Striking the Balance: Effective Prescribing and Deprescribing

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National Centre of Excellence in **Intellectual Disability Health**

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We acknowledge the contribution of all data custodians, the NSW Centre for Health Record Linkage, and the Australian Institute of Health and Welfare for providing the data and performing the linkage. We also acknowledge the Independent Health and Aged Care Pricing Authority for providing the ICD-10 AM information.

National Centre of Excellence in **Intellectual Disability Health**

Emerging controversy? → Defining the problem → How to prescribe well → More difficult areas → Resources and next steps

Talk Outline

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Talk Outline

Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability

Public Hearing 4: Health care and services for people with cognitive disability [including intellectual disability, autism, all forms of acquired cognitive disorder]

Public hearing 6: Psychotropic medication, behaviour support and behaviours of concern

Public hearing 10: Education and training of health professionals in relation to people with cognitive disability

Key finding “systemic neglect” in health care

“Following Public hearing 6, we found psychotropic medication is overprescribed to people with cognitive disability, particularly as a response to behaviours of concern.” (pg 84)

- prescription of psychotropic medication is failing to adequately protect people with disability.
- difficulty with distinction between using psychotropic drugs to treat a diagnosed mental health condition and using them as a chemical restraint
- medical practitioners lack training or experience
- data and research gap
- performance indicator gap

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Recommendation 6.35 Legal frameworks for the authorisation, review and oversight of restrictive practices

Recommendation 6.36 Immediate action to provide that certain restrictive practices must not be used

Recommendation 6.37 Data collection and public reporting on psychotropic medication

Recommendation 6.38 Strengthening the evidence base on reducing and eliminating restrictive practices

Recommendation 6.39 Improving collection and reporting of restrictive practices data

Recommendation 6.40 Targets and performance indicators to drive the reduction and elimination of restrictive practices

Recommendation 6.29 Improve specialist training and continuing professional development in cognitive disability health care

Joint Statement on the Inappropriate Use of Psychotropic Medicines to Manage the Behaviours of People with Disability and Older People

On 21 March 2022, the Australian Commission on Safety and Quality in Health Care, the Aged Care Quality and Safety Commission and the NDIS Quality and Safeguards Commission have launched the Joint Statement on the important issue of inappropriate use of psychotropic medicines with people with disability and older people as a form of restrictive practice, and committed to collaborative action to reduce it.

https://www.safetyandquality.gov.au/publications-and-resources/resource-library/joint-statement-inappropriate-use-psychotropic-medicines-manage-behaviours-people-disability-and-older-people

Emerging controversy? → **Defining the problem** → How to prescribe well → More difficult areas → Resources and next steps

Talk Outline

People with Intellectual Disability- a Diverse Population

Level of abilities

Complexity of physical health issues

Aetiology of disability- some associated with specific behavioural phenotypes and health trajectories/complexities

Social determinants of health

Diversity of experiences and interactions with support systems

Health literacy and access to resources to support health care journeys

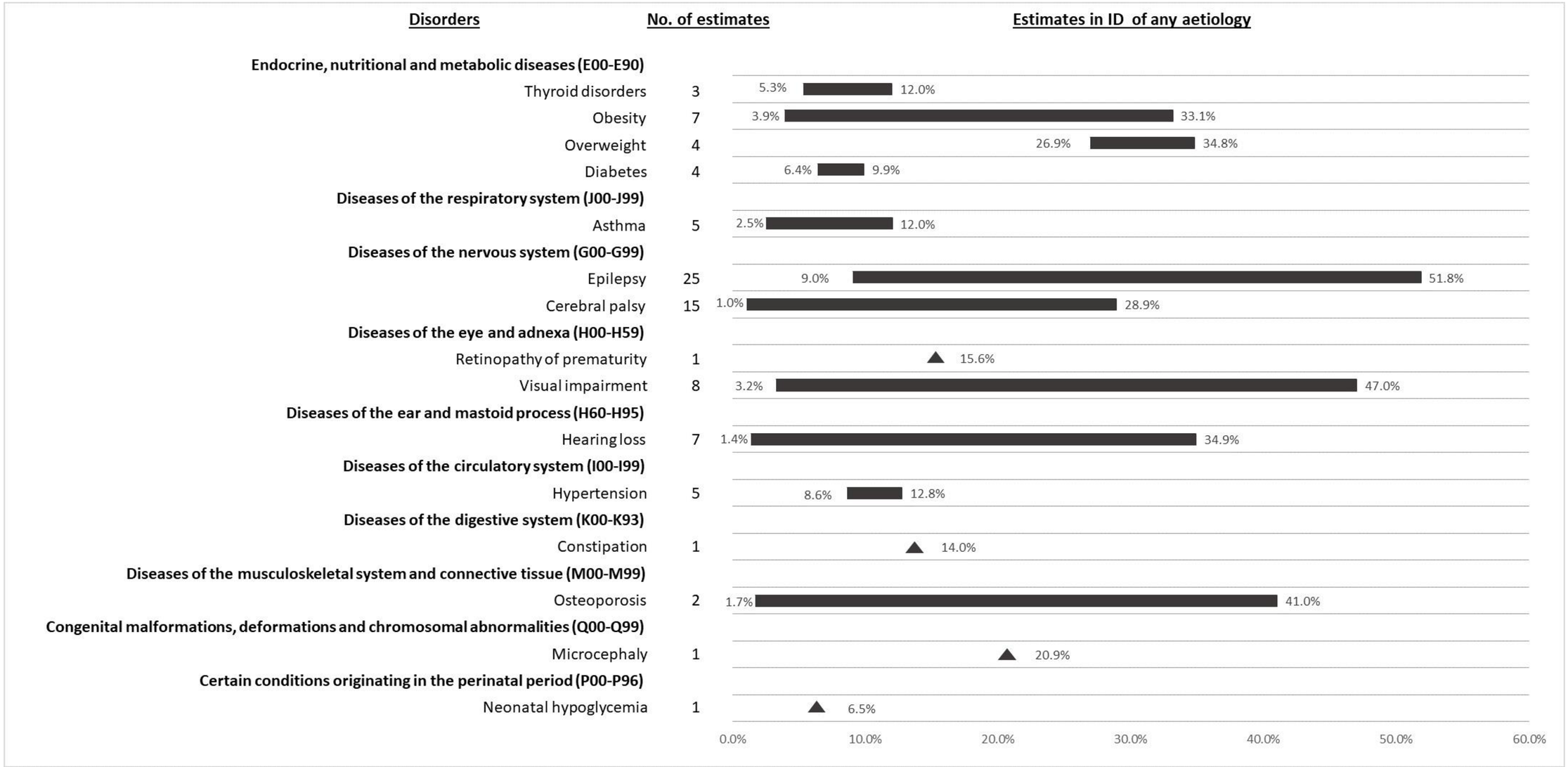
Severity	IQ Score	Proportion of population
Mild	50 — 70	~85%
Moderate	35 — 55	~10%
Severe	20 — 40	3 — 4%
Profound	<25	1 — 2%

People with Intellectual Disability May Have Complex Health Needs

Compared to the general population, people with intellectual disability are more likely to have...

- HEART PROBLEMS
- SIGHT AND HEARING PROBLEMS
- DENTAL PROBLEMS
- INFECTIONS
- MENTAL ILLNESS
- POORER MOBILITY
- STOMACH AND DIGESTION PROBLEMS
- EARLY ONSET AGE-RELATED ISSUES
- BONE WEAKNESS PROBLEMS
- EPILEPSY
- DIABETES
- LUNG PROBLEMS
- SLEEP PROBLEMS
- CERTAIN TYPES OF CANCER

Prevalence and incidence of physical health conditions in people with intellectual disability – a systematic review; Peiwen Liao ,Claire Vajdic,Julian Trollor,Simone Reppermund Published: August 24, 2021; https://doi.org/10.1371/journal.pone.0256294



Outcomes for People with Intellectual Disability

- Median age at death 27 years younger than the general population (54 v's 81 years)
  - causes of death similar to the general population
- Potentially avoidable deaths
  - 38%, more than double the proportion than in the general population 17%
- Serious Mental Illness associated with 4 x hazard for death; HR also higher for those with CP, epilepsy, DS
  - See: https://bmjopen.bmj.com/content/7/2/e013489 and https://onlinelibrary.wiley.com/doi/10.1111/jar.12684 and https://onlinelibrary.wiley.com/doi/10.1111/jar.12190

- Rates for Potentially Preventable Hospitalisations 3.5-4.5 times higher
  - See: https://doi.org/10.5694/mja2.51390

- ED and inpatient admission rates > 2 x that of the general population
  - See: https://doi.org/10.4178/epih.e2024054

- Health care is inefficient eg readmission rates for same condition very high:
  - Mental health eg readmission after first ever mental health episode see: https://bmjopen.bmj.com/content/8/2/e018613
  - Physical health eg epilepsy see: https://doi.org/10.1371/journal.pone.0272439 and https://doi.org/10.1111/jir.12987

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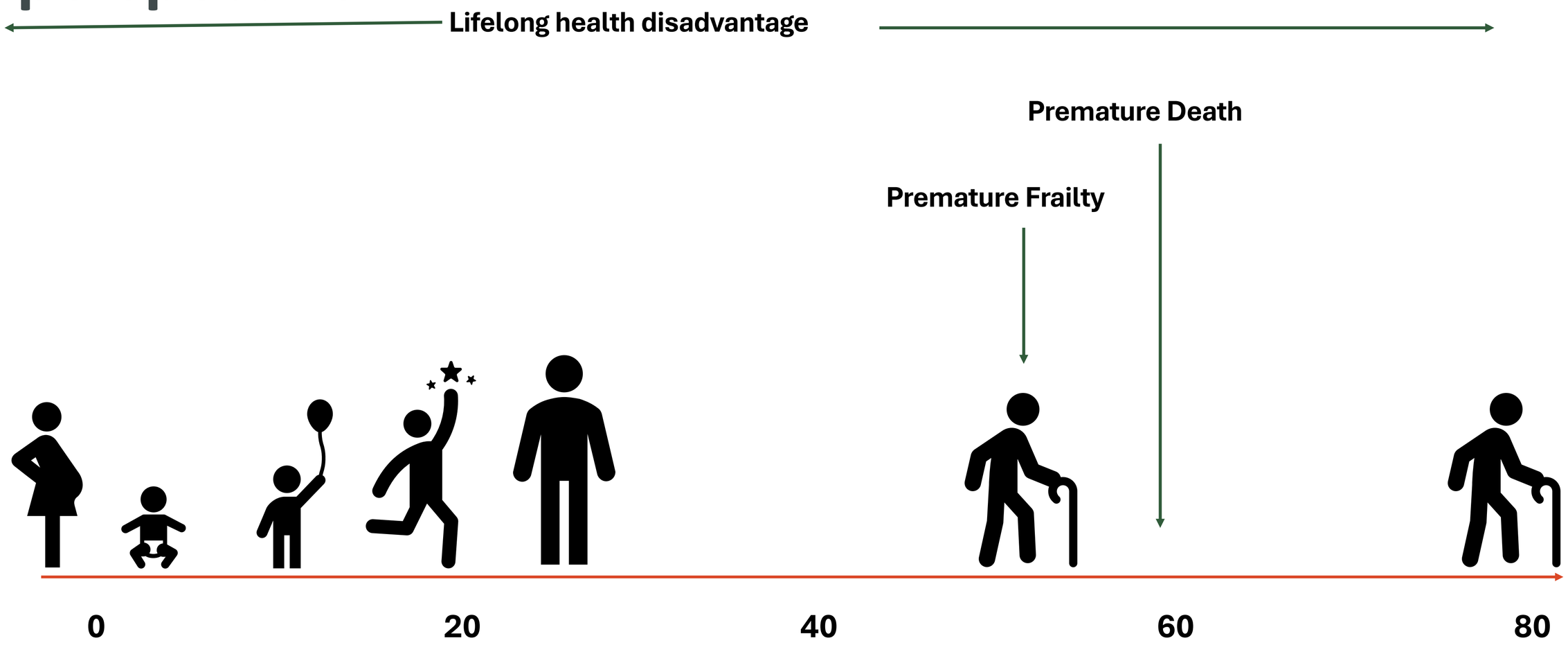
Health disadvantage- lifespan perspective



MENTAL HEALTH CONDITIONS

People with intellectual disability experience:

- higher rates of serious mental illness, with many of the same common mental health issues as people without intellectual disability

- increases in prevalence with increasing disability

- neuropsychiatric and other developmental disorder diagnoses are common (e.g. epilepsy, dementias, ADHD, ASD, tic disorders and drug induced movement disorders)

Prevalence of psychiatric conditions in people with intellectual disability: a record linkage study in New South Wales, Australia (accepted for publication ANZJP)

	People with ID	People without ID
	Total (n, %)	Total (n, %)
Any psychiatric condition	74,212 (76.0%)	172,866 (38.3%)
Serious mental illness	15,835 (16.2%)	22,920 (5.1%)
Mood/affective disorders	10,823 (11.1%)	23,970 (5.3%)
Depression	9,745 (10.0%)	22,810 (5.1%)
Bipolar disorder	2,562 (2.6%)	2,634 (0.6%)
Anxiety disorders	8,985 (9.2%)	18,019 (4.0%)
Substance use disorders	7,425 (7.6%)	21,333 (4.7%)
Psychotic disorders	8,048 (8.2%)	5,257 (1.2%)
Self-injury/suicidality	6,519 (6.7%)	12,853 (2.8%)

	People with ID	People without ID
Dementia	2,663 (2.7%)	2,762 (0.6%)
Non-dementia organic psychiatric disorders	5,151 (5.3%)	6,787 (1.5%)
Personality disorders	3,868 (4.0%)	4,733 (1.0%)
Developmental disorders	41,268 (42.3%)	4,116 (0.9%)
Autism and related conditions	30,977 (31.7%)	1,255 (0.3%)
ADHD and learning disorders	14,199 (14.5%)	2,572 (0.6%)
Other psychiatric conditions	16,020 (16.4%)	24,491 (5.4%)
Total	97644	451502

Psychotropic Medicines

Medicines that affect the mind, emotions and behaviour

Used to treat mental health conditions such as anxiety, depression, schizophrenia, bipolar disorder and sleep disorders

Direct influence on brain biochemistry

The main groups

- Antipsychotics
- Antidepressants
- Anxiolytics or hypnotics

Often the psychotropics are the focus but quality prescribing is a much broader issue

Pharmacotherapy balancing act

Pharmacological interventions:

- are indicated as primary treatment in many health and mental conditions as with the general population
- principles of prescribing are the same as for the general population
- May be responsibly prescribed and monitored

May be:

- inappropriately prescribed
- poorly monitored and infrequently reviewed
- not commenced when needed
- not ceased when no longer needed
- of a type not reflective of current practices

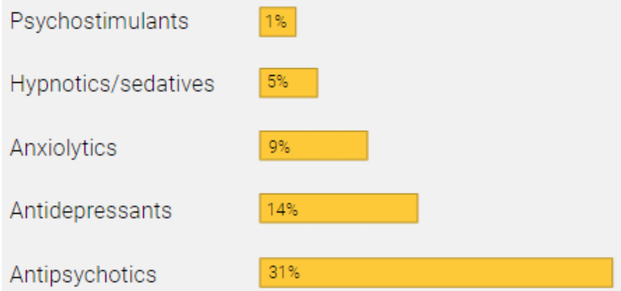
Psychotropic Medicines

Common- and often appropriate

But-

- Can be excessive and poorly targeted esp in behaviours of concern
- Exposures often prolonged, poorly monitored
- Polypharmacy common

Forty one percent of adults with intellectual disability take psychotropic medication compared to 4-36% of the general population. Below is a breakdown of the most prescribed psychotropic medicines in people with intellectual disability. [4]



Psychotropic polypharmacy is particularly common in people with intellectual disability

Polypharmacy – the concurrent use of five or more medications, or two or more psychotropic medications – is significantly higher in people with disability and is associated with:

- an increase of adverse effects from medications and medication-related hospitalisations,
- a decrease of benefit from individual medication
- poorer health outcomes.

The Disability Royal Commission found that:

"… psychotropic medication is over-prescribed to people with cognitive disability. In particular such medication is over-prescribed and over-used as a response to behaviours of concern displayed by people with cognitive disability"

Prescribing in primary care: Results from the Bettering the Evaluation and Care of Health (BEACH) program

People with Intellectual Disability have:

- Non uniform access to GPs (better access in States with initiatives, better in rural areas)
- Over-representation of presentations for psychological reasons
- Administrative rather than medical needs dominating their GP encounter
- Much higher rates of psychotropic medication recommendations eg 10 fold for antipsychotics
- Less attention to preventative health needs and preventative prescribing

ID Papers

Paper 1: doi.org/10.1111/jir.12301;
Paper 2: doi.org/10.3109/13668250.2016.1250252;
Paper 3: http://dx.doi.org/10.3399/bjgpopen18X101541

ASD Papers

Paper 1: http://dx.doi.org/10.1177/1362361317714588
Paper 2: http://dx.doi.org/10.1177/1362361317702560

Emerging controversy? → Defining the problem → How to prescribe well → More difficult areas → Resources and next steps

Talk Outline

Intellectual Disability
Mental Health Connect

Prescribing and monitoring principles

Take into account medical comorbidities

Develop a plan to monitor efficacy and side effects

Prescribe medication that does not require blood tests to monitor safety

Monitor cardiometabolic risk

Start with the minimum effective dose and treatment length

Minimise polypharmacy

Assess before you prescribe

Assessment of psychiatric symptoms

Home medicines review

Nutrition, diet and physical activity assessment

Assessment of home and work environment

Assessment of comorbidities

Communication assessment

Pharmacological history

Psychological and behavioral review

Sensory and functional profiles

Full medical history and review

When prescribing for mental health issues, consider physical comorbidities

Some medicines may need to be avoided/dose modified and their use rigorously monitored

Epilepsy	Exercise caution prescribing medications that lower the seizure threshold (e.g. tricyclic antidepressants, venlafaxine, many antipsychotics)
Obesity, Dyslipidaemia, Type 2 diabetes	Avoid medicines with high cardiometabolic liability as first line treatment
Hypertension	Caution prescribing medicines that raise blood pressure (e.g. venlafaxine, desvenlafaxine, duloxetine)
Hypotension	Avoid medicines that might exacerbate the condition (e.g. chlorpromazine, tricyclic antidepressants, quetiapine)
Respiratory or swallowing difficulties, or structural airway abnormalities	Avoid highly sedating medicines that may increase risk of respiratory failure, or those that exacerbate swallowing difficulties
Early onset dementia	Caution around medicines that have anticholinergic or sedative effects that can worsen cognitive dysfunction in dementia

Comprehensive treatment plans should include

How treatment impact will be measured

Communication strategies tailored to individual needs

Plan for documentation and records

How adverse effects will be monitored and measured

Contingency plan if medication is ineffective

Identification of signs and symptoms being targeted, including their frequency at baseline

Treatment timeline, including a timeline for review

Commencing psychotropic medicines

- Establish the person’s baseline before developing a treatment plan

✓ if possible, structured monitoring (e.g. ABC model)

- Psychotropic treatment should always be used in conjunction with other therapies, including psychological and behavioural

- Every new medication or changes of medication should be treated as a time-limited trial with reviews at planned intervals

✓ reviews should occur at 3 and 6 weeks (but may vary)

- Introduce medicine at a lower-than-normal dose and slowly increased

Monitoring of psychotropic treatment

- A person with intellectual disability might not recognise or report adverse effects
- The effects of medication may be difficult to recognise due to the idiosyncratic nature of responses to psychotropic medication common in people with intellectual disability
- Monitoring to ideally begin prior to treatment to establish a baseline
- Only continue treatment if there is evidence for efficacy and the medication is tolerated

Types of adverse side effects

Physical presentation

- Metabolic parameters
- Extrapyramidal side effects
- Akathisia
- Cardiovascular health
- Hormonal

Behavioural presentation

- New behaviours
- Exacerbation of existing behaviours

How to monitor medication treatments

Collect objective data

- Clear targets for prescribing
- For psychotropics:
  - metabolic side effects monitored via weight charts and blood tests
  - Behavioural changes monitored via sleep and behavioural charts
- Other specific data based on the risk profiles of the medication and patient

Collect subjective data

- Patient and carer reports on history, observations and experiences
- Ask about side effects

Home Medicines Review

Can be provided by a credentialed community pharmacist upon referral from a doctor

Pharmacist will:

- ensure the most beneficial medication regimen is in place
- assess that medicines are taken correctly and that they are effective
- check for potential medication interactions and side effects

Subsidised by Medicare for eligible patients once every 24 months

Reviews can be scheduled more frequently in some situations

Specialised review of psychotropic prescribing

Could be sought in following contexts

- Symptoms do not get better or worsen standard age-appropriate intervention
- Complex presentations
  - e.g. severe intellectual disability
  - presence of a complex genetic disorder with medical comorbidity
  - ambiguity regarding presence of psychotic symptoms)
- Nature of the problem is uncertain despite thorough initial assessments
- Condition or treatment requires specialised psychotherapeutic or pharmacological skills
- Deteriorating or unexpected course
- Continuing high risk to the individual despite treatment (self-harming behaviour or expressed suicidal ideation).

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Talk Outline

Cessation of psychotropic treatments

Deprescribing should be considered at each review and occur when:

- No relevant mental health diagnosis present and effective non-pharmacological treatment is in place
- Condition that psychotropic medicines were prescribed for has been resolved
- There are adverse effects
- There has been no response to the medicines

Deprescribing should be done slowly and carefully

Important to have a well-planned deprescribing program and a multi-disciplinary approach to monitoring the reduction process

Pharmacological management of behaviours of concern

Use of psychotropic medication to manage behaviours of concern is widespread, even in the absence of a mental illness

Evidence for the effectiveness and safety of medications used in this context is limited and of poor quality

In the absence of a medical or psychiatric condition, prescribing should be limited and used only:

- When positive behaviour support has had limited or no impact
- To enhance positive behaviour support in context of high risk

Previously discussed principles of responsible prescribing apply here

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Talk Outline

Resources for prescribing

https://idhealtheducation.edu.au/e-learning-on-responsible-prescribing/

Therapeutic guidelines: Developmental Disability

https://www.nps.org.au/australian-prescriber/articles/prescribing-psychotropic-drugs-to-adults-with-an-intellectual-disability

8 podcasts https://www.3dn.unsw.edu.au/education-resources/health-mental-health-professionals/positive-cardiometabolic-health-people-id/responsible-psychotropic-prescribing-people-intellectual-disability-podcasts

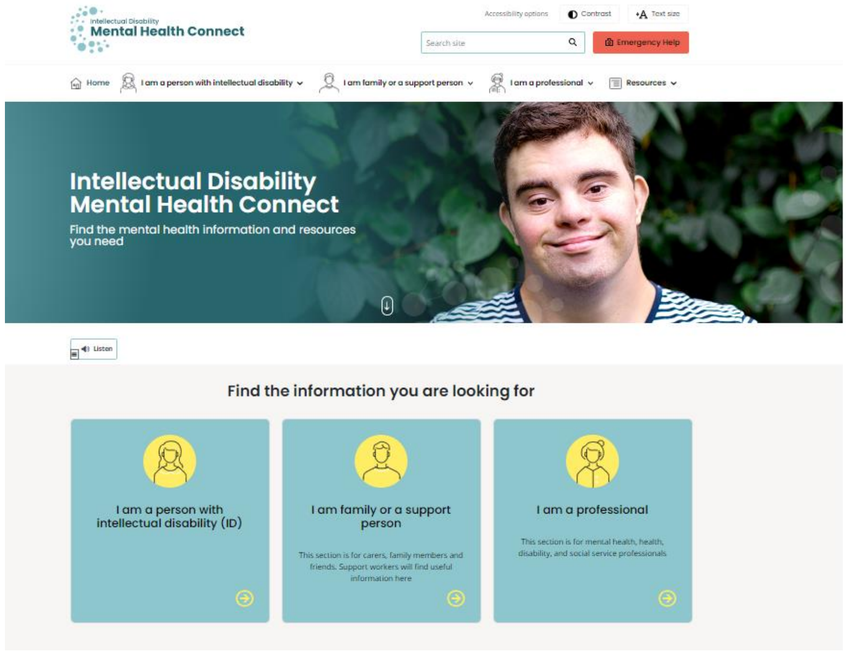
To manage cardiometabolic risk see our resources positive cardiometabolic health for people with intellectual disability

Our IDMH Connect Webtool: https://idmhconnect.health/

Helps people with intellectual disability get the right services and support for their mental health.

Information for people with intellectual disability, their supporters, and professionals.

Includes information about prescribing and trouble shooting clinical care



ID Health Education

Evidence-based online learning courses, aimed at equipping people to respond to the mental health needs of people with intellectual disability

Tailored to three groups:

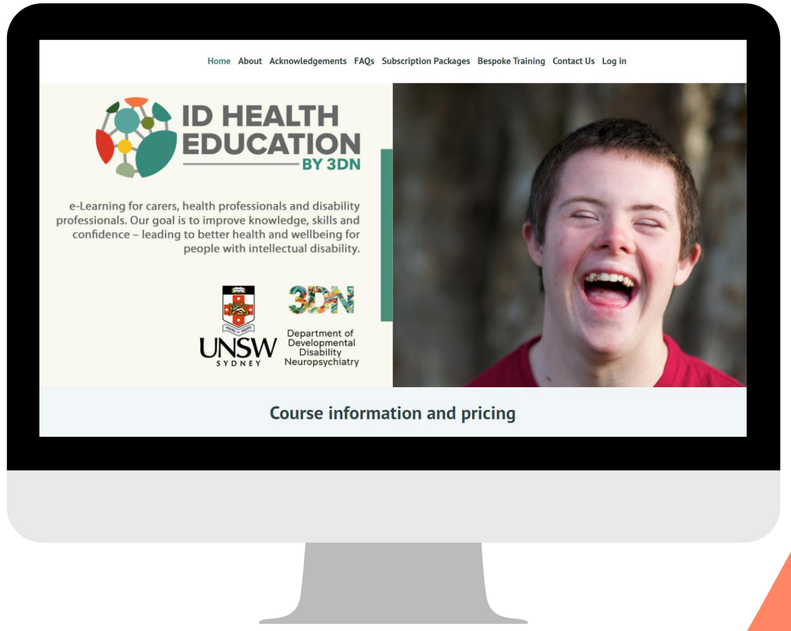
- Carers and family
- Disability professionals
- Health professionals (available free through MyHealthLearning for NSW Health employees)

Full catalogue of courses and pricing listed on the website

Aim for these to be free on Centre's Knowledge Exchange Hub

New module on prescribing

www.idhealtheducation.edu.au



Evidence Summaries

On this page:

https://www.ndiscommission.gov.au/resources/provider-and-worker-resources/evidence-summaries

National Framework for Reducing and Eliminating the Use of Restrictive Practices in the Disability Service Sector

The National Framework focuses on the reduction of the use of restrictive practices in disability services that involve restraint (including physical, mechanical or chemical) or seclusion.

It aims to contribute to the promotion and full realisation of all human rights for people with disability, including liberty and security of the person and freedom from exploitation, violence and abuse, in accordance with Articles 14 and 16 of the CRPD.

Restrictive practices should only be used where they are proportionate and justified in order to protect the rights or safety of the person or others.

https://www.dss.gov.au/our-responsibilities/disability-and-carers/publications-articles/policy-research/national-framework-for-reducing-and-eliminating-the-use-of-restrictive-practices-in-the-disability-service-sector

AUSTRALIAN COMMISSION ON SAFETY AND QUALITY IN HEALTH CARE

Clinical Care Standards

Psychotropic Medicines in Cognitive Disability or Impairment

Clinical Care Standard

May 2024

Goal

This clinical care standard aims to ensure the safe and appropriate use of psychotropic medicines in people with cognitive disability or impairment and to uphold their rights, dignity, health and quality of life.

What is a Clinical Care Standard?

Contains a small number of quality statements that describe the level of clinical care expected for a specific clinical condition or procedure.

Indicators are included for some quality statements to assist healthcare services monitor how well they are implementing the care recommended in the clinical care standard

How is a Clinical Care Standard Used?

Describe the expectations for key components of care

The standard explains what each quality statement means:

- **For people**, so they know what care may be offered by their healthcare system, and can make informed treatment decisions in partnership with their clinician
- **For clinicians**, to support decisions about appropriate care
- **For healthcare services**, to inform them of the policies, procedures and organisational factors that can enable the delivery of high-quality care.

Implementing them help healthcare services achieve actions within:

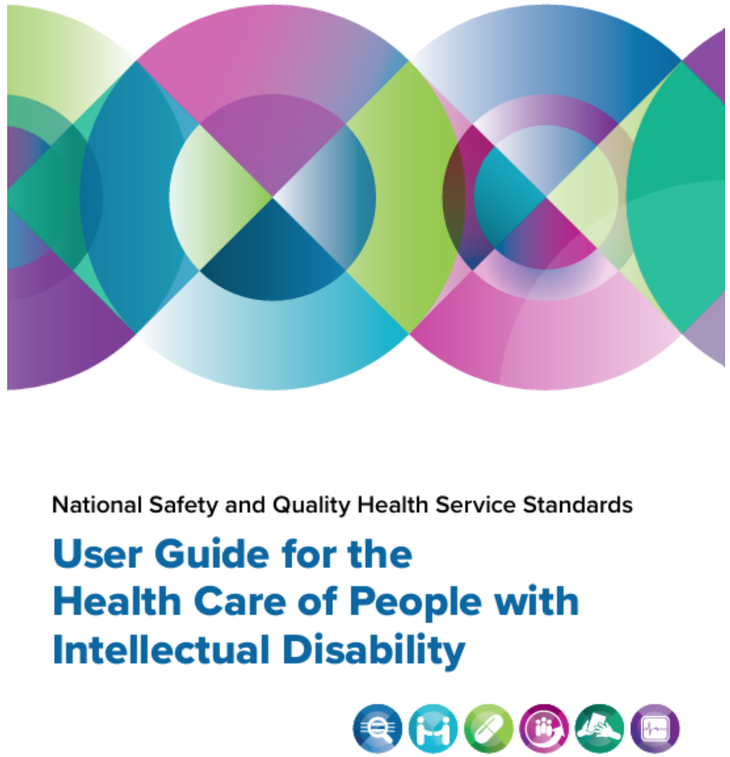
- the NSQHS Standards and the National Safety and
- Quality Primary and Community Healthcare Standards (Primary and Community Healthcare Standards)

Clinical Care Standard Quality Statements

1. Person-centred care
2. Informed consent for psychotropic medicines
3. Assessing behaviours
4. Non-medication strategies
5. Behaviour support plans
6. Appropriate reasons for prescribing psychotropic medicines
7. Monitoring, reviewing and ceasing psychotropic medicines
8. Information sharing and communication at transitions of care

Psychotropic Medicines in Cognitive Disability or Impairment Clinical Care Standard

NSQHS Standards User Guide for the Health Care of People with Intellectual Disability



Contextualises existing standards to clinical work with people with intellectual disability
Increased expectation on services

Safety and Quality Service Standards Expectations- People with Intellectual Disability

Specific content regarding medication review

Other content related to involving the person in decision making, risk and safety

Medication review

Action 4.10

The health service organisation has processes:

a. To perform medication reviews for patients, in line with evidence and best practice
b. To prioritise medication reviews, based on a patient's clinical needs and minimising the risk of medication-related problems
c. That specify the requirements for documentation of medication reviews, including actions taken as a result.

Intent

Medicine use is optimised, and medicine-related problems are minimised by conducting medication reviews and documenting the outcomes in partnership with patients.

Strategies for improvement

Set up processes to conduct and document medication reviews

Ensure medication reviews are prioritised for people with intellectual disability, given the higher risk of adverse medication events.

Require high-priority treatment when a person at substantial risk is identified in the risk assessment for a medication review. In these cases, the medication review should be documented and the prioritisation policy monitored for quality improvement purposes.[46] The NSQHS Standards include further information on **conducting structured medication reviews**.

Make reasonable adjustment to medication reviews

Reasonable adjustments to support the person's involvement in a medication review include making adjustments to communication approaches and gaining knowledge of the person's decision-making capacity. The person's family, supporters or guardian may be able to provide history and other relevant details to support the medication review.

Connect

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- **Seed funding Grant Rounds**
- **Events and Webinars**
- **Partner or Collaborate**
- **Scholarships**
- **Training and Resources**
- **Steering committees, working and advisory groups**

Working together every step of the way

National Centre of Excellence in Intellectual Disability Health Annual Conference 2025

3 - 4 July 2025 | Sydney Masonic Centre and Online

National Centre of Excellence in **Intellectual Disability Health**

National Conference 2025

When: Thursday 3 July and Friday 4 July 2025

Where: SMC Centre in Sydney , and Online

Who: Everyone interested in health for people with intellectual disability

Theme: Working together every step of the way

Highlights: Keynote speaker: Dr Gloria Krahn (USA),

Tickets: www.nceidh@unsw.edu.au

Conclusions

Prescribing landscape is changing

Aim is for good access to health care and responsible prescribing in all contexts

Doing so will support better mental and physical health outcomes for people with intellectual disability

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