



Linking Disability And Mental Health Data: Improving Mental Health Outcomes for Persons With An Intellectual Disability

Never Stand Still

Medicine

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Overview

- Background to project:
 - Data informing policy & service development in Intellectual Disability Mental Health (IDMH)
- Project phases:
 - Pilot phase: findings
 - Statewide phase: status
 - Future phase: NHMRC Partnerships for Better Health Project
- Possible ideas for IDMH data linkage
- Challenges to linkage

Background

- Limited data on mental illness in ID collected either in NSW or nationally.
- Only routine collection is in WA.
- Absence of baseline data:
 - limited awareness of IDMH issues;
 - difficult to demonstrate effectiveness of policy interventions.
- In NSW, IDMH data is collected by two separate agencies:
 - NSW Department of Family & Community Services, Ageing, Disability & Home Care (ADHC)
 - Mental Health & Drug & Alcohol Office, NSW Ministry of Health.
- Datasets do not currently talk to one another.

Pilot Phase: IDMH Data Linkage Project NSW



- 2011 - pilot test of data linkage (1 year ADHC funding)
- Linked NSW Health Mental Health Ambulatory data + ADHC Disability Minimum Dataset (MDS) 2005-2010.
- Representative area (36.7%) of NSW =
Local Health Districts (formerly Area Health Services):
South Eastern Sydney (SESLHD),
Illawarra Shoalhaven (ISLHD),
Sydney (SLHD) & South Western Sydney (SWSLHD)

Pilot Phase: findings

- People with ID compared to those without ID:
 - under represented in MH-AMB (only 1.6%)
 - x age = 28 years
 - 94% < 65 years
 - more likely to be treated for psychotic disorders
 - less likely to be treated for common disorders: depression & anxiety
 - greater uncertainty in diagnosis, ie. 'unknown category'
 - complexity of those with ID apparent from service use profile
 - more face-to-face contacts (1.5x)
 - as long than those without ID (2.2x).
- Findings presented at AADDM (2012), RANZCP, ASID (2013) Conf.
- Manuscripts submitted (pending) to peer-reviewed journals.

Statewide Phase: NSW IDMH data linkage

- 2012 – extending pilot linkage to Statewide datasets (2005 – 2016) (1 year Mental Health & Drug & Alcohol Office, NSW Ministry of Health funding)



- Data linkage will be annually refreshed from 2012 – providing longitudinal linked feed.

Statewide Phase: Status

- Approval for linkage from the NSW Centre for Health Record Linkage ([CHeReL](#)).
- Ethics approval obtained from the NSW Population Health Services Ethics Committee (at some length).
- Received linked data.
- Preparing database at front-end for analysis.
- Project funding has expired.
- Final project report due to MHDAO June 2014.

Future Phase: NHMRC Partnerships Project

- NHMRC Partnerships for Better Health Project grant.
- Awarded in March 2013 for future of linkage over 4 years.
- 11 Partners. 7 Chief Investigators. 5 Associate Investigators.
- Project scope includes:
 - Greater analysis of statewide linkage project data.
 - Extending linkage to other sets & data sources (e.g. NSW Dept of Education).
 - Policy analysis and qualitative research component to complement linkage work.

Possible ideas for data in future

- Better integration between data and policy making & service development in IDMH
 - eg. monitoring effectiveness of policy interventions in IDMH.
- Establish:
 - data cube format portal accessed by policy makers, clinicians, consumers, researchers etc.
 - an ID register (eg. WA Intellectual Disability Exploring Ideas (IDEA) register).
- ?Other collaborations and opportunities arising out of NHMRC Partnerships for Better Health Project.

Challenges to data linkage

- Ethics & other approvals processes:
 - Heavy administrative burden at odds with ltd research funding and timeframes
 - Variable approvals processes
 - No clear articulation of requirements at outset
 - Approvals processes not at pace with technology
 - Not supportive of exploratory projects
- Data cleaning required on data not collected for use in research.
- Ongoing project funding required to explore linkage opportunities.

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