A Collaborative Approach to Improve Mental Health Outcomes for People with an Intellectual Disability

Never Stand Still | Medicine | Department of Developmental Disability Neuropsychiatry

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Background

- Australian population prevalence of ID about 1.8% (~400,000 people)[1]
- High morbidity, mortality & unmet health needs
- Majority has mental disorder (57%)
- Only 10% received mental health intervention (compared to 35% of the general population)[2]

Reasons:

– poor access to mental health care
– frequent errors in diagnosis
– psychiatrists and GPs perceiving themselves to be inadequately trained

- In Australia, there is a relative lack of available data related to the mental health of people with intellectual disability.

[1] (AIHW, 2003), [2] (Einfeld, 2006)

NHMRC partnerships for better health project

Partnership between leading academics in the field and representatives from disability and health sectors

United in one common goal: to improve mental health outcomes for people with an intellectual disability

Aims of the partnership project: 1. Data Linkage

1. Create an annualised **linkage of datasets** to enable detailed examination of **mental health profiles and service utilisation**, and to enable **development of intellectual disability mental health services in NSW**

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Disability Minimum Dataset
N = 52 146

- Information on people who received disability services

Admitted Patient Data Collection N = 873 796

- Admissions and separations for each public, private psychiatric and repatriation hospital in NSW

Emergency Department Data Collection N = 62 465

- Presentations to emergency departments

Data Linkage

Mental health profile	• Investigate patterns of mental health diagnoses and service provision to identify common patterns of specific mental health and other services profiles of people with an ID
Health profile	• Investigate various aspects of health service provisions to identify common patterns of health and other services profiles of people with an ID
Death and causes of death	• Investigate deaths and mortality of people with an ID. Mortality rates, common causes of death and potentially avoidable deaths
Health care cost	• Estimate the cost of health care service use in people with an ID

Aims of the partnership project: 2. Policy Analysis

2. **Analyse** Commonwealth and State **mental health policy** to determine the current representation of people with an ID and to establish strategies **to enhance intellectual disability mental health policy**

- Identify key National and State/Territory mental health and health legislation and policies
- Develop and apply qualitative content analysis framework
- Identify strength and weaknesses in relation to project aim
- Map policy linkages
- Propose strategies to enhance intellectual disability in mental health policies

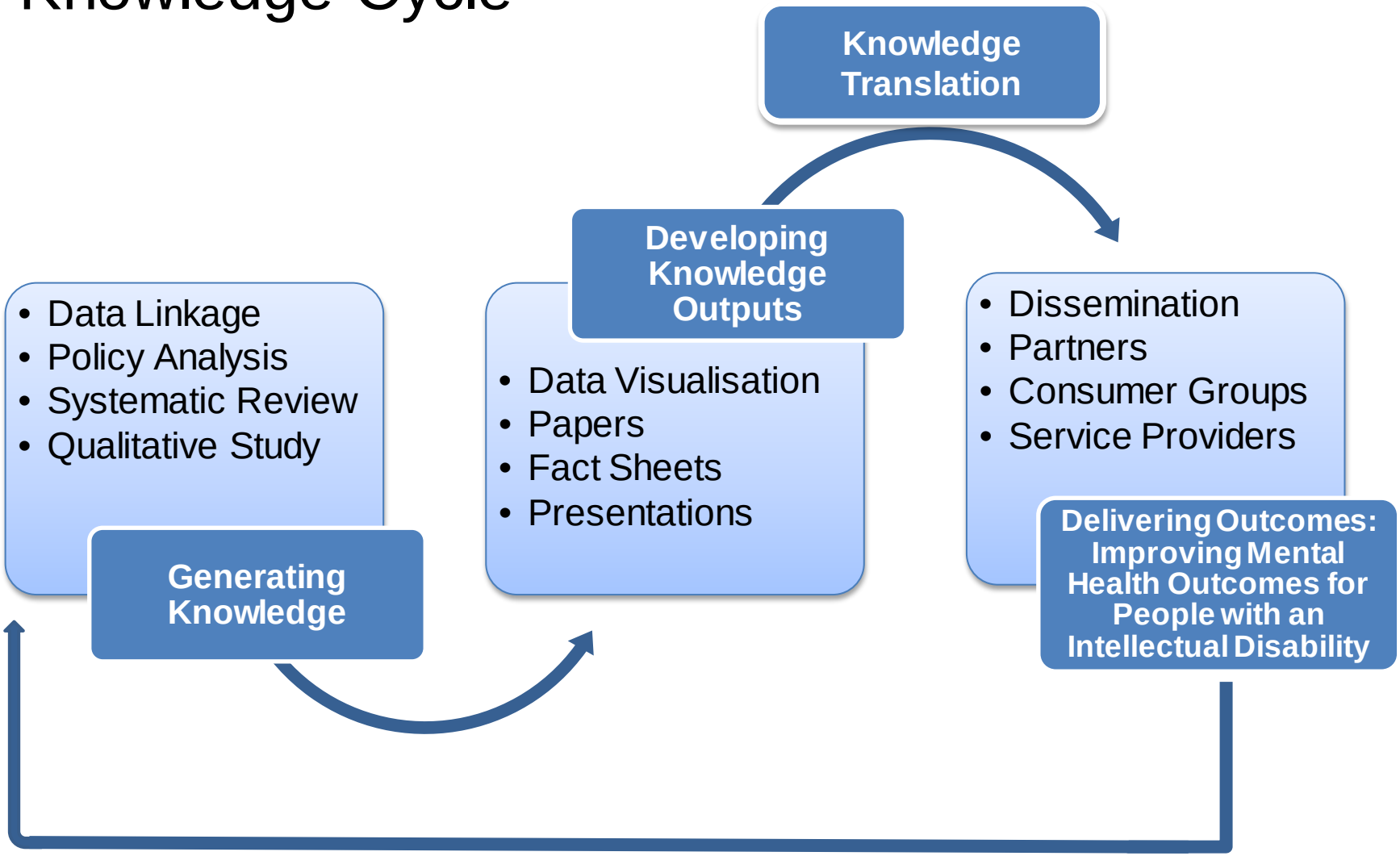
Aims of the partnership project: 3. Stakeholder Engagement

3. **Engage with stakeholders** including consumers and support persons, to inform **improved recognition of mental ill health**, **accessibility of mental health service development, policy and reform** across lifespan

- Investigating barriers and enablers to access to mental health services for people with an ID

- Qualitative, inclusive research (targeting people with an ID, carers, supporters and service providers)

Knowledge Cycle



Knowledge translation strategy

End of grant KT

- Conferences, publishing findings once the project has been completed

Integrated KT

- Engaging knowledge users into the research process
- Collaborative process with the aim to produce knowledge, its exchange and its translation into practice
- Integrating knowledge users at every stage:
  - make joint decisions to shape the research questions
  - interpret the study findings
  - craft messaging around the results and move the research results into practice

Consumer reference group

- Consumers (people with an ID) and carers/support persons

- Feedback on design and conduct of the research:
  - ensuring that the priorities of persons with an ID and their carers are considered throughout the project
  - ensuring that the research process is accountable to people with an ID and their carers
  - ensuring that the outcomes are meaningful for this group
  - advise on the involvement and representation of consumers and carers throughout the project

Knowledge and expertise derived from the Partnership Project will contribute to better lives and improved mental health for people with an intellectual disability

Communication strategy

- Report progress and findings between the 3 aims/project groups to facilitate collaboration and communication
  - Management committee meeting
  - Workshop/forum with partners
  - Newsletters/annual reports with updates from each project
  - Cross-project presentations and publications

KT and dissemination strategy	Target audience	Success measure
Peer-reviewed publications	Academic audience	Publications in high-impact journals, number of citations
Conference presentations	Academic audience, (Service providers and consumers for some conferences)	Feedback from peers, invitations to present at conferences
Training PhD students	Academic audience, students	Successful completion of PhD, attracting future students
Accessible website with data application procedure	Partner Organisations, people with an ID, carers, academics	Hits on website
Annual project report	Partner Organisations, people with an ID, carers, academics	Feedback from Partner Organisations, consumer reference group
Reports/fact sheets/2-page summaries of publications/ patient decision arms	Partner Organisations, people with an ID, NDIA	Feedback from Partner Organisations, requests for reports and fact sheets, consumer ref group
Partner Forum	Partner Organisations	Feedback from Partner Organisations, engagement of Partner Organisations
Social Media (Twitter)	General Public, people with an ID, carers	Re-tweets, followers, profile visits
Press releases	General Public, people with an ID, carers, NDIA, policy makers	Feedback from general public, people with an ID and carers

Thank you!

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