An introduction to Mental Ill Health in People with an Intellectual Disability

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Main Points

• The goal
• Mental ill health in people with an Intellectual Disability
• Barriers to access to good quality mental health care
• Improving mental health & mental health care
• Examples of recent progress and projects
• Summary
• Questions
THE HIGHEST ATTAINABLE STANDARD OF MENTAL HEALTH AND WELLBEING FOR PEOPLE WITH AN INTELLECTUAL DISABILITY

• Talk to:
  – consumers
  – family carers
  – health advocates
  – disability sector

• Examine:
  – available prevalence data
  – skills and training of mental health professional
  – mental health services
  – mental health policy
How Common are Mental Health Problems?

General Population

- About 1 in 10 people in a month (NB survey excluded people with an ID)

2007 National Survey of Mental Health and Wellbeing
How Common are Mental Health Problems?

General Population

- About 2 in 10 people in a year

2007 National Survey of Mental Health and Wellbeing
How Common are Mental Health Problems? For people with ID

• About 4 or 5 out of every 10 people in a year

Cooper et. al., 2007
How Common are Mental Health Problems?
For carers

• About 3 out of every 10 people in a year

Savage and Bailey, 2004
Mental Health of People with an ID

- People with an intellectual disability experience an over-representation of mental disorders
  - Conservative estimates for adults/children with ID 2.5/3-4x
- At any one time, an estimated 20-40% of people with an ID will be experiencing a mental disorder of some kind.
- Access to mental health supports and treatments is limited
- High impact for people with ID, families and carers
- Complexity
- Multiple vulnerabilities
ID Mental Health across the Lifespan

• predisposition to mental ill health across the lifespan
  – Children: neurodevelopmental disorders
  – Younger persons: Schizophrenia over-represented 2-4 x, earlier onset in people with an ID.
  – Older persons: higher rates of dementia.
Prevalence of Mental Disorders in Adults with ID (Cont)

- General Population:
  - 2007 National Survey of Mental Health and Wellbeing: 20% of general population experience some form of mental disorder in past 6 months

- People with ID:
  - Prevalence estimates vary – differing definitions and methodologies
  - Estimates from 7% to 97% (Cooper et al., 2007)
  - A conservative estimate for adults with ID = ~2.5 x higher
Vulnerabilities to Mental Disorder

**Biological risk factors**
- Physical inactivity
- Poor diet
- Multiple health conditions
- Polypharmacy
- Epilepsy
- Head injuries
- Family history of mental disorder
- Genetic anomalies – e.g., Velocardiofacial syndrome is associated with higher rates of mental disorder, particularly schizophrenia

**Social risk factors**
- Social isolation
- Social adversity
- Adverse life events
- Stigma
- Communication difficulties
- Reduced social skills
- Absence of meaningful social relationships

**Psychological risk factors**
- Maladaptation
- Feeling of isolation
- Stress and anxiety
- Low self-esteem
- Emotional issues
- Capacity

**Various combinations of social, psychological or biological risk factors**
- Social and communication impairments, e.g., those associated with autistic disorder
- Family stress or conflict
- Interpersonal difficulties
- Chronic pain
- Atypical physical appearance
- Motor impairment
- Lower IQ
- History of trauma and abuse
- Experiences of loss, grief, or unwanted life changes
- Being easily manipulated
- Deprivation or neglect
- Below average achievement
Profile of Mental Disorders Varies with Severity of ID

- Rates of specific disorders varies according to severity of ID
  - prevalence increases with increasing disability
  - psychopathology varies with increasing disability
Profile of Mental Disorders Varies with Severity of ID (Cont)

• Mild-moderate ID: full spectrum of mental disorders
• Moderate-severe ID: different symptom profile, discrete Sx difficult to identify
  – Behavioural analysis and 3rd party reports rather than self-reported Sx
  – Severe mental illness can sometimes be identified
    – 15-50% stereotyped behaviours
    – 10-20% self injurious behaviours
Monitoring

• Early intervention = just as important for adults with ID as it is for their non-ID peers
  – Eg psychosis
Prevention

- Increased opportunities for choice and independence
- Skill building & promoting resilience
  - teaching coping strategies, problem solving, relaxation strategies, communication skills
  - developing a support system e.g. who to talk to about problems/issues
Prevention cont...

- Increased activity
  - reducing boredom & increasing opportunities to feel a sense of achievement & purpose – via day programs, social groups, sports or hobbies, community college courses, etc

- Environmental modifications
  - family/staff training in mental health, early warning signs, and how to provide a supportive, validating environment
  - changes to light/noise/space
Poorer access to treatments

• Low rate of treatment & often unknown to mental health services
  – Only 10% of adults with ID and psychopathology received mental health interventions across a 14 year period (Einfeld et al., 2006)
  – cf. 34.9% of people with a mental disorder accessed mental health services within a 12 month period (Slade et al., 2009)

• Reasons?
  – Families & care staff untrained in mental health, unable to recognise indicators
  – Inadequate mental health professional training in ID
  – Diagnostic difficulties
  – Until recently there has been little research on the use of psychological therapies other than behavioural treatments for people with ID (Emerson & Holland, 1997)
Access to MH Services and Supports

- Policy
- Significant Barriers
- Silos
- Historical
- Workforce and skills
- Individual and Carer
- Conceptual
Presentation of Mental Disorders in Adults with ID – Reminder

• A mental disorder can affect mood, thoughts, behaviour, arousal, and social, interpersonal and physical functioning

• Presentations of mental disorders can include
  – subjective changes such as feelings of guilt, anxiety, auditory hallucinations, persecutory ideation, etc
  – changes that are readily observable by others such as changes in sleeping, appetite, weight, talkativeness, agitation, irritability, sociability, aggression, self-injurious behaviour etc
Presentation

• Adults with mild ID and/or reasonable verbal skills: *similar presentation to adults without ID*

• Adults with moderate-severe ID, ID & autism, or limited verbal skills: ↑ *changes in behaviour, including disturbed or regressed behaviour*
Presentation – ambiguities

• Changes that seem to indicate a mental disorder may have other causes, eg
  – medication side-effects, pain, or physical illness/disorder
  – bizarre behaviour in response to a stressor, or disorganised speech, giggling and silliness may be an idiosyncratic feature of the disability rather than signs of psychosis
Presentation – ambiguities

• Changes due to a mental disorder may be incorrectly perceived as normal in the context of the ID, eg
  – grandiosity may be mundane, such as imitating a staff member
  – withdrawal and decline in social skills due to psychosis are incorrectly ascribed to the ID
  – onset of a new disorder is missed, due to pre-existing high levels of unusual behaviours
Presentation – activity

• Typical criteria for mental disorders (eg DSM) rely heavily on self report of symptoms, or interpretation of complex verbal output

• Self report and comprehensive language may not be available in people with ID

• In small groups, chose one scribe and two spokes-people (one for mania and one for depression)

• Create operational observable diagnostic criteria for
  – a manic episode
  – a depressive episode

for adults with a mild-moderate intellectual disability
## Criteria for Depression & Mania

| Mania                                                                 | DSM-IV | ICD-10 |
|                                                                     |        |        |
| Elevated, expansive, irritable mood                                | ✓      | ✓      |
| Inflated self esteem, grandiosity                                  | ✓      | ✓      |
| Decreased need for sleep                                          | ✓      | ✓      |
| More talkative, pressured speech                                   | ✓      | ✓      |
| Flight of ideas, racing thoughts                                   | ✓      | ✓      |
| Distractibility/difficulty in concentrating                        | ✓      | ✓      |
| Increase in goal directed behaviour/agitation/increased activity   | ✓      | ✓      |
| Involvement in pleasurable activities despite consequences/ reckless behaviour | ✓      | ✓      |
| Marked increase sexual energy/indiscretions                        |        | ✓      |
| Increased sociability/over familiarity/loss of social inhibitions  | ✓      |        |

| Depression                                                           | DSM-IV | ICD-10 |
|                                                                    |        |        |
| Depressed mood, most of day, most days                              | ✓      | ✓      |
| Loss of interest/loss of pleasure                                    | ✓      | ✓      |
| Significant weight loss                                             |        | ✓      |
| Insomnia/hypersomnia/sleep disturbance                              | ✓      | ✓      |
| Psychomotor agitation/retardation                                    | ✓      | ✓      |
| Fatigue/loss of energy                                              | ✓      | ✓      |
| Feelings of worthlessness, guilt, self reproach                     | ✓      | ✓      |
| Diminished ability to think, concentrate, decide                    | ✓      | ✓      |
| Recurrent thoughts of death, suicide                                | ✓      | ✓      |
| Loss of confidence/self esteem                                      |        | ✓      |
Your turn

CRITERIA FOR DEPRESSION
DC-LD Criteria for Depression

E: Item 1 or 2 must be present and prominent:
1. Depressed mood (misery; failure to maintain usual mood state throughout the day)
   or irritable mood (includes onset of or increase in aggression; reduced level of tolerance)
2. Loss of interest or pleasure in activities
   or social withdrawal
   or reduction in self care
   or reduction in the quantity of speech/communication

F: Some of the following must be present so that at least four symptoms from E and F are present in total
1. Loss of energy; increased lethargy
2. Loss of confidence or increase in reassurance seeking behaviour/ onset of or increase in anxiety or fearfulness
3. Increased tearfulness
4. Onset of or increase in somatic symptoms
5. Reduced ability to concentrate/distractibility or increased indecisiveness
6. Increase in a specific problem behaviour
7. Increased motor agitation or increased motor retardation
8. Onset of or increase in appetite disturbance or significant weight change
9. Onset of or increase in sleep disturbance
Approach

Vision
• The highest attainable standard of mental health and wellbeing for people with an intellectual disability.

Mission
• To improve mental practice and policy for people with an intellectual disability.

Guiding Principles
• Human rights
• Equity in mental health care
• Person centred approach
• Promoting independence
• Recovery-oriented practice
• Evidence based
• Innovation in health services
• Collaboration
People

Macro Strategies

• Improved pre, peri & postnatal care
• Improved access to housing, education, employment
• Strengthening community networks

Enhancing Resilience

• Early intervention in developmental lags
• Childhood disorders
• Reducing neglect and abuse
• Enhancing social skills and peer relationships
• Strengthening families
• Work place participation and interventions
• Mental and physical activity across the lifespan
• Addressing medical risk factors for mental ill health
People

• The experience of mental ill health
• The experience of mental health care
• Barriers and enablers to access for the person and their carers
• Consumer, carer and advocate perspectives on:
  – priorities for reform and service development
  – Attributes expected of the workforce
• Data
  – Epidemiology
  – Outcomes

“the person is the expert in their own experience”
Mental Health professional, disability service
Workforce

• Understanding training needs
• Access to appropriate training
• Competencies
• Professional development
• Professional bodies
• Champions

“Respectful interactions are not only mutually rewarding but assist the process of recovery.”

Mental health professional, ID mental health service
Systems

- Clinical
  - Consumer health information
  - Diagnostic tools
  - Clinical pathways
- Service Mapping
- Service Development
  - Tiered
  - Joint service planning
  - Flexible boundaries
- Outcomes
  - Measures of effectiveness

“It took many years to get the help that my son needed. He was misdiagnosed with autistic disorder when he was actually psychotic. Regrettably, it was only after he had contact with the law that he was provided with the assessment and management he needed.”

Alan, parent and carer
Policy

• Proactive approach
• Universal inclusion of people with ID in all mainstream mental health policy development
• Adequate consultation with key stakeholders

“Troy aged 45, has a mild intellectual disability and autistic disorder. He lives independently and enjoys fishing, going on holidays, and spending time with his father. He developed depression, and became isolated from his community and family. He came close to disengaging from services and was at risk of homelessness. A Memorandum of Understanding between mental health and disability services guided collaboration between service providers. Troy was provided with flexible service delivery and holistic support from staff who respected and responded to his needs. He has made significant gains in health, is engaged in decision making and is a valued member of his local community.”

Mental Health Professional, mental health service
National Round Table in ID & Mental Health

Key elements of reform
• Priorities for action
  – Inclusion in all mental health initiatives
  – Prevention and timely intervention
  – Equitable access and skilled treatment
  – Specialists in Id mental health
  – Collaboration between agencies
  – Workforce education and training
  – Data collection and interrogation

Approach to People with an ID

Capacity Building Projects

- ADHC Funded IDMH Fellowships
- Training pathways in IDMH
- National audit of ID health content in Australian Medical and nursing schools
- NSW Mental Health Staff Survey
- IDMH Core Competencies Project
- Data linkage
- National Guide for mental health services
- IDMH e-learning
‘Accessible Mental Health Services for People with ID: A Guide for Providers’

The Goal

• To improve mental health service access for people with an intellectual disability by developing a guiding framework of action for all front line mental health service providers.
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<tr>
<th>Guiding Principles</th>
<th>Key Components</th>
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<tbody>
<tr>
<td>• Rights</td>
<td>• Adaptation of Clinical approach</td>
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<td>• Inclusion</td>
<td>• Access to mental health services</td>
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<tr>
<td>• Person centred approach</td>
<td>• Access to specialised IDMH services</td>
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<tr>
<td>• Promoting independence</td>
<td>• Identification of care pathways</td>
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<td>• Recovery-oriented practice</td>
<td>• Training for practitioners</td>
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<td>• Evidence based</td>
<td>• Interagency partnerships</td>
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<td></td>
<td>• Data collection and evaluation</td>
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<td>• Inclusion in policy</td>
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## Key Issues for Health Professionals

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<th>Health Professional</th>
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<td>• Competent mental health assessments.</td>
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<td>• Appropriate management plans.</td>
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<td>• Timely reviews.</td>
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<td>• Regular review of psychotropic medications and monitoring any potential side-effects.</td>
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<td>• Identification and familiarity with care pathways</td>
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<td>• Partnerships with local or regional disability services.</td>
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<td>• Availability of specialised ID health and mental health services.</td>
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<td>• Referral as appropriate for a second opinion.</td>
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<td>• Skill development in ID mental health</td>
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Key Issues for Services Include:

For the Organisation

- Recognition and promotion of the rights of people with an ID to access appropriate mental health services.
- Viewing the mental health of people with an ID as core business in mental health services.
- The development of partnerships with local or regional disability services.
- An understanding of the referral processes to disability and related services, including the development of networks and partnerships with local disability services.
- The development of staff resources outlining the availability of, and access to, local or regional specialised ID health and mental health services.
- The development of identified care pathways through typical service components.
- The development of accessible information (e.g. Plain English, modified or Easy English materials) where appropriate to consumers and their families.
- Fostering staff development of skills in ID mental health through the provision of education and access to training resources.
- Awareness and engagement with the academic sector.
- The development of joint initiatives between local disability and mental health services including:
  - priority referrals of urgent cases from disability or health sector to one another;
  - the establishment of regular meetings between designated mental health and disability staff to discuss specific cases;
  - the conduct of joint training and education initiatives;
  - the establishment of pathways for case escalation;
  - the development of long-term accommodation models for people with an ID and mental disorders, including those with offending behaviours;
- Identification of expertise in ID mental health to act as ‘ID mental health champions’
‘Accessible Mental Health Services for People with ID: A Guide for Providers’

Launch

• May 2014
• pre-launch from late March on web 3dn.unsw.edu.au
Free e-learning intellectual disability mental health

www.idhealtheducation.edu.au

- Introduction to Intellectual Disability
- Living with Intellectual Disability
- Changing Perspectives of Intellectual Disability
- Introduction to Mental Disorders in Intellectual Disability
- Communication: the basics
- Improving your Communication
- Assessment of Mental Disorders in Intellectual Disability
- Management of Mental Disorders in Intellectual Disability
Challenges

• NDIS
• People with complex disabilities
• People in contact with the criminal justice system
• State-based Disability services
• Mental health reforms
In conclusion

- **Adults with Intellectual Disability:**
  - Experience ~2.5 times the rate of mental disorders of the general population
  - Prevalence of mental disorder increases with increasing disability
  - Often experience many risk factors for mental disorders
  - Experience all the same disorders as those without ID
  - Have much lower access to services and treatment
  - Presentation in mild-moderate ID = similar to non-ID adults; presentation in more severe ID = ↑ disturbed behaviour
  - Some modification of usual diagnostic criteria are necessary
  - Monitoring and prevention are important and effective
Implications

- A complex problem requires a multilevel solution
- Guiding principles are apparent
- There are key priorities for reform
- There are individual and corporate responsibilities
- Improvement must be quantifiable (people, workforce, system, policy)
- The new wave of psychiatrists must be skilled in this area of practice
THE HIGHEST ATTAINABLE STANDARD
OF MENTAL HEALTH AND WELLBEING
FOR PEOPLE WITH AN INTELLECTUAL
DISABILITY
Acknowledgements/Declarations

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• Australian Research Council (ARC)
• National Health and Medical Research Council (NHMRC)
• NSW Institute of Psychiatry
• Autism CRC