ST VINCENT'S
Better and fairer care. Always.

Systemic, Legal And Ethical Issues in the Management of People with Intellectual Disability and Mental Illness

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)

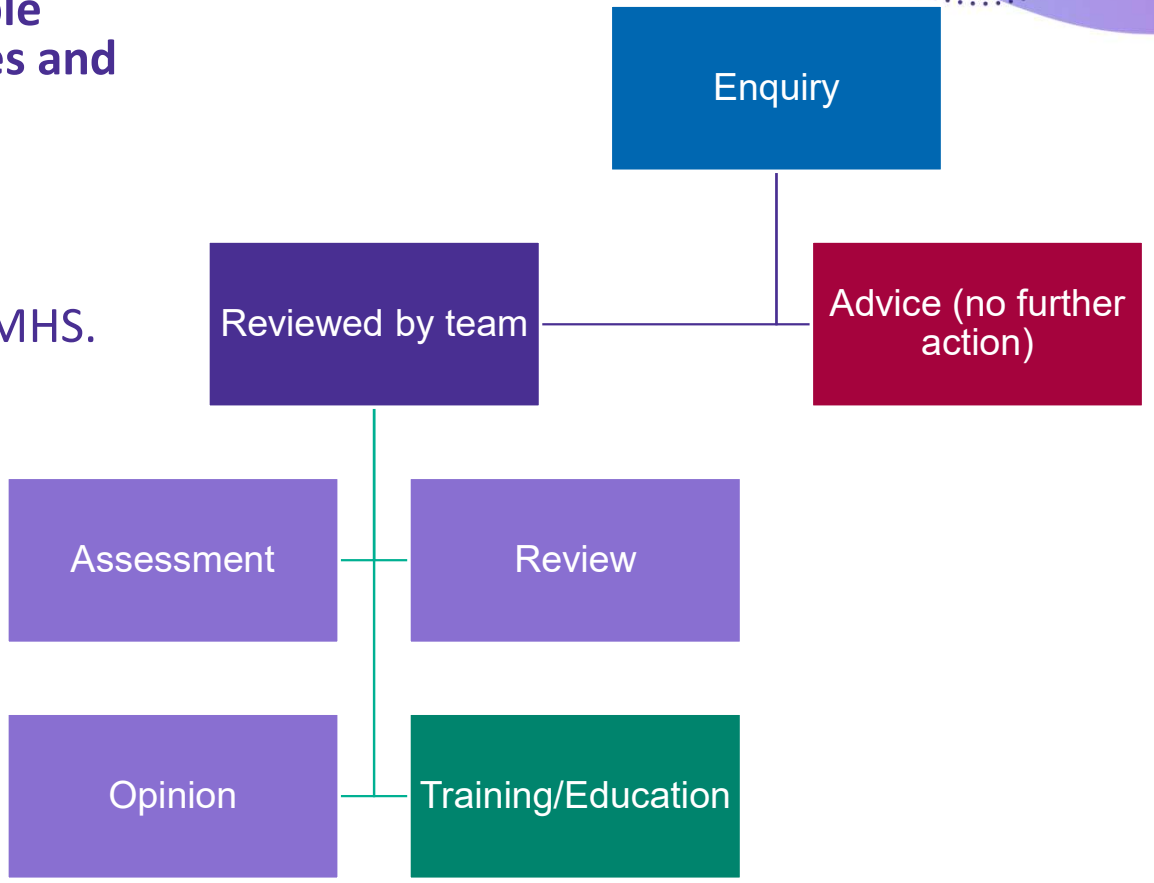
State-wide mental health service for people with co-occurring mental health challenges and a developmental disability.

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*



AIMS

1. Outline service structures and significance to people with ID.

2. Identify major legal considerations in treating people with ID.

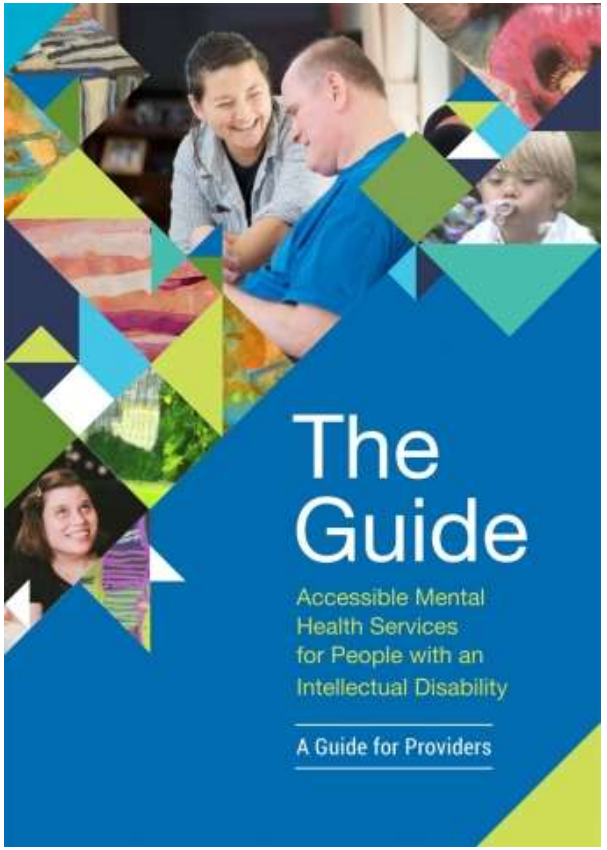
3. Describe stigma and impact

Accessible Mental Health Services

- People with an ID have a right to timely access to mental health services at any stage of life, including proactive primary health care and health promotion strategies.

- Having an ID should not be a reason for exclusion from mainstream mental health services.

- Reasonable adjustments by mental health services



Introduction

The ability of service delivery to help someone judged in relation to ethics

Two cases during course of presentation:

- **SM:** presented with significant mental health issues but unable to access services as no “Mental illness”
- **CK:** severe ID incapacitated by the effects of treatment despite being unable to consent.

Case example - SM

- 35 year old female with extensive history from age 5
- Seen by CAMHS but no specific diagnosis
- Long involvement with adult mental health services: naked in public, property damage, assaults, poor self care, odd beliefs (in love with police constable, contamination with HIV, bottom smelling, fear of dying).
- Unable to explain herself
- 20 + admissions and numerous presentations to Emergency Department
- Diagnoses included Schizophrenia, OCD, PD & ID
- Prolonged admission to CCU, *'no psychotic symptoms'* - medication ceased with little change

Case example - SM

- Referred to VDDS by CCU
- IQ = 90 (*does not meet DSM 5 criteria for ID*)
- Diagnosed with PDD-NOS (*autism spectrum disorder*)
- Discharged by AMHS as *'no mental illness' and 'not treatable'*
- Parents refused to have her home - homeless
- SRS x 5 failed, several readmissions, involvement with police
- AMHS directed to admit and spent further 2 years in mental health settings (IPU & SECU)

Case example - SM

- Discharged but continued to offend & present to emergency services
- Several court appearances & eventually sent to prison
- Unable to manage & isolated for 3 years (subject of Ombudsman report)
- Released to community care, multiple complaints by neighbours, throwing things at passing cars, taking things from shops (stealing), naked in street
- Carers from NGO monitoring from a block away, (told by her to f@#! off) Call police if needed
- S/B VDDS: unkempt, smelly, burnt eyebrows, barefoot, lost weight ++, not able to provide history, talked about wanting to get married and have children.

Ombudsman's Report

- Gaps in therapeutic services for people with mental impairment, under-resourcing of existing services, and disputes between services about who is responsible for finding solutions.
- Compounded by fragmented responsibilities at the bureaucratic level
- Doubts about NDIS capacity to respond to people with complex needs
- Consider options for specialist units and services
- Significant work to clarify the interface between the NDIS and other service systems, including the health and mental health sectors
- Significant changes to service responses to people subject to CMIA proceedings

Why did this situation arise?

Why was SM unable to access services?

She is clearly severely disturbed & this cannot be solely explained by developmental disability

The current service system and gaps…

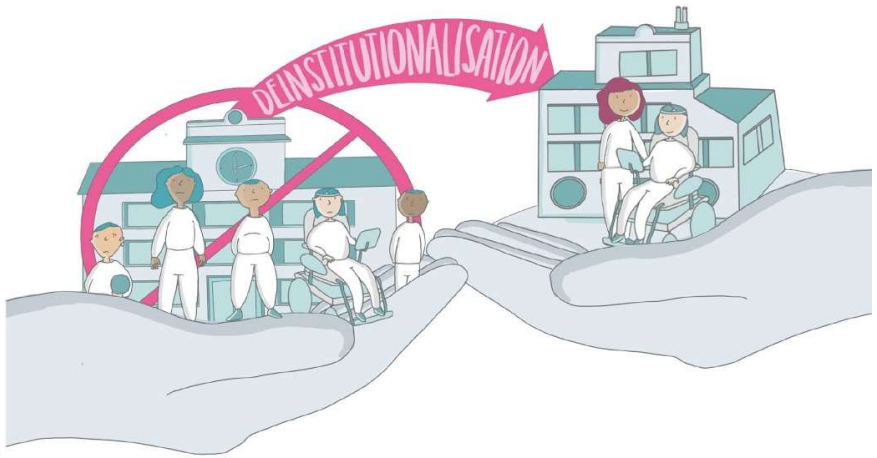
History of Service System

Ancient Civilisations	Middle Ages	19th and 20th Century	21st Century
• ID caused by demons, punishment by god for wrongdoings. • Burden on society: killed at birth.	• ID caused by unhealthy lifestyle, marriages between blood relatives, heredity, gluttony, and excessive or deviant sexual activity • Care in poor houses, institutions, prisons, slavery, entertainment	• Eugenics • Institutional Care	• Human rights • Choice and control • Inclusion and independence • NDIS

The Institutions

- Institutional model of care
  - Removed from society/family
  - Custodial (Medical) model
  - Holistic model of care (housing, health, recreation, vocation)
  - Single point of accountability
  - Focus on natural settings to soothe troubled minds
- One department for ID and MI (nature of disorder not important)
- Exclusion, lack of opportunity, lack of choice
- Difficult to leave (lack of appeal processes)
- **Kew Asylum, Larundel Mental Asylum, Aradale Asylum**

De-institutionalisation



- Civil rights, Human rights movement, normalisation
- Scandals, abuse, toxic environment, control, loss of skills, independence = Institutionalized
- Costs (now prime real estate)
- Effective Rx for MI (need treatment and therapy)
- PWID not ill (need social support)
- PWID able to learn and develop (? ID = slow rate of development or limit to development)
- De-institutionalisation into care of 2 departments (mental health and disability)

De-institutionalisation Assumptions

Low rate of MI in PWID

Behaviour disorders due to model of care

PWID would be able to access generic services

Assumption 1: Low rate of MI in PWID

- Lack mental capacity
- Childlike
- Low stress
- Behavioural
- Related to the ID

ST VINCENT'S
Better and fairer care. Always.

Prevalence of MI

Few studies, select populations, different criteria.

- Prevalence of mental disorders is higher in and consensus rate is between **30%** and **50%**
- At any point in time up to **50%** receiving treatment for a mental illness
- Schizophrenia ~ **3%**
  - G. M. Khandaker 2011: *IQ has "dose-response" effect, with each 1-point decrease in IQ associated with a significant **3.7%** increase in the risk for schizophrenia.*
- Bipolar affective disorder **1.5%**

High Rates of Risk Factors

- **Biological:** Genetic, brain injury
- **Social:** 60% excluded from study because no one known them for longer than 6 months.
- **Psychological:** Abuse, coping strategies
- **Developmental:** Sexual behaviour

Assumption 2: Behaviour Disorders due to Model of Care

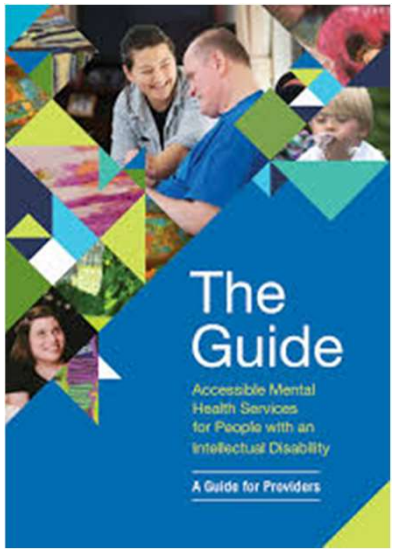
Behaviours of Concern

- Thought to be due to housing PWID with people with MI in institutions.
- Since deinstitutionalization studies indicate rates of problem behaviors unchanged.
  - 8 to 12 % had serious challenging behaviour limiting their access to services requiring limitation of rights to manage
  - In over 80% persists over 1 year, whatever intervention and across a range of settings
- Aetiology not due to model of care or disability.
- Aetiological factors can be understood in bio-psycho-social framework (comorbidity, genetic, abuse, boredom etc.)

Prader-Willi Syndrome (Biological)

Assumption 3: PWID would be able to access generic services

Access to generic mental health services



https://www.3dn.unsw.edu.au

- Often excluded from mental health services
  - Difficult to identify mental health problems
  - Disorder not SMI
  - Staff lack confidence and skills (non verbal assessments)
  - Infrastructure inappropriate for PWID (ward mix)
  - Treatment not appropriate (10 sessions of psychotherapy, DBT, CBT)
  - Needs better met by disability services / NDIS
- Diffuse accountability
  - No policy
  - No guidelines
  - No reporting requirements

Service Gap

Assumptions underpinning service models have led to the development of a ‘service gap’

1. Difficulty in accessing generic services (dependent on others, transport, modified presentations, overshadowing, unclear responsibility).
2. Generic service models inappropriate for people with a disability (even when ‘eligible’ because of SMI).
3. Lack of specialist residential services for people with significant mental disorders who need long term treatment and management by a skilled workforce (persistent behaviour disorders, severe autism, personality disorder, treatment resistant schizophrenia).

Ask yourself…

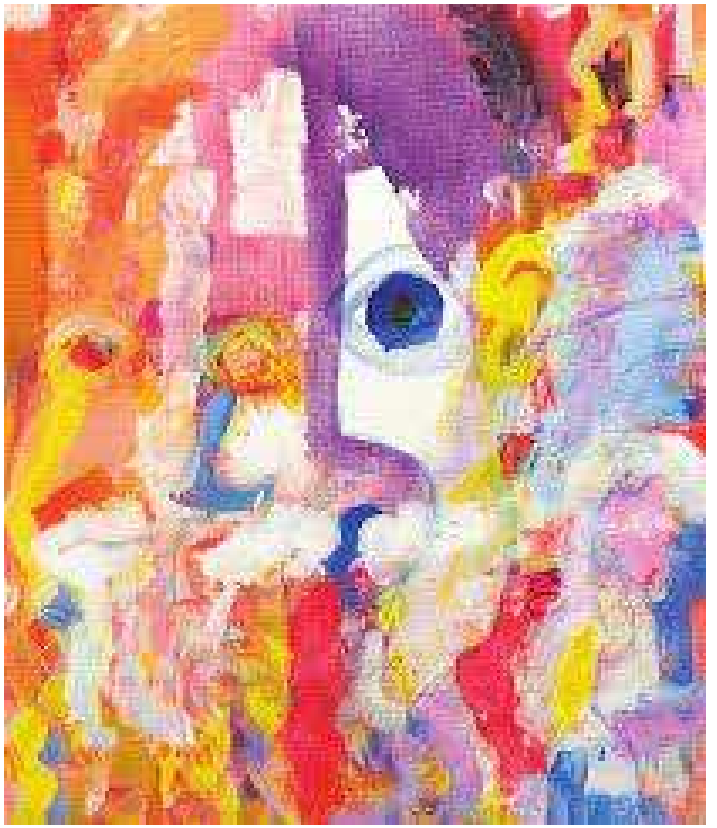
What ‘Reasonable Adjustments’ would you make to your practice in relation to supporting someone with Intellectual Disability?

Policy and Legislation

Mental Health Policy and Intellectual Disability

There is a lack of recognition of people with Intellectual Disability in Federal and State health policy OR of health needs in Disability policy:

- Despite high rates of Mental health problems
- Despite different patterns of health problems and higher mortality (20 years younger than normal population).
- Despite modifications needed to service delivery and practice



United Nations

Australia has ratified:

- The Convention on the Rights of Persons with Disabilities (2006)
- The Principles for the Protection of Persons with Mental Illness (1991)

- Federal and State Policy and legislation are required to be complaint with these charters.
- Courts able to declare statutory provisions incompatible with human rights.

Selected Principles: Mental Illness

- Diagnosis based internationally accepted medical standards.
- Protection from harm or abuse including unjustified medication
- Treated by qualified staff in the least restrictive environment
- No treatment to be given without informed consent
- The right to be treated voluntarily if possible
- Involuntary admission only by authorised and qualified mental health practitioner
- The right to review
- The right to appeal

Selected Rights: Disability

- An adequate standard of living (food, clothing and housing).
- To live independently and participate fully in all aspects of life.
- Equal recognition before the law and legal capacity of the persons with disabilities.
- Highest attainable standard of health (including mental health) without discrimination on the basis of disability.
- Disability should not be used as justification for treatment.
- To take all appropriate measures to eliminate discrimination.

Federal Policy and Legislation

Fifth National Mental Health plan

- Recognises higher rates and mental health problems
- Recognises difficulties in accessing services
- No specific recommendations.

The Disability Discrimination Act 1992 (DDA)

- Legislates against discrimination in most areas of public life
- The Australian Human Rights Commission (AHRC) has the power to investigate and attempt to resolve complaints of discrimination

National Disability Strategy 2021-2031

- Commits governments to specific actions, and the first five are in the areas of employment, community attitudes, early childhood, safety and emergency management

Federal Policy and Legislation

National Disability Insurance Scheme Act 2013

1. Establishes NDIA and NDIS and rules (access criteria and exclusions)
2. Funds “reasonable and necessary supports” for permanent disability.
3. Insurance based model and NDIS provides funds (~Medicare)

- **The NDIS Quality and Safeguards Commission (independent)**
  - Registers and regulates NDIS providers
  - Oversees NDIS Code of Conduct and Practice Standards
  - Monitors restrictive practices and behaviour supports5 regulated interventions (chemical, physical, mechanical, environmental restraint & seclusion)
  - Manages complaints

Victorian Policy and Legislation

Disability Act 2006 (VIC)

- Legislates against discrimination (not for positive inclusion)
- Disability Services Commissioner to investigate complaints
- The Senior Practitioner oversee restrictive practices, compulsory treatment for NDIS participants

Inclusive Victoria: State Disability Plan 2022-2026

- Review of the Disability Act 2006
- Requires public authorities, state government departments and local governments to prepare disability action plans that describe how the agency will address access and inclusion barriers for people with disability
- Co-design with people with disability
- Aboriginal self-determination
- Intersectional approaches
- Accessible communications and universal design
- Disability-confident and inclusive workforces
- Effective data and outcomes reporting

Inclusive Victoria: State Disability Plan 2022-2026 Health

General

- Evaluating the Disability Liaison Officer program in health services
- Establishing a framework for health services to share their disability action plans
- Developing ‘disability champion/lead’ models in each health service
- Supporting health services to enhance referral pathways
- Develop e-learning and other training packages and courses to support professional development

Mental Health

- Convening a diverse communities working group to give expert advice
- Co-designing a diverse communities mental health and wellbeing framework
- Building the capacity of specialist mental health services and the capability of the mental health workforce

Royal Commission into Victoria's Mental Health System

Evidence suggests clinicians lack sufficient training in the management and care of clients with dual disabilities

There is a need for specialist dual disability training and higher qualifications in dual disability for psychiatry and psychology, and across the disability sector.

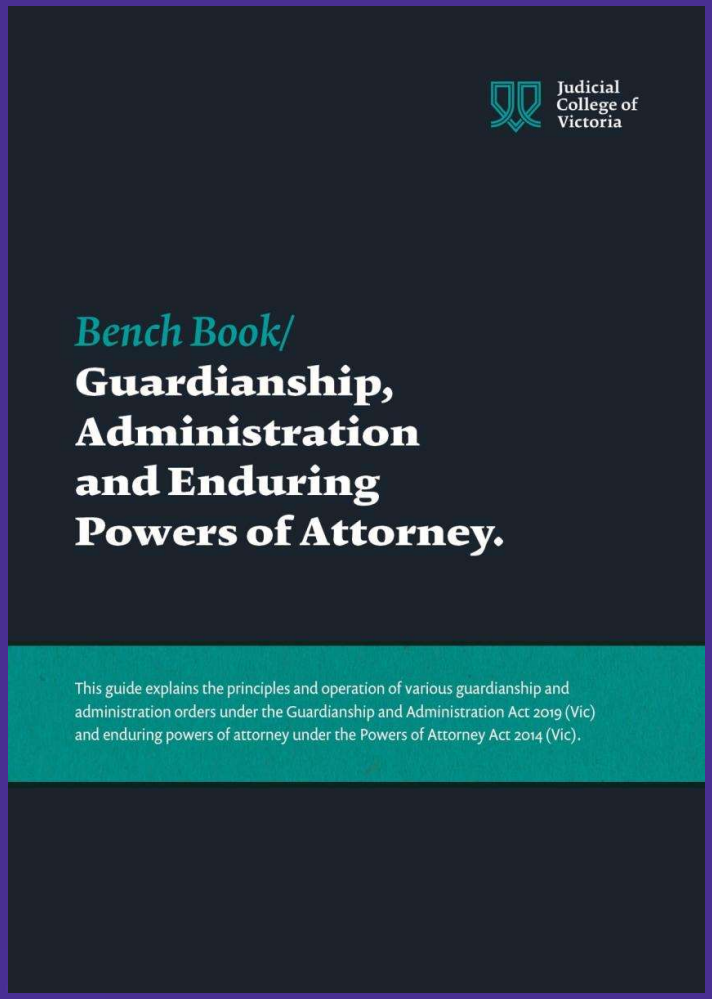
There is also a need to promote greater expertise and training in dual disabilities in the wider mental health workforce

Mental Health and Wellbeing Act 2022

- Previous Mental Health Act (2014) focused on determining circumstances for involuntary treatment and appeal processes
- Principles of least restrictive option, supported decision making, individual rights promoted
- Came into effect 1st September 2023.
- Rights-based objectives and principles, guided by lived experience.
- Compulsory Treatment Criteria is still under review

- Creates new positions/bodies:
  - Regional Mental Health and Wellbeing Boards
  - Chief Officer for Mental Health and Wellbeing
  - Mental Health and Wellbeing Commission
  - Youth Mental Health and Wellbeing Victoria

Guardianship & Administration Act (VIC) 2020

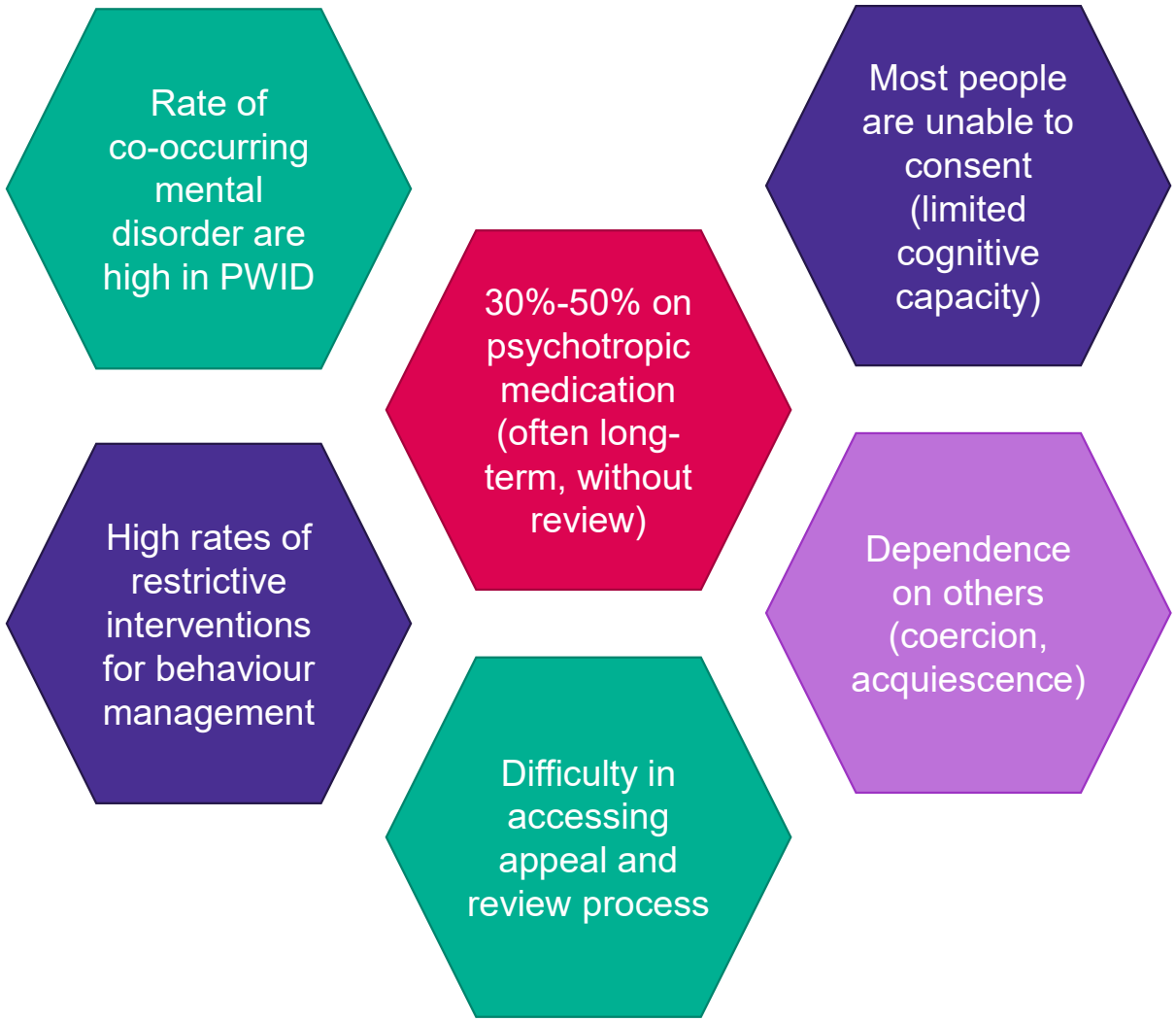


- Focus on will and preferences (not best interests)
- Guardian appointed if a decision is required
- Decision making capacity requires ability to understand, retain and weigh relevant information and communicate decision
- Guardian can be any one who consents to role under the act or a public guardian
- Can make decisions on personal matters *including* medical treatment and access to services
- Can be appointed urgently

Medical Treatment Planning & Decisions Act (VIC) 2016

- If no decision making capacity can treat under duty of care, MHW Act or Medical Treatment Act
- Significant treatment needs consent
- Includes treatment for major mental illness; medications and psychotherapy.
- Advance care directives must be followed
- Appointed decision-maker
- Guardian appointed under the G & A Act
- First of spouse, primary carer, adult child, parent, adult sibling
- If no decision maker and significant treatment, health practitioner MUST consult with OPA
- ? Pressure on prescriber to diagnose a mental illness

Significance to PWID



ST VINCENT'S
Better and fairer care. Always.

Case Example - CK

25 y.o man. Severe ID, Autism, Epilepsy

- Living in shared supported accommodation
- Longstanding behaviour including vocalizations, high activity levels, self harm, occasional assault, doesn't sleep
- Diagnosed with mood disorder
- Mostly in room as assaulted by flat mate
- No day placement

Case Example - CK

- Risperidone 8mg BD
- Lithicarb 125 mg BD (no blood tests)
- Alprazolam 2mg TDS
- Carbamazepine 400mg TDS
- Olanzapine 50mg Nocte
- Difficulty walking, drooling, oculogyric crisis, several seizures a day
- Referred to AMHS but no ‘mental illness’ problems ‘due to his ID’

Case Example - CK

- Needs treatment but unable to communicate and therefore to consent
- Not clear what preferences he might have
- Father acting as guardian (informed ???)
- Lack of effective safeguards allows inappropriate treatment and restrictive practices
- Excluded from services as no clear mental illness and due to ID (Diagnostic overshadowing and stigma)
- Unable to classify MI (DSM-5) and difficult to use MHA

Service User & Carers Views on Mental Health Care

Not listened to & left to own devices

Treated as different & difficult

All problems attributed to disability

Unsafe & confusing with frequent changes

Treatment = medication only

“There was nowhere to go for help!”

ST VINCENT'S
Better and fairer care. Always.

Experiences of PWID

- Death by indifference (Mencap UK 2007) – higher mortality due to difficulty accessing services or inadequate care

88%	• Reported being bullied
23%	• Were physically assaulted in the past year
60%	• Reported people talked down to them.
40%	• Felt people thought they weren't as good as others.
40%	• Reported doctors and nurses treat them badly
54%	• Reported people make fun of them
58%	• Reported people treat them like a child

Survey of AMHS Staff

Experience

- 65% agreed they had adequate knowledge and skills
- 50% experience in ID
- 33% received adequate training

Access

- 80% thought it was more difficult to get an assessment and to liaise with other services

Standards

- 80% thought people with an ID got a poor standard of care
- 70% thought community care was inadequate to meet needs

Survey of AMHS Staff

Policies

- 90% thought there was a need to develop specific policies.

Services

- 85% thought PWID needed a specialist service.
- 70% thought AMHS had a key role.

Personal

- 40% preferred not to treat people with ID.

What is the impact?

- Silos of **mental health** vs **disability services**
  - People get missed / fall through the gaps
  - Minimal collaboration
- Frustration for individuals, families, carers & services
- Service learned helplessness
- Reinforces negative perceptions of PWID
- Loss of momentum for change, empathy

Summary

- PWID and mental health problems are not considered in legislation, policy or service delivery.
- Systemic factors are probably the major factor in supporting people with ID and MI
- People with ID experience discrimination, exclusion & harassment; resulting in service access being more difficult
- **What's needed is:**

➢ Collaboration between services based on individual need

➢ Adopting a stepped approach to complexity, that can address disability and mental health needs and manage seriously challenging behaviour in light of significant levels of uncertainty.

Are people with disabilities receiving the…

'Highest attainable standard of health without discrimination on the basis of disability?
(UN Convention on the Rights of Persons with Disabilities)

Thank you

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

PLEASE COMPLETE THE POLL

References

- United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), https://social.desa.un.org/issues/disability/crpd/convention-on-the-rights-of-persons-with-disabilities-crpd
- Accessible Mental Health Services for People with an Intellectual Disability: A Guide for Providers
- https://www.3dn.unsw.edu.au/projects/accessible-mental-health-services-people-intellectual-disability-guide-providers
- Evans, E., Howlett, S., Kremser, T., Simpson, J., Kayess, R., & Trollor, J. (2012). Service development for intellectual disability mental health: a human rights approach. Journal of Intellectual Disability Research, 56(11), 1098-1109.
- Pelleboer-Gunnink, H. A., Van Oorsouw, W. M. W. J., Van Weeghel, J., & Embregts, P. J. C. M. (2017). Mainstream health professionals' stigmatising attitudes towards people with intellectual disabilities: a systematic review. Journal of Intellectual Disability Research, 61(5), 411-434.
- Whittle, E. L., Fisher, K. R., Reppermund, S., Lenroot, R., & Trollor, J. (2018). Barriers and enablers to accessing mental health services for people with intellectual disability: a scoping review. Journal of Mental Health Research in Intellectual Disabilities, 11(1), 69-102.
- Weise, J., & Trollor, J. N. (2018). Preparedness and training needs of an Australian public mental health workforce in intellectual disability mental health. Journal of Intellectual & Developmental Disability, 43(4), 431-440.

References

- Ee, J., Stenfert Kroese, B., & Rose, J. (2022). A systematic review of the knowledge, attitudes and perceptions of health and social care professionals towards people with learning disabilities and mental health problems. British Journal of Learning Disabilities, 50(4), 467-483.
- O'Connor, M. (2014). The National Disability Insurance Scheme and people with mild intellectual disability: Potential pitfalls for consideration. Research and Practice in Intellectual and Developmental Disabilities, 1(1), 17-23.
- NDIS Legislation, https://www.ndis.gov.au/about-us/governance/legislation
- https://www.ndiscommission.gov.au/legislation-rules-policies
- Disability Act 2006, https://services.dffh.vic.gov.au/disability-act-2006
- Victorian Ombudsman, Investigation into the imprisonment of a woman found unfit to stand trial
- https://www.ombudsman.vic.gov.au/our-impact/investigation-reports/investigation-into-the-imprisonment-of-a-woman-found-unfit-to-stand-trial/
- Department of Developmental Disability Neuropsychiatry, Making Mental Health Policy Inclusive of People with Intellectual Disability
- https://www.3dn.unsw.edu.au/sites/default/files/documents/MHID%20Policy%20Review%20Report_final_new%20template.pdf