The Mental Health of Older Adults with Intellectual Disabilities

(Integrated findings from a mixed-methods study: in association with UCD dept of disability studies)

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Ageing and Intellectual Disability

- Experience ‘old age’ earlier than the general population (Janicki & Dalton 2004)
  - >50 years cut-off used for this study
- Share many age-related concerns with the general population (Walsh 2005)
- Have unique age-related concerns (Bigby & Balandin 2004)
- Are heterogeneous in their needs and abilities (Bigby and Balandin 2004)
Presentation Outline

1. Ageing as a complex process
2. The present study
3. Patterns of quantitative findings relating to mental health
4. Patterns of Qualitative findings relating to mental health
5. Integration of findings
6. Conclusions
Ageing as a Complex Process

- Physical
  - Psychiatric Illness (Strydom 2005)
  - Dementia (Cooper, 1997)
  - Psychotropic medication
  - Mobility & Sensory impairments (Evenhuis, 1999)
  - Health Problems (Beange, 2002)

- Psychological/Social
  - Retirement (Hogg et al. 2001)
  - Bereavement (Summers et al. 2003)
  - Residential care (Bigby 2002; Dodd 2008)
The Present Study: St Michael’s House

- Founded as a charity 52 years ago by the families of children with ID
- Government funded
- Entirely community based (never had an institutional component)
- Provides services to over 1,500 people with intellectual disabilities
The Present Study: Design

- This study addresses an identified gap in policy and service provision
- Multidisciplinary team – researcher\clinician\manager
- Four phases
  1. Quantitative needs assessment
  2. Qualitative interviews with key stakeholders
  3)/(4) Design and implementation of pilot service
Phase 1: Quantitative Measures

- VABS: Vineland Adaptive Behaviour Scales (Sparrow, 2005)
- CANDID: Camberwell Assessment of Need for Adults with ID (Xentidis, 2003)
- MINI PAS-ADD: The Psychiatric Assessment Schedule for Adults with Developmental Disabilities (Moss et al, 1998)
Phase 2: Qualitative Semi-Structured Interviews

- Conducted with service users, key workers and family carers
- Semi-structured interviews asking about the needs of older adults with ID in various life-domains
- Carried out face-to-face with service users and key workers and over the phone with family carers
Demographic Breakdown: Phase 1

- 81 individuals were randomly selected from all service users over 50 years old
- Data collected for 75 service users
- Six service users did not consent to take part in the study
- Age range is between 50 and 72 years (mean=57.6, SD=5.4)
- Sample included females and males, from across the broad spectrum of ID served by SMH, and across the 3 main service regions
Phase 1: Gender Breakdown
Phase 1: Disability Level Breakdown

![Bar chart showing disability levels]

- **Mild**
- **Moderate**
- **Severe/Profound**

Disability Level
Phase 1: Mini PAS ADD

- Assess psychiatric ‘caseness’
- Informant interview
- Good validity & reliability (Prosser, 1998)
- Detailed glossary
- Psychosis/Hypomania/Autism/Depression/Anxiety/OCD/Unspecified
- Based on ICD 10
Quantitative Mental Health findings: Mini PAS-ADD

Disorder
- Depression
- Anxiety
- Hypomania/Mania
- Obsessive Compulsive Disorder
- Psychosis
- Other Disorder not Specified
- Autism
- Overall prevalence

Prevalence Values:
- Depression: 5.3
- Anxiety: 10.7
- Hypomania/Mania: 5.3
- Obsessive Compulsive Disorder: 5.3
- Psychosis: 5.3
- Other Disorder not Specified: 2.7
- Autism: 2.7
- Overall prevalence: 19.1
Quantitative Mental Health Findings: Group Classification

Group 1
N = 14 (18.7%)
Evidence of caseness on at least 1 PASADD scale

Group 2
N = 34 (45.3%)
No evidence of caseness but currently on medication

Group 3
N = 27 (36%)
No evidence of caseness & not on medication
Phase 1: Supports Intensity Scale

- AAMR 2004

- Covers
  - Home Living
  - Community Living
  - Lifelong Learning/Employment
  - Social/Advocacy
  - Medical & Behavioural
    - Exceptional needs

- Support
  - Frequency
  - Type
  - Time
Supports Intensity Scale: Relevant Findings

- Section 3: *Exceptional Medical & Behavioural Support Needs*
  - Externally directed destructiveness
  - Self-directed
  - Sexual
  - Other

- 12%: require extensive support
Phase 2: Demographic Breakdown

- 20 individuals were selected in a stratified sample of Phase 1, with family carers and key workers.
- Data collected for 20 service users, 19 key workers and 15 family carers.
- Age range is between 50 and 72 years (mean=59.1).
- Sample included females and males, from across the broad spectrum of ID served by SMH, and across the 3 main service regions.
Phase 2: Gender Breakdown
Phase 2: Disability Breakdown

![Bar Chart showing disability levels]

- Mild
- Moderate
- Severe/Profound

Disability Level
## Qualitative Mental Health Findings

| **Service user themes** | Bereavement closely linked with mental health needs  
| | Satisfied with support  
| | Sought support from informal sources (care staff/families) |
| **Key worker themes** | Saw dementia as a mental health need  
| | Also viewed bereavement as key need (felt ill-equipped to deal)  
| | Sought more clinicians |
| **Family carer themes** | Dementia as a mental health need  
| | Generally satisfied with care  
| | Need for more awareness (staff and family) |
Mental Health Needs of Older Adults with ID (Integrated Findings)

- Mini PAS-ADD provides clear survey of psychiatric symptoms and SIS shows specialised behaviour support needs
- These findings are supplemented by rich data from phase 2 (subclinical support networks and needs around bereavement)
- Integrated findings show that older adults with mental health needs perhaps conceptualize these needs differently than the instruments used.
- Findings were integrated into a larger ecological model of need that demonstrate further connections between life domains which need to be taken into account
Summary/Conclusions

- Findings imply that services need to provide training for subclinical support systems to meet mental health needs for this group (e.g. training around bereavement counselling)
- Importance of multiple perspectives when assessing need to inform service provision
- The further integration of findings into an ecological model demonstrates the complexity and interrelatedness of needs across the life-domains of older adults with ID