Systematic approaches to improving outcomes for people with intellectual disability:
An Australian Perspective

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CRICOS 00026A   TEQSA PRV12057

Overview

Australian context

Challenges in managing challenging behaviour

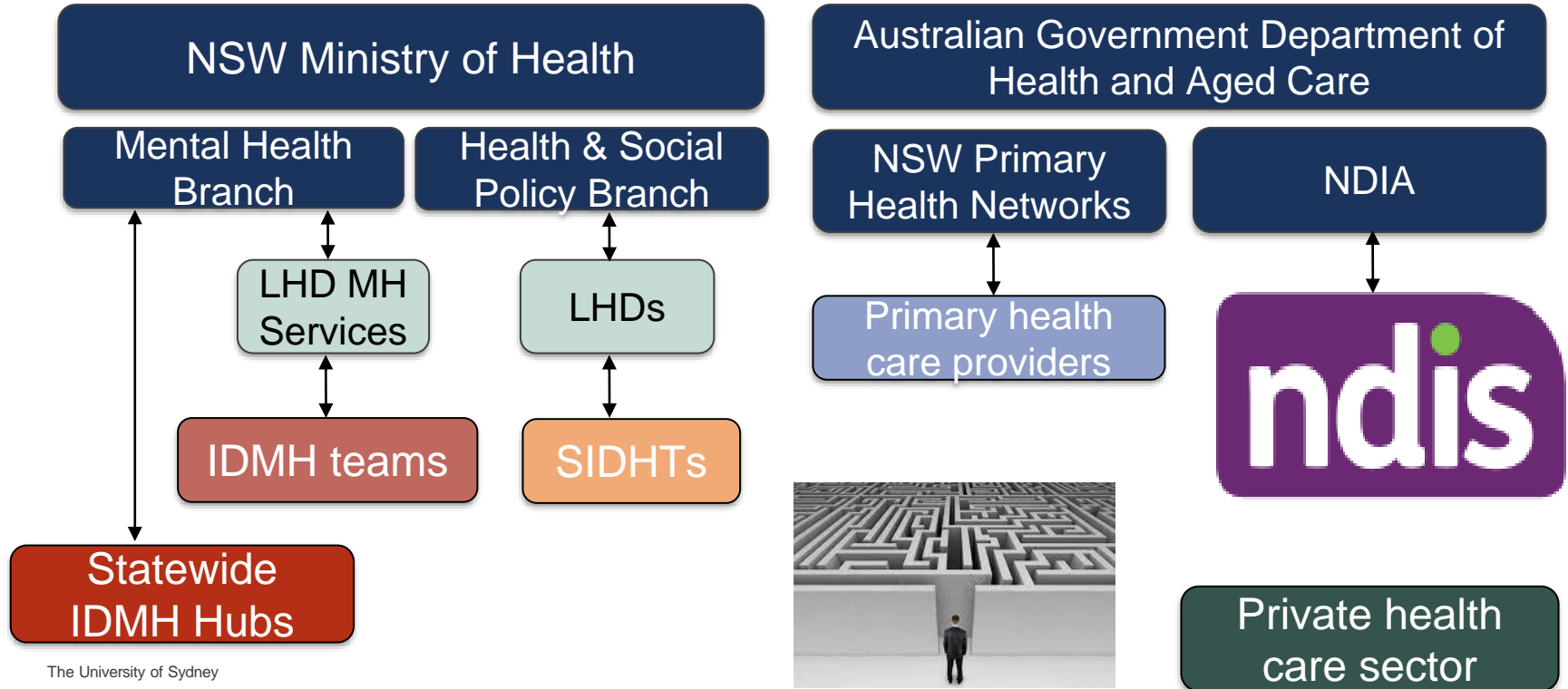Approaches to improving outcomes

Caveat…

Australian context

Estimated 450000 adults are living with an intellectual disability

Rates of physical comorbidity significantly higher

Rates of mental disorders are 2-3 higher in this population

Complex interrelationships between disability and other medical, social and psychological factors

AIHW, https://www.aihw.gov.au/reports/disability/intellectual-disability-australia/summary, updated 15.08.2023

Systemic barriers to obtaining health and mental health care

Limited specialist services

Pathways to health care are disjointed and poorly defined

Health and disability sectors are siloed

Lack of knowledge, training and confidence of health professionals

"Diagnostic overshadowing"
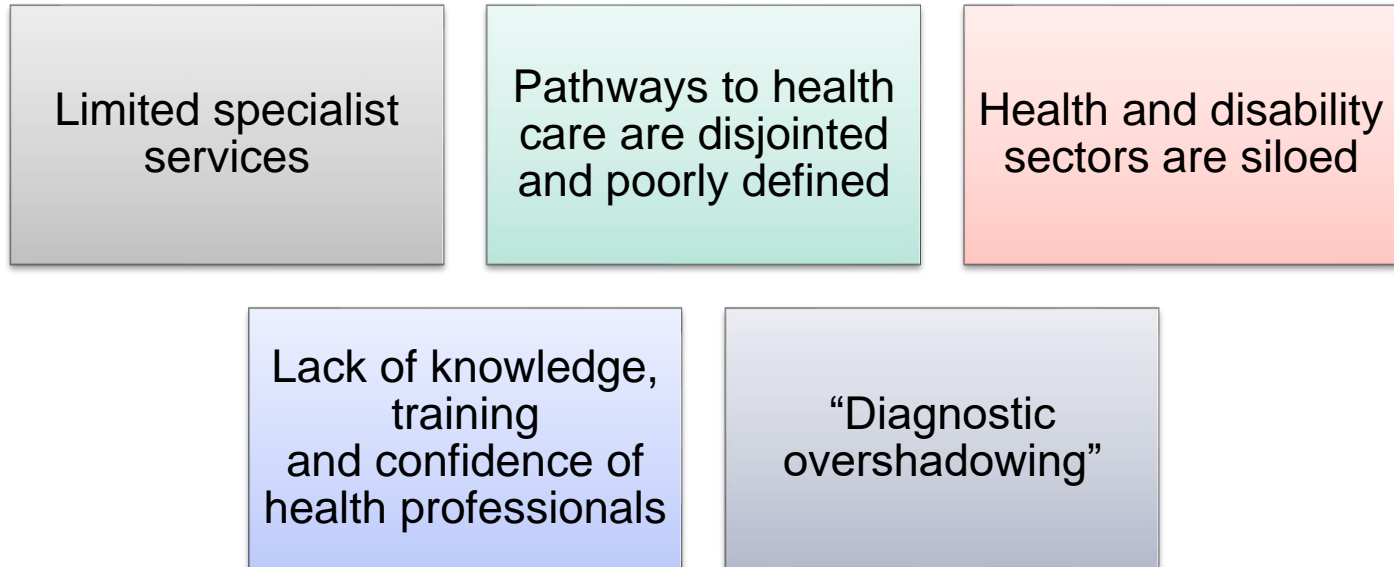
Shea et al (2022). Access to general practice for people with intellectual disability in Australia: a systematic scoping review. BMC Prim. Care 23, 306;

Whittle et al. (2018) Barriers and Enablers to Accessing Mental Health Services for People With Intellectual Disability: A Scoping Review, JMHRID, 11:1, 69-102

Trollor et al. (2016) Intellectual disability health content within medical curriculum: an audit of what our future doctors are taught. BMC Med Educ 16, 105

Intellectual disability services in NSW: A complex landscape

NSW Ministry of Health

- Mental Health Branch
- Health & Social Policy Branch

LHD MH Services

LHDs

IDMH teams

SIDHTs

Statewide IDMH Hubs

Australian Government Department of Health and Aged Care

- NSW Primary Health Networks
- NDIA

Primary health care providers

ndis

Private health care sector

Lack of specialist training

Intellectual disability health training content in medical schools in Australia is inadequate

- Median of 2.55 h of compulsory intellectual disability content included in medical school curricula[1]
- Only 1/3 of participating medical schools provided education on mental health needs of people with intellectual disability[1]

No recognised training pathway for intellectual disability psychiatry in Australia

- Recognised as a "Section" but not Faculty within RANZCP

1. Trollor, J.N., Ruffell, B., Tracy, J. *et al.* Intellectual disability health content within medical curriculum: an audit of what our future doctors are taught. *BMC Med Educ* **16**, 105 (2016).

Lack of ownership of and appropriate response to the problem

- "It's just behavioural"
- "No evidence of mental illness" = discharge from mental health service
- Lack of psychiatric assessment for behaviours of concern
- Significantly higher rates of prescribing of psychotropics (particularly antipsychotics & anticonvulsants) in a primary health care settings[1]

1. Salomon C, Britt H, Pollack A, Trollor J. Primary care for people with an intellectual disability - what is prescribed? An analysis of medication recommendations from the BEACH dataset. BJGP Open. 2018 May 30;2(2):bjgpopen18X101541

The impacts of systemic failures in Australia

Potentially preventable hospitalisations, New South Wales

A All potentially preventable hospitalisations
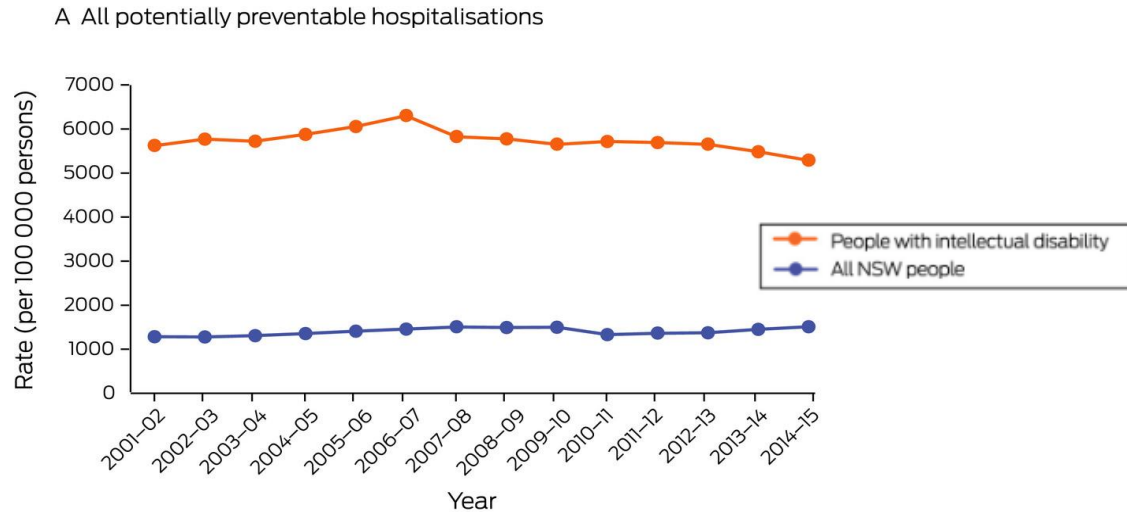
Weise, J.C., Srasuebkul, P. and Trollor, J.N. (2021), Potentially preventable hospitalisations of people with intellectual disability in New South Wales. Med J Aust, 215: 31-36

Premature mortality
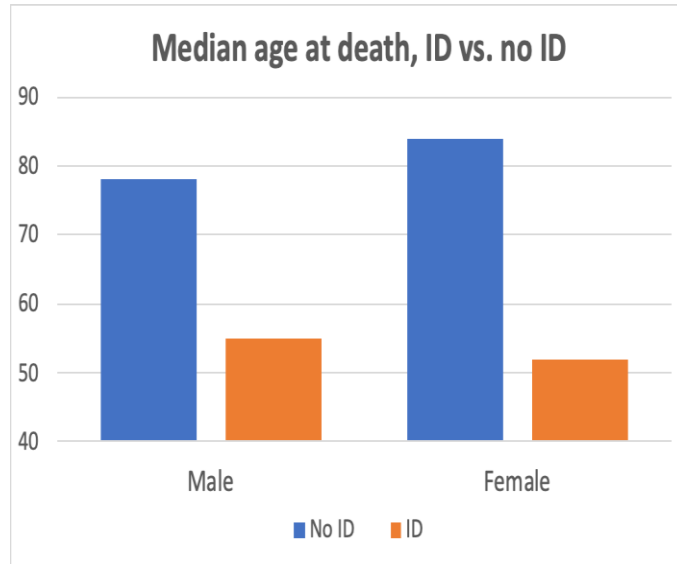
Median age at death, ID vs. no ID

People with intellectual disabilities twice as likely to suffer preventable death, study finds

7.30 By Elise Worthington

Updated 9 Feb 2017, 1:19am

38% of deaths in the ID cohort (vs. 17% in the comparison cohort) were potentially avoidable

Trollor et al., *BMJ Open*, 2017; 7:e013489

What can be done in Australia to address the health inequalities for people with an intellectual disability?

A suggested strategic approach

Specialist teams

Capacity building of mainstream services

Policy

Legal frameworks

Recognition of and action to address the needs
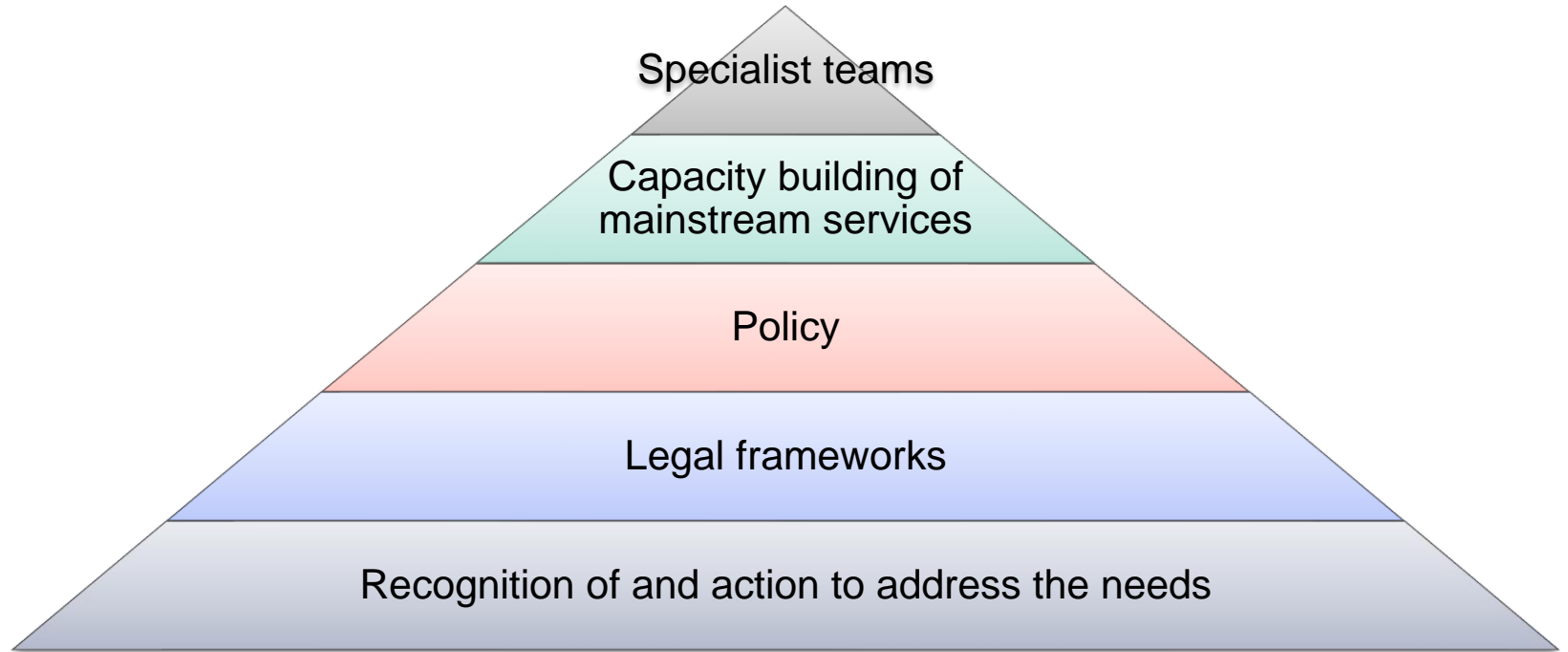
Recognition of the need: Disability Royal Commission recommendations

☑ Develop and implement a 'cognitive disability health capability framework', including improved access to clinical placements in disability health

☑ State and territory governments fund, establish and evaluate specialised health and mental health services

☑ Introduce 'disability health navigators' to assist people with intellectual disability to find their way through the health system

☑ Reform processes for restrictive practices
- Ensure appropriate legal frameworks are in place
- Reduce inappropriate prescribing of psychotropic medications
- Improve data collection and research around behaviour support planning and restrictive practices

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

https://disability.royalcommission.gov.au
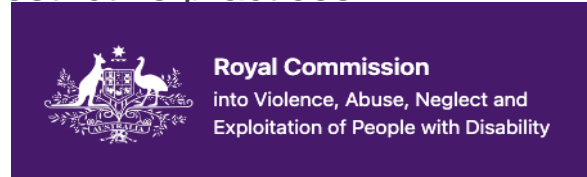
National initiatives: The Roadmap
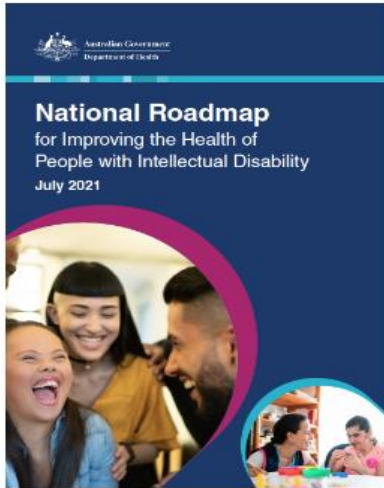
www.health.gov.au

The Roadmap aims to:
- Develop better models of care
- Support health professionals to deliver quality care for people with intellectual disability
- Improve health monitoring

Concurrent funding for action priorities, including the **National Centre of Excellence in Intellectual Disability Health**
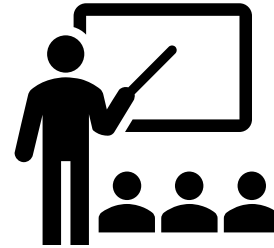- Lead by UNSW Sydney
- Launched late 2023

State-based initiatives: NSW statewide specialist IDMH services
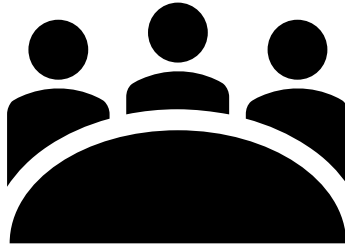
Specialist clinical consultation

- ✓ Improved wellbeing of people with ID
- ✓ Improved access to specialist care
- ✓ Increased coordination and engagement across services

Capacity building

Purcal et al. (2021) Sydney: UNSW SPRC

Capacity building in IDMH: Project ECHO

- Standardised model of telehealth education
- Developed by University of New Mexico
- Pilot evaluation
  - ✓ Waitlist-controlled trial
  - ✓ Improved participant knowledge
  - ✓ Improved participant confidence in working with adults with intellectual disability
- 500+ participants from across NSW since 2020 and growing

EMPIRICAL REPORT

Effectiveness of Project ECHO Programs in Improving Clinician Knowledge and Confidence in Managing Complex Psychiatric Patients: a Waitlist-Controlled Study

Erica Bessell[1] · Ji Sun Kim[2] · Lyn Chiem[2] · Andrew McDonald[2] · David Thompson[2] · Nicholas Glozier[1] · Andrew Simpson[2] · Lisa Parcsi[2] · Richard Morris[1] · Rebecca Koncz[1]

https://projectecho.unm.edu
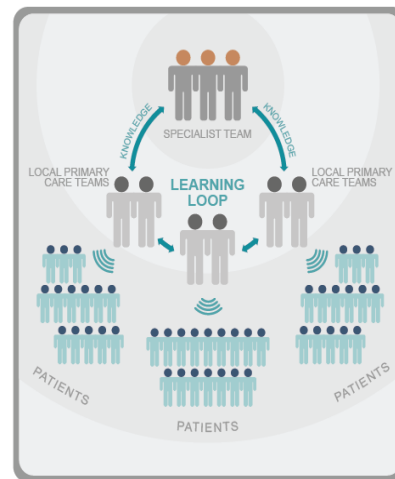
Capacity building of mainstream mental health services

www.3dn.unsw.edu.au
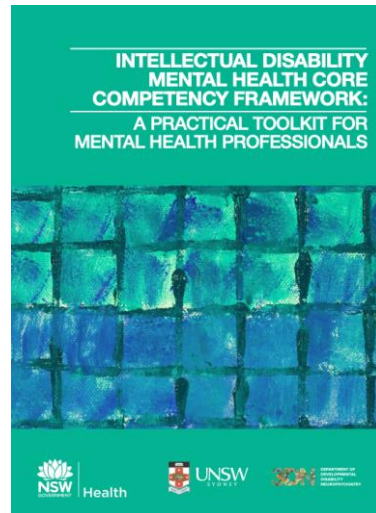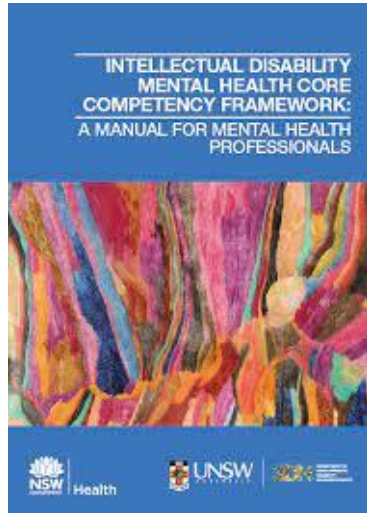
- Targets mainstream mental health professionals
- Outlines the specific skills and necessary approaches to guide the provision of quality mental health care to people with an intellectual disability
- Toolkit provides practical information, assessment tools and links to resources

Development of online knowledge hubs

idmhconnect.health

Summary

1 Serious health inequities persist for people with intellectual disability in Australia

2 Several initiatives now exist to start to close this gap

3 There is a still a long way to go

Thank you
Questions? Comments?

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