



Review

Measurement tools for mental health problems and mental well-being in people with severe or profound intellectual disabilities: A systematic review



Samantha Flynn^{a,*}, Leen Vereenooghe^b, Richard P. Hastings^a, Dawn Adams^c, Sally-Ann Cooper^d, Nick Gore^e, Chris Hatton^f, Kerry Hood^g, Andrew Jahoda^d, Peter E. Langdon^e, Rachel McNamara^g, Chris Oliver^h, Ashok Royⁱ, Vasiliki Totsika^a, Jane Waite^h

^a CEDAR, University of Warwick, UK

^b Fakultät für Psychologie und Sportwissenschaft, Universität Bielefeld, Germany

^c Autism Centre of Excellence, Griffith University, Australia

^d Institute of Health and Wellbeing, University of Glasgow, UK

^e Tizard Centre, University of Kent, UK

^f Faculty of Health and Medicine, Lancaster University, UK

^g Centre for Trials Research, Cardiff University, UK

^h School of Psychology, University of Birmingham, UK

ⁱ Coventry and Warwickshire Partnership NHS Trust, UK

HIGHLIGHTS

- Few mental health measures for people with severe and profound ID are available.
- Very few studies have examined the reliability and validity of measures.
- No papers reporting on measures for children with severe/profound ID were found.
- The ABC, DASH-II and MIPQ are reliable for use with adults with severe/profound ID.

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ABSTRACT

Mental health problems affect people with intellectual disabilities (ID) at rates similar to or in excess of the non-ID population. People with severe ID are likely to have persistent mental health problems. In this systematic review (PROSPERO 2015:CRD42015024469), we identify and evaluate the methodological quality of available measures of mental health problems or well-being in individuals with severe or profound ID. Electronic searches of ten databases identified relevant publications. Two reviewers independently reviewed titles and abstracts of retrieved records ($n = 41,232$) and full-text articles ($n = 573$). Data were extracted and the quality of included papers was appraised. Thirty-two papers reporting on 12 measures were included. Nine measures addressed a broad spectrum of mental health problems, and were largely observational. One physiological measure of well-being was included. The Aberrant Behavior Checklist, Diagnostic Assessment for the Severely Handicapped Scale-II and Mood, Interest and Pleasure Questionnaire are reliable measures in this population. However, the psychometric properties of six other measures were only considered within a single study – indicating a lack of research replication. Few mental health measures are available for people with severe or profound ID, particularly lacking are tools measuring well-being. Assessment methods that do not rely on proxy reports should be explored further.

1. Background

Children and adolescents with intellectual disabilities (ID) are 4–5 times more likely to present with symptoms of diagnosable mental

health problems in comparison with children who do not have ID (Emerson & Hatton, 2007). Similarly, adults with ID are at increased risk of mental health problems (Cooper, Smiley, Finlayson, et al., 2007), with a recent UK based cohort study reporting that between 21 and

* Corresponding author at: CEDAR, University of Warwick, New Education Building, Westwood Campus, Coventry CV4 7AL, UK.
E-mail address: s.flynn.1@warwick.ac.uk (S. Flynn).

Table 1
Example search strategy (for ProQuest databases)*.

Psychological assessments	Mental health/well-being	Intellectual disabilities
(MJSUB.EXACT("Psychological Assessment") OR TI(clinical NEAR/2 (outcome* OR diagnosis OR evaluat*)) OR TI (assess* OR index* OR instrument* OR interview* OR inventor* OR item* OR measure* OR subscale* OR scale* OR screen* OR tool* OR survey* OR self-report* OR test*form OR observ* OR rating* OR rated OR score*) OR TI (validat* OR validity OR reliab* OR accura* OR sensitive* OR specific* OR predictab*))	(SU.EXACT.EXPLODE("Mental Disorders") OR (TI (mental* NEAR/2 (ill* OR well-being OR health* OR disease* OR disorder* OR abnormal* OR patholog* OR problem* OR condition*)) OR AB(mental* NEAR/2 (ill* OR well-being OR health* OR disease* OR disorder* OR abnormal* OR patholog* OR problem* OR condition*)) OR AB(psych* NEAR/2 (ill* OR well-being OR health* OR disease* OR disorder* OR abnormal* OR patholog* OR problem* OR condition*)) OR (SU.EXACT.EXPLODE("Depression (Emotion)") OR SU.EXACT.EXPLODE("Anxiety Disorders") OR SU.EXACT.EXPLODE("Personality Disorders")) OR (TI(anger NEAR/3 (problem* OR disorder*)) OR AB(anger NEAR/3 (problem* OR disorder*)) OR (TI(anxiet* OR anxious* OR "gad" OR phobia OR phobic OR traum* OR post*traumatic) OR AB(anxiet* OR anxious* OR "gad" OR phobia OR phobic OR traum* OR post*traumatic) OR (TI (depress* NEAR/2 (disorder* OR symptom* OR behavio* OR thought*)) OR AB(depress* NEAR/2 (disorder* OR symptom* OR behavio* OR thought*)) OR (TI(dysthymi* OR dysphori* OR melancholy* OR schizophren* OR schizoaffective OR dementia OR psychosis OR psychotic OR alcoholism OR addiction OR obsessive-compulsive) OR AB(dysthymi* OR dysphori* OR melancholy* OR schizophren* OR schizoaffective OR dementia OR psychosis OR psychotic OR alcoholism OR addiction OR obsessive-compulsive)) OR (TI((psychological OR psychosocial) NEAR/2 function*) OR AB((psychological OR psychosocial) NEAR/2 function*)) OR (TI(well-being OR "quality of life") OR AB(well-being OR "quality of life"))))	(SU.EXACT.EXPLODE("Intellectual Development Disorder") OR (TI(mental* NEAR/3 (disab* OR impair* OR handicap* OR subnormal* OR deficient* OR retard*)) OR AB(mental* NEAR/3 (disab* OR impair* OR handicap* OR subnormal* OR deficient* OR retard*)) OR (TI(learning NEAR/3 (disab* OR impair* OR difficult* OR disorder*)) OR AB(learning NEAR/3 (disab* OR impair* OR difficult* OR disorder*)) OR (TI(moron* OR imbecile* OR feeble*minded OR subnormal* OR retard*) OR AB (moron* OR imbecile* OR feeble*minded OR subnormal* OR retard*)) OR (TI(intellectual* NEAR/3 (disab* OR impair* OR handicap* OR disorder* OR subnormal* OR deficient*)) OR AB(intellectual* NEAR/3 (disab* OR impair* OR handicap* OR disorder* OR subnormal* OR deficient*)) OR (TI ((low*functioning OR severe) NEAR/3 autis*) OR AB ((low*functioning OR severe) NEAR/3 autis*)) OR (TI ("Smith-Magenis" OR Rett* OR "Lesch-Nyhan" OR "Prader-Willi" OR Angelman OR "fragile X" OR "Cri-du-chat" OR "Cornelia de Lange" OR "de Lange" OR "Rubinstein-Taybi" OR velocardiofacial OR DiGeorge OR "22q11.2" OR (Down* NEAR/2 syndrome)) OR AB("Smith-Magenis" OR Rett* OR "Lesch-Nyhan" OR "Prader-Willi" OR Angelman OR "fragile X" OR "Cri-du-chat" OR "Cornelia de Lange" OR "de Lange" OR "Rubinstein-Taybi" OR velocardiofacial OR DiGeorge OR "22q11.2" OR (Down* NEAR/2 syndrome))))

* Search strings were connected by the Boolean Operator "AND".

34% of participants had a mental health problem over the course of the study (Sheehan et al., 2015). There is evidence that the incidence of severe mental health problems is heightened in people with ID compared to people without ID (cf. Sheehan et al., 2015 with Hardoon et al., 2013). Within the population of people with ID, there is some indication that those with severe ID are at a greater risk of mental health problems (Cooper, Smiley, Finlayson, et al., 2007; Cooper, Smiley, Morrison, et al., 2007; Hove & Havik, 2010; Smiley et al., 2007). Furthermore, longitudinal data from a cohort of Australian children and adolescents with ID over a period of 14 years using the Developmental Behaviour Checklist (Einfeld & Tonge, 1992, 1995) suggest that mental health problems are more likely to persist for people with severe or profound ID, whereas mental health problems for people with mild ID may decrease over time (Einfeld et al., 2006).

Assessing mental health problems and mental well-being in people with severe or profound ID presents multiple challenges. Methodological challenges include people with severe or profound ID having difficulties with self-report, difficulties labelling and communicating emotions (Adams & Oliver, 2011) – although this is not unique to people with severe to profound ID, and is a challenge for people with mild and moderate ID too (Mellor & Dagnan, 2005) – concern about the accuracy of proxy reports (Emerson, Felce, & Stancliffe, 2013), and the process of diagnostic overshadowing whereby symptoms of a mental health problem are ascribed to the person's ID or another co-morbid problem rather than being recognized as a mental health problem (Deb, Thomas, & Bright, 2001). Measurement of mental health problems and mental well-being in this population is also conceptually difficult as some mental health problems may have overlaps with behavioural problems (Hayes, McGuire, O'Neill, Oliver, & Morrison, 2011; Marston,

Perry, & Roy, 1997; Ross & Oliver, 2002), and some standard diagnostic criteria may be appropriate for people with mild or moderate ID (e.g., negative cognitions), but less so for people with severe or profound ID (Evans, Cotton, Einfeld, & Florio, 1999).

To examine mental health problems and mental well-being in people with severe ID in the context of research and clinical practice, robust measurement tools are needed with supporting data specifically with the severe/profound ID population. Previous systematic reviews have explored the assessment of depression (Hermans & Evenhuis, 2010; Perez-Achiaga, Nelson, & Hassiotis, 2009; Walton & Kerr, 2016) and anxiety (Hermans, van der Pas, & Evenhuis, 2011; Reardon, Gray, & Melvin, 2015) in people with ID. However, these reviews did not focus on people with severe or profound ID and did not extend across the lifespan. All five of these systematic reviews did present some quality appraisal of the identified mental health measurement tools. Additionally, a non-systematic narrative review by Matson, Belva, Hattier, and Matson (2012) offered a representation of broad mental health measures across the lifespan; no quality appraisal was undertaken within this review, and evidence pertaining specifically to people with severe or profound ID was not included. Moreover, Matson et al.'s review exclusively reported evidence for rating scale instruments, excluding other methods of assessment. Additionally, none of the aforementioned reviews included both measures of mental health problems and mental well-being.

Considering the identified gaps in current knowledge, the main questions for this systematic review were: (a) What are the tools available to measure mental health problems and mental well-being in children and adults with severe ID, and (b) What is the methodological quality of these measurement tools?

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