo female referred to SAIDHS for advice re her medications

PMHx: Intellectual disability, Autism, Depression, Obesity Metabolic Syndrome, Fatty liver disease

Adverse drug reaction – Sodium valproate (hyperammonaemia)

Relevant medications

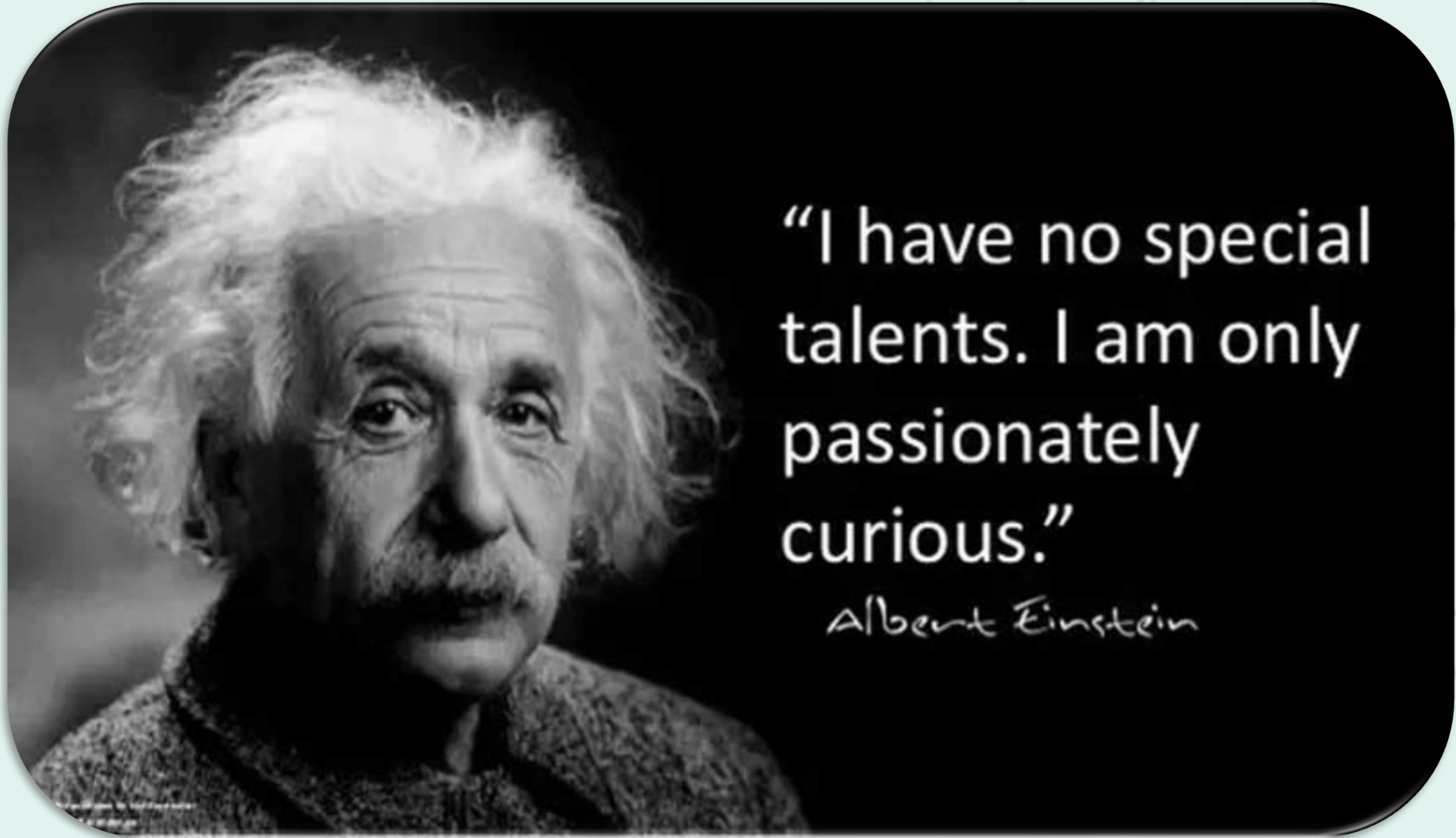
- Escitalopram 20mg po mane
- Quetiapine 200mg XR po mane and 400mg XR po nocte
- Olanzapine 5mg po tds
- Carbamazepine 150mg po mane, 200mg po nocte

- *Hannah had 35 presentations to ED in 2012 (age 19), including four admissions for behaviours of concern and situational crisis.*
- *During this period it was noted that due to the environmental nature of her behaviours, the hospital environment would be counterproductive.*
- *However while her accommodation and supports were arranged she had repeated hospital presentations and multiple incidents involving challenging behaviors which led to escalation of her psychotropic prescription.*

“Restrictive practices should only be used by prescribed NDIS providers in limited circumstances, as a last resort, in the least restrictive way and for the shortest period possible in the circumstances”

Disability Inclusion (Restrictive Practices—NDIS) Amendment Act 2021

Chemical restraint requires regular monitoring and review


"I have no special talents. I am only passionately curious."
Albert Einstein

Thank you

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