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for Disability and Wellbeing

The use of proxy measurement of internal states in people with intellectual disability: A scoping review.

The use of proxy measurement of internal states in people with intellectual disability: A scoping review.



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Loneliness and disability

- Depression (Heiman, 2001; Dupuis, 2004)
- Behaviours of concern (McVilly, 2002)
- Increased Psychopathology (Borthwick-Duffy, 1994)
- Decreased quality of life (Katz & Yekutiel, 1974)
- Greater risk of suicidal ideation (Mollison et al., 2014)

****The adverse outcomes associated with loneliness may contribute to the health inequalities that further exaggerate social exclusion for those with intellectual disability ****

(Gilmore & Cuskelly, 2014)



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Loneliness and disability –Increased vulnerability to loneliness

- Have very low cognitive ability (by definition)
- Profound neuromotor dysfunctions, communication and sensory impairments and medical problems (including seizures, respiratory and feeding problems) (Nieuwenhuijse et al., 2020).
- Reliance on support staff (Johnson et al., 2014).
- Initiation of almost all activities by others (Callus, 2016).
- Attendance at structured day service activities (Callus, 2017).
- External assistance with interpersonal regulation (Margalit, 2004).
- More likely to experience negative life events (Jobling & Cuskelly, 2006).



Background to this review

➡ Loneliness is an internal state; and ‘emotion cluster’

➡ People with intellectual disability may need support in areas which may include identification and mediation of emotional needs

➡ Understanding the emotions of people with intellectual disabilities can lead to a better understanding of their support needs

➡ This often is the responsibility of parents and carers



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➔ Methods of assessing internal states of emotion include:

- ★ Self-report (**Gold Standard**)
 - Clinical Interview
 - Ratings by others

➔ Problems with these

- Self-reporting requires the ability to understand the question being asked, identify the emotional state and report a response
- Questionnaires can include difficult words and understanding, negatively worded questions and metaphors
- Communication and cognitive impairments mean interview can be difficult

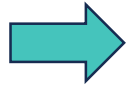


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Ratings of others – Proxy report



- Use different information
- Influenced by length of relationship
- Difficulties understanding another person's mental state

★ When relying on another person to understand / intervene to assist with emotional needs, a good understanding of from whom and how to collect information about these needs is crucial ★



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Scoping Review

- **Scoping review**

- **The objective** - to identify the available evidence regarding the use of proxy respondents for people with intellectual disabilities and to determine the factors that influence the accuracy of proxy respondents' ratings of internal states.

- **Method-** Arksey and O'Malley (2005) + Joanna Briggs Institute methodology



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Search Strategy- PsycINFO, Pubmed, Scopus



Intellectual Disability



Proxy Measurement



Internal States

- Date 2006-2023
- English
- Journal
- Intellectual disability (eg not ASD without intellectual disability)
- Children and adults



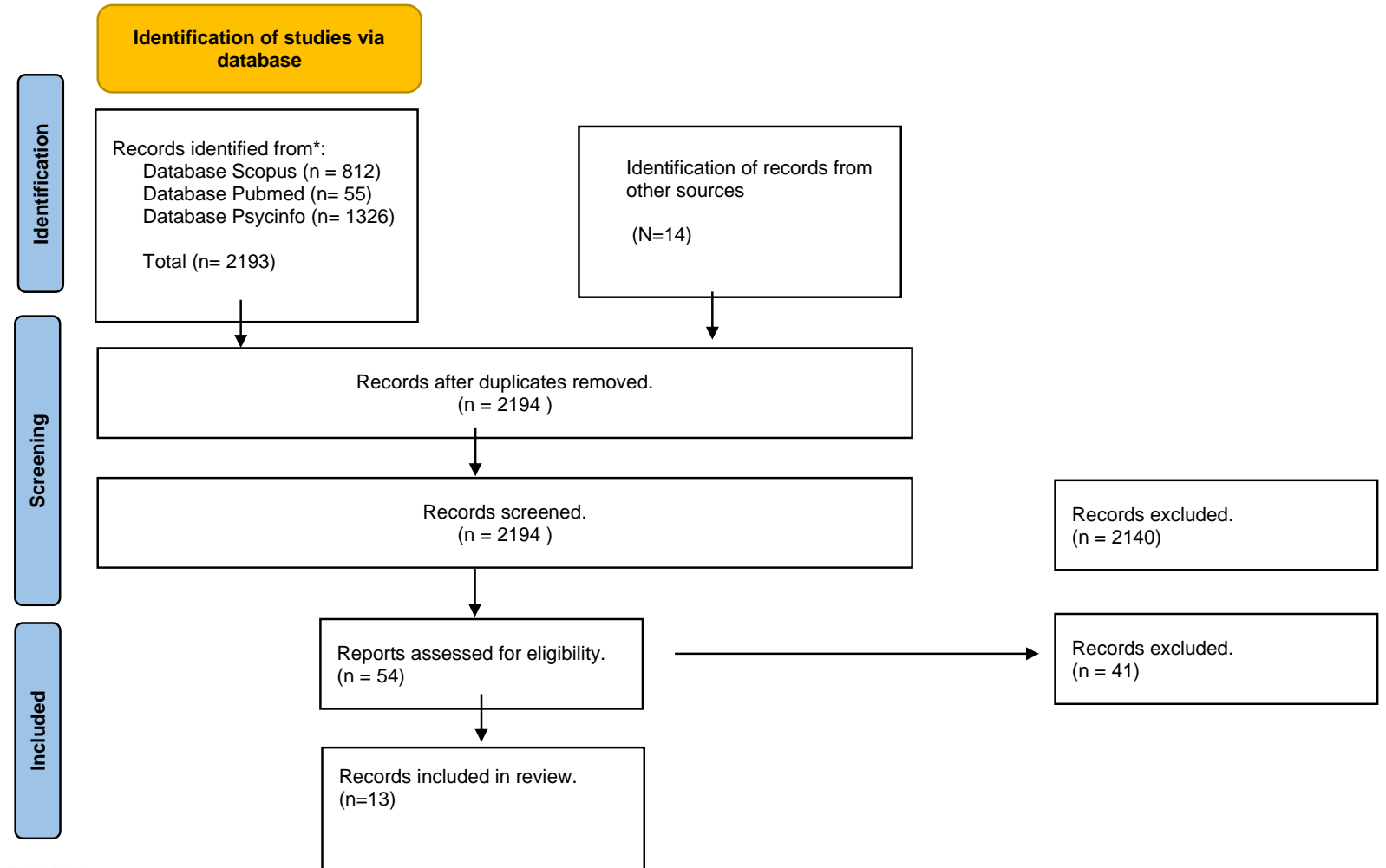
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Search Results

Summary of papers that met the inclusion criteria





Results

Parameter	Results [†]
Population included (age)	Children 0-17years = 1 Adults (18+ years) = 12 Mix of children & adults = 2
Population included (level of disability)	Mild intellectual disability only = 4 Moderate intellectual disability only = 0 Mild and moderate intellectual disability = 5 Mild, moderate & severe/profound intellectual disability = 2 Unspecified/no standard descriptor used [‡] = 4
Proxy type	Paid staff = 8 Combined family or paid staff = 6 Teachers & parents = 1
Assessment domain	Quality-of-life (where an internal state was measured) = 8 Mental health = 2 Grief = 1 Anger = 2 Life stress = 2

Results (cont.)

- **Emotional Well-being**

- Studies (6)
- Correlation between self-report and proxy-staff (5)
- Correlation between self-reports and proxy-family (2)
- Good correlation (1) (proxy-family)
- No correlation(1)

- **Difference**

- Significant differences found between self report and proxy-staff
- Significant differences found between self report and proxy-family

- Self report higher levels of emotional wellbeing than proxy family and staff

- **No Agreement (1)**

- Mild, moderate, severe



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Summary

- Comparison is difficult to many different methods employed
- Mixed agreement was found- consistent with previous studies
- Inconsistencies may be due to variations in the age of people reporting, assessment measures used, level of disability, type of proxy and length of relationship



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Recommendations for future research

- Level of disability
- Type of proxy/relationship
 - Length of relationship
 - Frequency of contact
- Proxy type- Proxy-proxy vs Subject-proxy
- Agreement should be measured in terms of correlation and difference



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