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

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Overview

- The importance of data in informing policy & service development in Intellectual Disability Mental Health

- Our Pilot Data Linkage Project:
  - Findings

- Current & future ideas for data:
  - how these can be built upon and used into the future

- Challenges to linkage
Policy & Service Development

- Ability to influence policy hinged on:
  - Translational value of research
  - Good, collaborative relationships with stakeholders, such as:
    - Consumers, families and carers,
    - Advocacy groups, eg. NSW Council for ID
    - Key interest groups, eg. RANZCP and AADDM
    - Academic institutions: e.g. Queensland Centre for Intellectual and Developmental Disability (QCIDD) and University of Sydney Centre for Disability Studies
    - Policy makers & funding bodies: Federal and State government.

- Some current key policy initiatives ID health and mental health:
  - Chair IDMH (2009)
  - NSW Service Framework (2007)
  - NSW MOU with Ageing, Disability & Home Care (ADHC) (2011)
Importance of Data

- No baseline data → Difficult to demonstrate effectiveness.
- Data in NSW (and nationally) is presently limited.
- Not systematically collected anywhere but WA.
- In NSW, IDMH data is collected by two separate agencies:
  - ADHC
  - NSW Ministry of Health.
- Datasets do not currently talk to one another.
Pilot IDMH Data Linkage Project NSW

- 2011 - pilot test of linkage (ADHC Funding)
- NSW Health Mental Health Ambulatory data + ADHC Disability Minimum Dataset (MDS) 2005-2010.
- Representative area of NSW:
  - Local Health Districts (formerly Area Health Services): South Eastern Sydney (SESLHD), Illawarra Shoalhaven (ISLHD), Sydney (SLHD) & South Western Sydney (SWSLHD)
  - ADHC Regions: Metro South and Southern.
What we found

- People with ID compared to those without ID:
  - Under represented in MH-AMB (only 1.6%)
  - Mean age of 28 years
  - 94% aged under 65 years
  - More likely to be treated for psychotic disorders
  - Less likely to be treated for common disorders: depression & anxiety.
  - No significant difference in personality disorders.

- Uncertainty in diagnosis - ‘Unknown category’

- Complexity of those with ID apparent from service use profile:
  - 1.5x more face-to-face contacts than those without ID.
  - 2.2x as long than those without ID.
NSW IDMH data linkage - Current

- 2012 – State-wide linkage
  (funding - Mental Health & Drug & Alcohol Office (MHDAO), NSW Ministry of Health)

- 2005 - 2016
  Longitudinal, establishing annually refreshed link feed

Disability Minimum Dataset (MDS)

Admitted Patient Data Collection (APDC)

Mortality Data (ABS and RBDM)

Emergency Department Data Collection (EDDC)

MH-Ambulatory Data (MH-AMB)
Challenges to using data

- Ethics & other approvals processes
  - Burden of administration
  - Variable processes
  - No clear articulation of requirements at outset
  - Approvals processes not at pace with technology
  - Not supportive of exploratory projects
Possible ideas for data in future

- Integration of data in policy making & service development in IDMH.

- Monitoring effectiveness of policy interventions in IDMH.

- Establish a data cube format portal for policy makers, clinicians, consumers & researchers etc.

- Establish register of persons with ID (akin to WA IDEA register).

- The NHMRC Partnerships Grant – 4 years

- Other collaborations and opportunities – NHMRC Partnerships
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