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

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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).

- 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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