

***Mental health assessment for people with intellectual disability and complex communications needs:  
designing accessible self-report instruments.***



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# The Bridging Project

- A project being undertaken by Scope in collaboration with the Centre for Developmental Disability Health Victoria, Monash University.
- The Bridging Project has as its mission to progress the knowledge and resource base to ensure that individuals with complex communication and mental health needs have access to quality services.

# Complex Communication Needs

- Complex communication needs describe the communication of people who are unable to use speech to meet their daily communication needs.
- Co-morbidity of intellectual disability and complex communication needs is 71 per cent (Bloomberg & Johnson, 1990, Johnson & Bloomberg, 1988).

# Mental health and Intellectual Disability

- The reported prevalence of mental illness among adults with intellectual disability (ID) varies widely between 10 and 39% (Deb et al., 2001)
- Prevailing view is that people with ID experience a higher rate of psychiatric illness than people without ID
- People with intellectual disability can experience a complex set of biopsychosocial stressors, which may contribute to the development of mental health problems

# Mental health assessment

- A process of gathering information about a person's psychological wellbeing and functioning with the purpose of making a diagnosis. The assessment is usually the first stage of a treatment process.
- The assessment often includes social and biographical information, information about current functioning, direct observations, and data from specific psychological tests. It is typically carried out by a mental health practitioner as part of a collaborative, multi-disciplinary process.

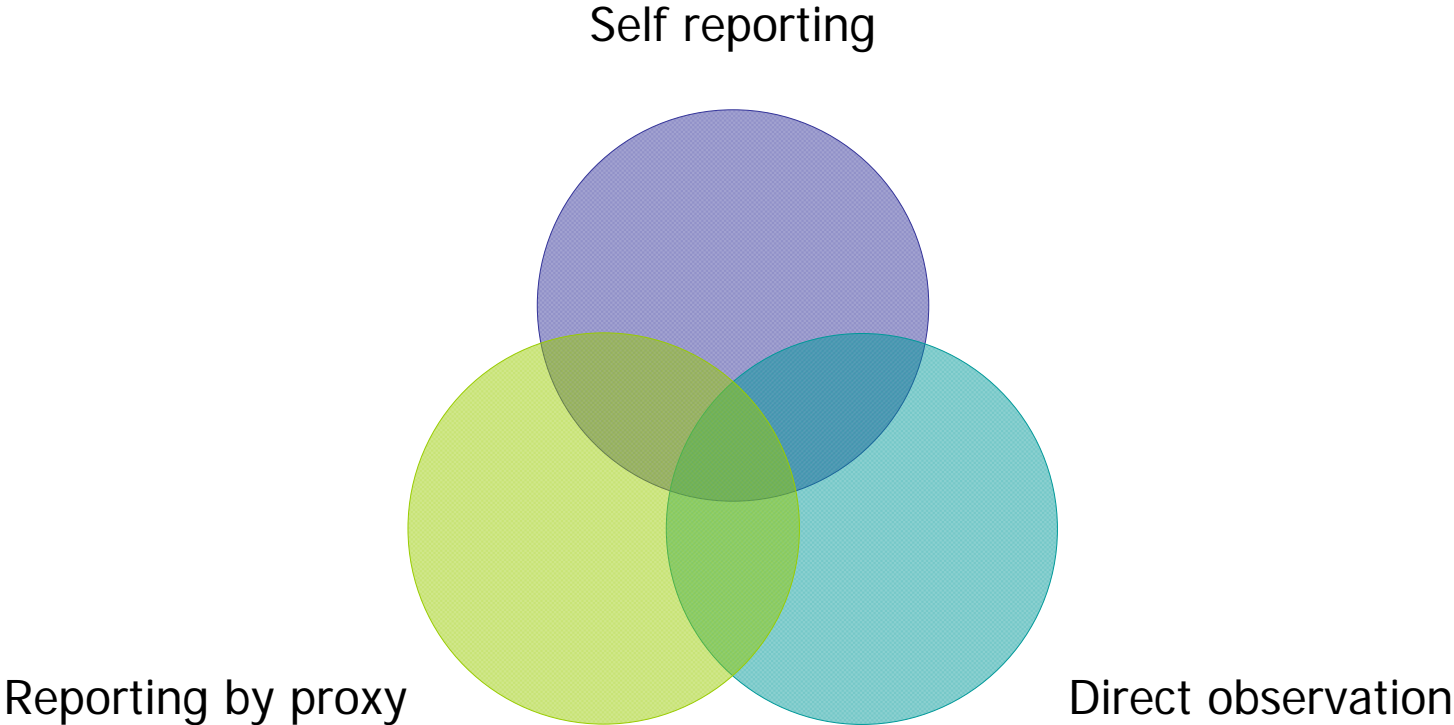
# The role of self-report

- Mental health practitioners rely on a combination of self-report, carer-report, and behavioural observations to diagnose the presence of a mental illness.
- Informant measures are popular because they can be completed by carers of people with a range of abilities.
- Can lead to an overemphasis of externalizing problems (Hogg & Langa, 2005) and have poor reliability (DiMarco and Iacono, 2007).
- Reliance on observable behaviours may or may not be symptoms of psychiatric disorders (DiMarco and Iacono, 2007).

# The role of self-report

- Self-report measures
  - have particular utility in yielding an index of a person's internal state (Antony & Barlow, 2002).
  - yield a greater amount of information than would be possible using carer-report/behavioural observations only (Barlow & Antony, 2002).
  - embody a client-directed assessment approach.
- Even with maximal supports and modifications, self-report measurement may still be inaccessible to people with profound disabilities.

# Inclusive Mental Health Assessment



# Key barriers in self-report MH assessment

- Memory load
- Conceptual load
- Literacy load
- Item Relevance
- Internal reliability
- Over emphasis on somatic symptoms
- Under emphasis on behavioural symptoms
- Communication breakdowns

## Loss of interest

- (0) I have not lost interest in other people or activities
- (1) I am less interested in other people or things than before
- (2) I have lost most of my interest in other people or things
- (3) It's hard to get interested in anything

# Accessible Depression Instruments

- Pressing need to develop tools for the diagnostic assessment of depression accessible to people with a range of abilities.
- Gold-standard self-report measures are those that are ***maximally accessible*** which concurrently assesses symptoms with a high degree of psychometric rigour.
- An accessible measure is one that removes or minimises communication and information access barriers such that it is usable by people with a range of abilities.

# Accessible Depression Instruments

- Perez-Achiaga, Nelson, & Hassiotis (2009)
  - Review instruments for the detection of depressive symptoms in people with intellectual disabilities.
  - Appraised measures based on established psychometric properties (validity, reliability, sensitivity, specificity, reliability).
  - 21 studies reviewed; full reports on psychometric properties given for 3 instruments:
    1. The Psychiatric Assessment Schedule for Adults with Developmental Disability (PAS–ADD)
    2. The Glasgow Depression Scale (GDS)
    3. The Self Report Depression Questionnaire (SRDQ)

# Accessible Depression Instruments

- The Glasgow Depression Scale (GDS)
  - A depressive-symptom rating scale for people with mild to moderate disability.
  - Questions avoid linguistic and cognitive complexity
  - Response format requires a simple “yes/no”, and if required a follow-up response of “sometimes/always”.
- The Self Report Depression Questionnaire (SRDQ)
  - Aimed at adults with mild to moderate level of intellectual disability.
  - Item responses to questions (e.g., “I feel sad”) are *almost never, sometimes, most of the time*.
  - Among the items is one depicting ‘smiley’ faces asking the participant to indicate how he/she feels.

# Accessible Depression Instruments

- GDS & SRDQ
  - Extensive scale development process.
  - The GDS has a parallel informant version.
  - Do not extensively address behavioural change.
  - Do not assess the presence and extent of a response set due (e.g., due to acquiescence, cognitive rigidity).
  - Application for people with more severe disabilities is not well understood.

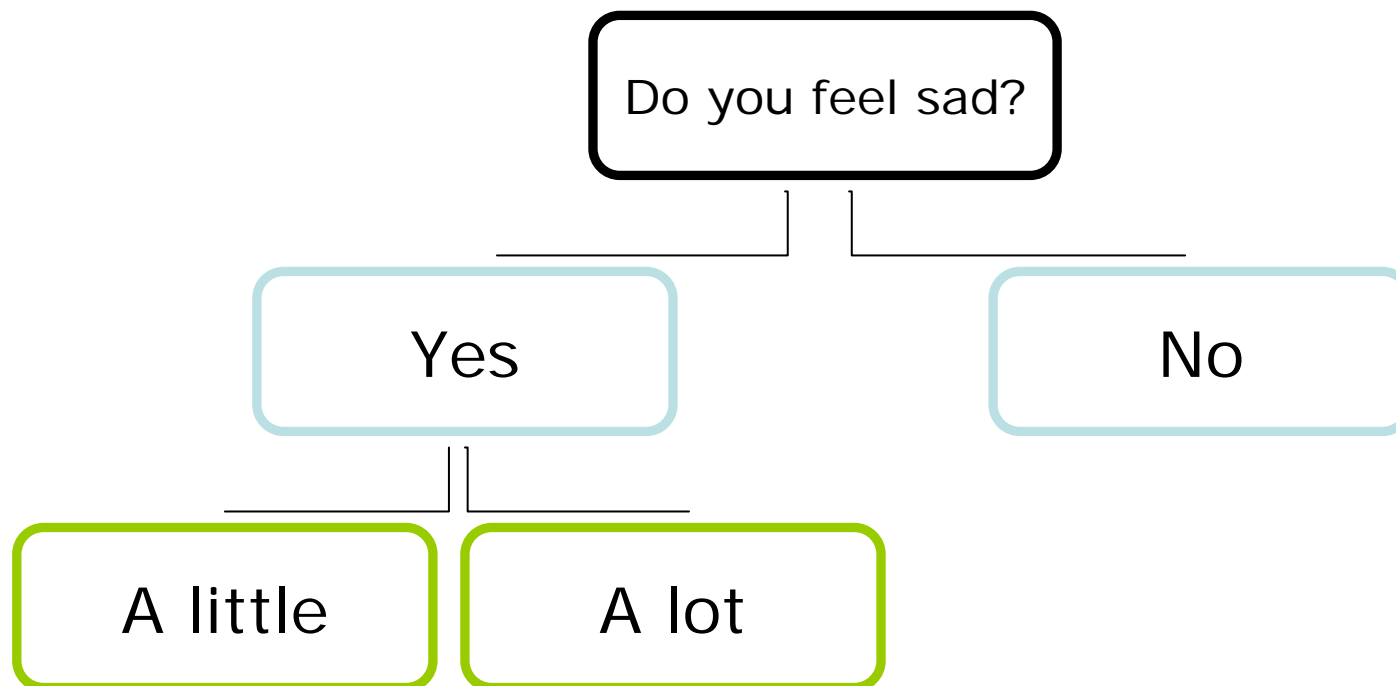
# Accessible Depression Instruments

- The Accessible Depression Tool (ADep)
  - Developed for people who fall at the more severe end of the communication impairment severity continuum.
  - Similar to the GDS, its response format requires a simple “yes/no”, and if required a follow-up response of “sometimes/always”.
  - Includes reliability index and Items tapping behavioural change.
  - No established psychometric data – pilot study addressed accessibility issues prior to a larger scale psychometric study

## Guide points for the development of accessible self-report measures

- Allow for **simple verbal responses**, such as yes or no, which is more likely to be within the grasp of people with complex communication needs.
- Provide the person opportunity to communicate their response through **alternative and augmentative communication strategies** (e.g., gestures, AAC device).
- **Avoid burdening** the client with physical administration demands, and transfer this responsibility to the clinician.
- Include **short statements** that allow the person with memory problems to process the information while listening to it.
- Avoid the need for respondents to simultaneously consider and respond to **more than two choices at a time**.

## Guide points for the development of accessible self-report measures



## Guide points for the development of accessible self-report measures

- Avoid using **complex psychological terms** and concepts, and should include wording that is clear and unambiguous.
- Be translated into **easy-language** format (information summarised and expressed in short sentences so that each conveys a single idea or concept).
- Include instructions and items checked for **comprehensibility**:
  - readability (e.g., Flesch-Kincaid Grade Levels)
  - linguistic complexity (e.g., QUAID, a computational linguistics tool for evaluating questionnaire items; Graesser et al., 2000).
- Provide for administration procedures that are **not heavily dependent on written language**, or should avoid written language altogether and allow for oral administration.

## Guide points for the development of accessible self-report measures

- Include questions that have been assessed as having **face-value**, **credibility** and **relevance** to the lives and experience of people with disabilities.
- Include an **internal reliability** check, which provides an index of the extent to which answers are free from systematic response.
- Not overemphasise **physical symptoms**, or at least contextualise them for people with physical disabilities.
- Address **behavioural change**, a major factor in depression in persons with intellectual disability (Davis, Judd, & Herman. 1997).
- Include communication characteristics that inherently avert **communication breakdowns** during administration.

## Guide points for the development of accessible self-report measures

- Self assessments should also include:
  - established psychometric properties, including validity, reliability, sensitivity, specificity.
  - documented scale development process.
  - suggested clinical cut-offs.
  - parallel informant measure.
  - cross-validation with other samples.

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