

# Straight from the horse's mouth: Increasing self-report in mental health assessment in individuals with intellectual disability

Susan M. Havercamp<sup>1</sup>  | L. Jarrett Barnhill<sup>2</sup> | Alexandra Bonardi<sup>3</sup> |  
 Richard A. Chapman<sup>4</sup> | Chelsea Cobranchi<sup>1</sup>  | Robert J. Fletcher<sup>5</sup> |  
 Paula Rabidoux<sup>1</sup> | John R. Seeley<sup>6</sup> | Marc J. Tassé<sup>7</sup> | The Nisonger Center RRTC on  
 Health and Function

<sup>1</sup>Department of Psychiatry and Behavioral Health, The Ohio State University Nisonger Center, The Ohio State University, Columbus, Ohio, USA

<sup>2</sup>Psychiatry and Psychology, University of North Carolina, Chapel Hill, North Carolina, USA

<sup>3</sup>Human Services Research Institute, Cambridge, Massachusetts, USA

<sup>4</sup>Kansas Center on Developmental Disabilities, University of Kansas, Tampa, Florida, USA

<sup>5</sup>National Association on Dual Diagnosis, Kingston, New York, USA

<sup>6</sup>Special Education and Clinical Sciences, University of Oregon, Eugene, Oregon, USA

<sup>7</sup>Psychology and Psychiatry, The Ohio State University Nisonger Center, Columbus, Ohio, USA

## Correspondence

Susan M. Havercamp, The Ohio State University Nisonger Center, 1581 Dodd Drive, Columbus, OH 43210, USA.  
 Email: havercamp.1@osu.edu

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## Abstract

**Background:** Mental health conditions are common among individuals with intellectual disability. Under recognition of mental health disorders leading to unmet treatment needs is common in this population. This article addresses one major contributing factor, the lack of cognitively accessible self-report measures for individuals with intellectual disability.

**Method:** In this literature-informed overview of the state of the field, we discuss the need for, and complexities of, including individuals with intellectual disability in mental health assessments.

**Results:** With appropriate supports, many individuals with intellectual disability can respond to mental health questions. We discuss evidence-based strategies to make mental health assessments more accessible.

**Conclusion:** We highlight the need to engage individuals with intellectual disability to provide first-hand information about their health and well-being. New instruments and research procedures should be developed in partnership with individuals with intellectual disability. Self-report may be essential to advancing the science of mental health research.

## KEYWORDS

cognitive accessibility, intellectual disability, mental health, proxy-report, self-report

## 1 | INTRODUCTION

Tim Jones is 30-year-old man with a history of moderate intellectual disability and no history of known genetic or medical/neurological disorders. He has no history of previous anxiety-related symptoms or

trauma. He was originally referred to psychiatry secondary to declining responsiveness to staff and apparent panic attacks. This is his third clinic follow-up appointment. Tim attends his psychiatric appointments with his direct support professional who has worked with Tim during the evening shift for the past three

months. The psychiatrist interviews Tim about how he is doing. She uses plain language and short sentences and allows Tim extra time to respond. The psychiatrist gives Tim a form to complete about how he is feeling. Although Tim does his best, he does not understand some of the words on the page and is confused by the number of choices for each question.

This scenario represents a simplified, yet prototypical assessment for an individual<sup>1</sup> with intellectual disability who is seen by a mental health professional due to changes in mood, increased aggressiveness, self-injurious behaviour or other externalising and internalising behaviours. Intellectual disability is a complex neurodevelopmental disorder with a multitude of underlying genetic, metabolic and medical/neurological pathophysiologies. The risk for developing mental health conditions represent a convergence of multi-directional interrelationships between the severity of intellectual disability and interactions between individual, ecological and psychosocial risk factors. The risk for mental health problems is greater in individuals with intellectual disability (Cooper et al., 2007; Drum et al., 2009; Fletcher et al., 2016; Hassiotis & Turk, 2012; Hatton et al., 2017; Hithersay et al., 2014; Summers et al., 2017) than in the neurotypical population (see Canino et al., 2019, for neurotypical population prevalence rates). In a systematic review of prevalence research, Mazza et al. (2020) estimated that 33.6% of individuals with intellectual disability have co-occurring mental health conditions, which is much higher than in the neurotypical population, although prevalence rates across mental health conditions varied significantly.

The presence of cognitive and communication impairments associated with intellectual disability frequently requires clinicians and researchers to rely on teacher, support staff or caregiver reports (Emerson et al., 2013). This is a particular concern since the individual may not be capable of reporting mood or cognitive experiences and caregivers may not be able to provide descriptions of the individual's internal states (e.g., loneliness, worry). It is important to explore the most effective strategies for collecting such information from individuals with intellectual disability as well as from their caregivers.

The purpose of this article is to provide a literature-informed overview of the state of the field in mental health self-reporting in research with individuals with intellectual disability. We did not engage in a systematic review of the literature, which typically addresses a narrow research question with bounded outcomes. This methodology allowed us not to evaluate the strength of previous research but rather to draw conclusions from extant literature. A limitation in this methodological choice is that it is possible that relevant studies on this topic were overlooked in our search. We first used existing research and practice to present the need to shift away from a reliance on third-party reports to fully engaging individuals with intellectual disability to provide first-hand information about their mental health. Second, we identified key considerations when

designing accessible self-report assessments for individuals with intellectual disability. Third, we summarised research on combining sources of information (self and third-party report) in clinical assessment. We end with recommended action steps derived from our literature-informed overview to guide the field in considering how to incorporate self-reporting of mental health symptoms by individuals with intellectual disability in research and practice.

We limit this article to individuals with intellectual disability who have some capacity to communicate, either verbally, using gestures or with augmentative and alternative communication (AAC) techniques.

## 2 | THE NEED FOR SELF-REPORT IN MENTAL HEALTH ASSESSMENT

The health care needs of individuals with intellectual disability are often unrecognised and, consequently, unmet due to limitations in their ability to self-report conditions or symptoms of mental distress (Hassiotis & Turk, 2012; Summers et al., 2017). Individuals with intellectual disability vary greatly in their communication ability, which impacts self-reporting in relation to comprehension (understanding the meaning of words and questions), cognitive processing (e.g., recalling information, ordering information and making comparisons) and expression (e.g., articulating a response) (Emerson et al., 2013). The severity of the communication disability does not necessarily correlate with the level of intellectual disability and may range from mildly impaired speech and language to minimal functional communication skills. (Belva et al., 2012; Sutherland et al., 2014). Also affecting communication skills in many adults with intellectual disability is hearing loss. Although there are few studies of hearing impairment in non-institutionalised individuals with intellectual disability, one study from The Netherlands (Meuwese-Jongejugd et al., 2006) reported of 1598 individuals ages 18–70 with intellectual disability, the overall prevalence rate for hearing loss was 36%, twice the prevalence rate reported among people without an intellectual disability.

Clinicians and researchers often rely on informants to respond on behalf of the individual with intellectual disability. These 'proxy reporters' either respond as they think the individual they represent would respond or provide their own perspective of the person's situation. The extent to which such responses accurately reflect the perspective of the individual with intellectual disability may depend on several factors. Relevant factors include: (a) the length and depth of the relationship between the proxy and the individual with intellectual disability, (b) the extent to which the proxy has a full or only partial knowledge of the individual, (c) the degree to which self-interest may conflict with an unbiased appraisal of the other person's experience and (d) and whether the information being sought is observable by the proxy respondent (Emerson et al., 2013). Objective indicators are potentially verifiable by a third party, provided the third party knows the individual sufficiently well. In contrast, subjective indicators such as a person's feelings about life, emotional distress, personal satisfaction and happiness cannot be directly observed nor fully understood by a third party (Esbensen et al., 2005; Lindsay & Skene, 2007).

<sup>1</sup>The term 'individuals' with intellectual disability is used throughout this manuscript. This term was preferred over 'people' or 'persons' by the adults with intellectual disability who contributed to this research; they felt it better expressed the unique individuality of each person with a disability.

Therefore, the accuracy of proxy reports for internal states is dubious (Emerson et al., 2013). Self-reported information is especially critical when examining mental health and other potentially sensitive issues (Argus et al., 2004; Hassiotis & Turk, 2012; MacHale et al., 2009; O'Keeffe et al., 2019; Ruddick & Oliver, 2005).

Mounting evidence suggests that reliance on proxy reporting can lead to under-reporting of mental health symptoms (Todorov & Kirchner, 2000). Even informants who know the individual well (e.g., family members, guardians and direct support professionals), struggle to identify internalised mental health symptoms (Hassiotis & Turk, 2012; Schützwahl et al., 2018). In a study comparing proxy and self-reported mental health symptoms, Scott and Havercamp (2018) found that 23.6% of adults with intellectual and developmental disabilities were identified at risk for mental health problems according to proxy report. When the adults self-reported symptoms, 67.8% screened positive for possible mental health problems. The authors attributed this difference to the fact that a third party cannot accurately report on internal states. Without the voice of individuals with intellectual disability, assessment and mental health treatment outcomes in individuals with intellectual disability is compromised.

The development of self-reported assessment aligns with the movement in health research toward patient-reported outcome measures to understand health conditions and particularly mental health conditions (Esbensen et al., 2005; Kramer & Schwartz, 2017; Lindsay & Skene, 2007). However, self-report mental health measures may not be accessible to individuals with intellectual and other cognitive disabilities. Clinicians almost uniformly lack the expertise and tools to conduct a cognitively accessible assessment (Nicolaidis et al., 2015). Barriers related to the question content, the layout of questions and images, and administrative procedures have been noted (Kramer & Schwartz, 2017). Content examples that increase cognitive load include negatively phrased questions, passive voice, complex response formats (e.g., rating scales), and questions pertaining to frequency, comparisons, abstract concepts, generalisations and unfamiliar or sensitive topics (Finlay & Lyons, 2001; Fujiura & RRTC Expert Panel on Health Measurement, 2012). Socially reflexive questions require a complex level of social understanding as they ask individuals to reflect on how they are viewed or evaluated by others, for example, 'Do people like being with you?' Accurate assessment and diagnosis of mental health problems is essential to effective treatment, a better prognosis, and may inform preventative health practices. Yet, accessible, standardised and reliable self-report mental health measures for individuals with intellectual disability are lacking.

Often cited as limiting the validity of self-reports in individuals with intellectual disability, response biases may warrant a closer look. These biases include acquiescence (tendency to say yes), social desirability (tendency to agree with perceived authority figures) and recency bias (tendency to select the last alternative mentioned), irrespective of one's true opinion. Several researchers (Finlay & Lyons, 2002; Rapley & Antaki, 1996) have suggested that acquiescence is, at least partially, a function of the conceptual and linguistic complexity of the questions. Individuals with intellectual disability are more likely to acquiescence when they do not understand the

question or do not know the answer to the question (Finlay & Lyons, 2002; Prosser & Bromley, 2012). Rapley and Antaki (1996) suggested that inconsistent responding to yes/no questions could be motivated by submissive agreeableness, as is often assumed in acquiescence research, but it could just as well reflect memory failure or lapsed attention. They cautioned researchers to consider the context of a research interview from the perspective of participants with intellectual disability. These individuals may view the interview as a test situation with potentially serious stakes where their responses are often queried until the interviewer appears satisfied with their answer. Another concern is that researchers, vigilant for signs of acquiescent responding, may assume that every 'yes' response is acquiescence. In fact, participants may say 'yes' not in answer to the question but as a conversation-management signal to indicate that they are paying attention. In their conversational analysis, Rapley and Antaki (1996) also found fault with the interviewers for narrowly listening for specific responses (e.g., always/ sometimes/never) and failing to understand or accept when participants responded 'yes'. When using rating scales, interviewers often ignored responses given while they were reading the list of possible responses (always/sometimes/never). Participants often answered the question before all responses were listed and, when their answer was ignored, were likely to try a different response, assuming that their first answer was incorrect. This particular problem with multiple choice and rating scales may be mitigated by using consistent choice options and by presenting options visually, as suggested by Kramer and Schwartz (2018).

Four techniques have been used to detect acquiescent responding in individuals with intellectual disability (Perry & Felce, 2002): (a) nonsense questions (e.g., Does it snow during the summer here?); (b) pairs of questions that are opposite in meaning (e.g., Are you mostly happy? Are you mostly sad?); (c) pairs of questions in which the same question is asked in different formats (e.g., yes/no, either/or and open-ended); and (d) informant checks. Rapley and Antaki (1996) caution that nonsense questions risk insulting respondents' dignity. Additionally, they questioned whether responses to bizarre questions were even comparable to the types of questions asked in the research study. Similarly, opposite questions designed to evoke different responses are not always truly opposite (e.g., are people nice to you vs. are people mean to you) as participants may respond based on memories of different events. Rapley and Antaki (1996) cautioned that many questions designed to detect response bias may, in fact, detect limitations in memory and generalisation skills. Instead, they suggested using questions that asked factual information about everyday activities (Rapley & Antaki, 1996).

The following paragraphs discuss strategies toward better mental health assessment for individuals with intellectual disability.

### 3 | CONSIDERATIONS FOR SELF-REPORT ASSESSMENT

Mental health research and practice with individuals with intellectual disability will benefit from the development of self-report measures,

tools and techniques. Individuals with mild to moderate impairments in intellectual functioning can reliably provide a valid self-report of psychological constructs including symptoms of depression, anxiety and overall well-being when presented with appropriately adapted, cognitively accessible measurement instruments (Esbensen et al., 2005; Lindsay & Skene, 2007). Kramer and Schwartz (2017) described content, layout and administration features to make patient reported outcome measures accessible for individuals with intellectual disability and other cognitive impairments. These strategies were applied to a patient-reported measure of functional performance (Kramer & Schwartz, 2018). Unfortunately, cognitively accessible validated instruments have not been developed to assess many aspects of health and mental health (Feldman et al., 2014; Nicolaidis et al., 2015).

Rating scales (e.g., always/sometimes/never) offer an efficient method for capturing information about private behaviours, mental experiences and subjective perspectives and attitudes. Hartley and MacLean (2006) reviewed the reliability and validity of self-report in adolescents and adults with intellectual disability. They found response rates, reliability and validity for rating scales, including Likert-type questions, were related to the level of intellectual functioning of adolescents and adults. They noted that response rates and psychometrics could be improved with changes to the measure layout and administration procedures including pictorial representations of item stems or response alternatives, allowing interviewers to paraphrase and/or to expand upon question stems or response alternatives. With appropriate supports, many individuals with intellectual disability can respond to questions using rating scales (Kramer & Schwartz, 2017; O'Keeffe et al., 2019).

We review evidence-based strategies for comprehensive accessible mental health assessment.

### 3.1 | On the importance of sensitivity and establishing rapport

Taking the time needed to establish a rapport can improve communication and valid responding. In addition to following the guidelines for accessible communication discussed earlier, Gentile and Gillig (2012) suggested that interviewers should begin the assessment by stating something positive to set a non-threatening tone.

Once established, rapport and reliable communication must be maintained throughout the encounter. Participants should be explicitly told that there are no right or wrong answers to the questions and interviewers must abide by this assertion. Interviewers should take care to avoid suggestive or leading questions, to avoid challenging the respondent's answer in any way such as asking, 'are you sure?', and to allow the individual with intellectual disability sufficient time to respond. As previously noted, interviewers should guard against the tendency to force the participant's response into predetermined response categories and, in so doing, invalidate or cause the participant to assume their answer was unacceptable (Rapley & Antaki, 1996). Introducing each question with an acknowledgement

that 'some people feel' normalises and may reduce the stigma associated with the emotion or sensitive topic, thereby reducing response bias. Finally, the issue of confidentiality must be carefully and clearly discussed with individuals with intellectual disability. Researchers and clinicians are ethically bound to protect the confidentiality of participant/client information. The only exception to this standard is if the client is at-risk of being hurt or of hurting someone else. These limits to confidentiality must be clearly explained. In the research context, participants should be reminded that they can refuse to answer any question and can stop participating at any time.

### 3.2 | Pre-assessment and training

Researchers have recommended using pre-administration screening of understanding and responsiveness (including response bias) to indicate the potential of self-report measures for each individual and, especially, to stretch these limits by training participants to use rating scales (Emerson et al., 2013; Finlay & Lyons, 2002; Hartley & MacLean, 2006; Perry & Felce, 2002). O'Keeffe et al. (2019) added that pre-assessment provides an opportunity to develop rapport with participants to put them at ease, develop an understanding of the participant's comprehension levels, practice the interview method (e.g., response format) and gather background information about the participant's life.

The participant's functional communication repertoire, communication methods, and sensory needs can be assessed and accommodated during pre-assessment. For participants with complex communication needs, this process should include the individual's use of AAC. AAC is a set of tools and strategies an individual uses to address communication challenges based on the context of the interaction and the skills of the communication partner. Communication can take multiple forms: speech, gesture, sign language, pictures, speech-generating device, and so on, with form being less important than the understanding of the message (Burkhart, n.d.).

The use of AAC can facilitate effective communication and the use of self-report in mental health assessments. As communication with a person who uses AAC requires competencies in both the user and the communication partner, the assessor's knowledge of and use of communicative strategies such as providing an expectant delay and modelling the use of multiple modes of communication is important to support successful communication. Other general strategies and techniques to improve communication may include writing, drawing, and photographs to support spoken communication. When health care professionals are unfamiliar with the participant's communication repertoire, the use of trained communication assistants may be necessary for participation in the self-report (McNaughton et al., 2019; Simmons-Mackie, 2018).

Pre-screening can also be used to determine the complexity of rating scales to which each participant can reliably respond (e.g., a three-point scale vs. five-point scale). The actual test questions can then be modified accordingly. Cummins et al. (1997) developed a pre-testing protocol containing three tasks. The first was concrete,

involving the size ordering of two to five wooden cubes. The second involved matching cube-size to a printed scale of importance. Finally, the participant was asked to rank an item known to be personally valued on an importance scale, thereby demonstrating the ability to generalise the use of the rating scale. Based on this pre-test, Cummins et al. (1997) screened out participants unable to give a valid response and then administered scales with either binary, three-point or five-point response options, depending on the participant's performance.

### 3.3 | Accessible health assessment: Strategies to improve cognitive accessibility

Scales developed specifically for individuals with intellectual and developmental disabilities can more effectively garner reliable self-report. Stancliffe et al. (2014) compared two self-report instruments in adults with mild to moderate intellectual disability. They found a much higher rate of responding (83% vs. 25%) when the questionnaire used a simple response format (e.g., yes/sometimes/no).

Designing cognitively accessible self-report measures increases valid self-reporting significantly among individuals with intellectual disability (Emerson et al., 2013; Finlay & Lyons, 2002; Prosser & Bromley, 2012). The following strategies to minimise the cognitive load and reduce biased responding in individuals with intellectual disability were adapted from Finlay and Lyons (2002), Kramer and Schwartz (2017), and Prosser and Bromley (2012), except where indicated:

1. Simplify question content. Vocabulary and meaning should be plain and simple. Use short words and simple sentences. If written surveys are used, strive for a fourth grade reading level. When reading questions aloud, simplify the sentence if the person does not seem to understand and avoid unexplained technical terms. It is important to remember that individuals with intellectual disability may assign different meaning to even familiar terms. For example, they may count paid staff among their friends (Barlow & Kirby, 1991; Lunskey, 2006). Flexible administrative procedures may be helpful, adapting the assessment to the individual and using follow-up questions to fully understand what the respondent is communicating. Including pictorial representation of response options as well as the item stem may improve comprehension, reduce biased responding, and contribute to more successful outcomes (O'Keeffe et al., 2019). AAC assessment may help in the consideration of an individual's current skills, strengths and needs, and may suggest options for different symbols, systems, and access modes (Binger & Kent-Walsh, 2017).
2. Simplify phrasing. Single clause sentences written in an active tense are preferred. Negatively phrased questions (*I have no energy*) and questions with modifiers (*what do not you like about ...?*) are more complicated and may be answered as if the question had been phrased positively (e.g., *I have energy*). For this reason, it is better to use affirmative forms of statements (e.g., *I am often tired*).
3. Questions about time or that require judgement of frequency or degree are cognitively demanding. To facilitate estimates of time, situational anchors in the participants' lives may be used instead of asking for specific dates or time periods. When the timing of significant events in the persons' life (e.g., birth of a child, moving to a new home, etc.) are established, the timing of other events can be determined with respect to those anchor points. Comparisons of present to past functioning may be difficult for respondents with intellectual disability (e.g., mood, preferences and symptom severity). If comparisons are difficult for respondents, it may be better to ask about current state first and then about the past.
4. Avoid asking about abstract concepts and generalisations. Abstract questions are generally more difficult for interviewers to adapt or simplify without changing the meaning. Concrete questions referring to specific activities or events are more easily understood and evaluated than abstract concepts. For example, 'What is your job?' is better than 'What do you do for a living?'. Respondents may have difficulty aggregating from the specific to the general in responding to 'in general' type questions. Questions about attitudes and future actions 'What do you expect to do in the future?' are cognitively loaded and should be avoided in favour of concrete questions about the present and the past.
5. Avoid socially reflexive questions as they require a high level of abstract reasoning and conjecture. Individuals with intellectual disability may be unable or unfamiliar with making such judgements.
6. Be mindful that extra care is needed with sensitive content. Questions with sensitive or taboo content have been found to be prone to error and bias in the neurotypical population (Barnett, 1998). These questions are especially problematic for individuals with intellectual disability, who may worry that endorsing taboo behaviour could negatively impact their services. Barnett (1998) described techniques that can reduce the impact of sensitive questions, including using explicit statements that information will not be shared with caregivers or service workers (see Prosser & Bromley, 2012, for suggestions on how to explain research to participants), using vignettes or nominative techniques (e.g., asking what other people would do), and using open-ended questions and conversational styles that allow for rephrasing and comprehension checks.
7. Because intellectual disability is associated with a limited attention span, it is often helpful to recap and summarise what the respondent has said to re-engage and focus the respondents' attention. This provides the opportunity to add more detail and to concur or refute the interviewer's interpretation.
8. Monitor your own speech for colloquialisms and discourse particles, for example 'you know?', 'OK?', and 'It's like'. These statements might distract the individual from the real question you would like them to answer.

## 4 | COMBINING SELF AND PROXY REPORT IN MENTAL HEALTH ASSESSMENT

Self-report is essential for a complete understanding of the mental health of individuals with intellectual disability. However, it is important for clinicians and researchers to recognise that, even with our most accessible tools and techniques, we will not be able to obtain an

accurate self-report from every individual with intellectual disability (Emerson et al., 2013; Finlay & Lyons, 2001). The ability to communicate views accurately depends on a number of factors of the assessment and characteristics of the individual. It is important for clinicians and researchers to use a pre-assessment screen and training to assess understanding and responsiveness of the individual with intellectual disability. If there is evidence that the self-report responses to an instrument are not accurate or do not reflect what the respondent means to communicate, then it is inappropriate to use that tool. As Emerson et al. (2013, p. 337) stated so eloquently, 'Although such a rigorous approach may mean that some people's voices are silent, misrepresenting people's views seems at least as troubling'. In the mental health field, researchers and practitioners often triangulate information from multiple informants and sources.

Developmental psychopathology researchers and practitioners commonly use multiple informants when conducting diagnostic interview schedules to assess psychiatric symptoms and disorders. Direct and informant reports of child and adolescent psychopathology have been the standard for several decades across both semi-structured (e.g., Schedule for Affective Disorders and Schizophrenia—Kiddie version [K-SADS]; Chambers et al., 1985) and structured interview schedules (Diagnostic Interview Schedule for Children [DISC]; Costello et al., 1982). This standard of collecting both direct and informant reports has also been incorporated in the assessment of mental health problems among individuals with intellectual disability (e.g., Psychiatric Assessment Schedules for Adults with Developmental Disabilities [PAS-ADD]; Friedlander & Moss, 2011). Although multi-informant assessments of psychopathology are conducted to enhance the validity of psychiatric diagnoses and symptomatology, the mental health field continues to struggle with how to interpret and combine information across informants given the discrepancies often found between direct and informant reports.

In a seminal meta-analysis of 341 studies on cross-informant correspondence published between 1989 and 2014, De Los Reyes et al. (2015) found low-to-moderate correlations for child and adolescent mental health assessments (mean internalising  $r = .25$ ; mean externalising  $r = .30$ ). Vandeleur et al. (2015) also found low to moderate ( $kappa = .28-.40$ ) agreement between self-report and informant reports of psychopathology in a sample of adults for all mood disorders except mania ( $kappa = .68$ ). However, research on the correspondence between direct and informant mental health assessments among individuals with intellectual disability is much more limited. Scott and Haverkamp (2018) found only modest concordance between self- and proxy report of mental health symptoms ( $r = .28$ ) among adults with intellectual disability. This finding is consistent with the original research conducted on the PAS-ADD in which low agreement between direct and informant reports was found in the majority of cases interviewed (Friedlander & Moss, 2011). In sum, modest concordance between informants of mental health assessments appears to be the rule rather than the exception in mental health research.

As De Los Reyes (2013) pointed out, discrepancies between multi-informant assessments continue to vex the field despite over

50 years of empirical data. There are several reasons that may explain informant discrepancies in mental health assessments. Informant biases may contribute to discrepant reporting, including acquiescence, recency, mood-congruent and social desirability biases. Variability in the reliability of assessments (i.e., measurement error) may also contribute to discrepancies between informant reports. Yet another explanation is systematic variability in the context in which the target behaviours are observed (De Los Reyes, 2013). Given the discrepancies between direct and informant reports of psychopathology, and the various possible explanations that may account for the lack of congruence, approaches for combining multi-information assessments warrants careful consideration.

Due to the lack of agreement between direct and informant reports on the PAS-ADD, the developers concluded that there was no valid basis on which to decide that ratings from one source were more valid than the other sources (Friedlander & Moss, 2011). As such, their recommendation for combining report was to defer to the judgement of experienced clinicians in weighing the information collected from different sources. Other approaches for combining diagnostic information across informants include the family study method for best-estimate diagnoses (Leckman et al., 1982), Spitzer's LEAD standard (Spitzer, 1983), and Boolean logic using 'and' and 'or' rules (Offord et al., 1996). The family study method for best estimate diagnoses is based on two expert diagnosticians who independently derive diagnoses based on all available information and resolve disagreements between the two experts by consensus. Similarly, the LEAD standard requires expert clinicians to use all available data over time, including psychological evaluation, hospital records, information from family members and laboratory results to make independent diagnoses and resolve disagreements by consensus. The 'or' rule has been used with fully-structured diagnostic interviews at the criterion level for a given disorder to determine the combined diagnosis. For example, a criterion for a given disorder is considered to be met if reported by either informant on the DISC-IV (Shaffer et al., 2000) as well as on the Composite International Diagnostic Interview (CIDI) (Green et al., 2012).

Consideration for which approach to use should be based on the intended purpose of the assessment. In clinical practice, the more rigorous approaches to combining multi-informant assessments that involve expert clinicians would be appropriate to inform treatment decisions. However, such rigorous approaches may not be viable for large-scale epidemiological studies in which fully-structured diagnostic interviews and algorithms using Boolean logic are used to derive combined diagnoses.

## 5 | CONCLUSION AND FUTURE DIRECTIONS

Emerson et al. (2013) challenged the claim that all people have views that can be measured reliably with the right supports, stating that this view approaches a denial of disability. The authors concluded that 'where the limits lie for gaining valid subjective information in this

population have not been adequately determined' (Emerson et al., 2013, p. 336). Fujiura and RRTC Expert Panel on Health Measurement (2012) called for cognitive science to identify avenues for enhancing valid self-report by helping researchers re-evaluate and adapt the self-report measurement to the individual. More work is needed to identify and stretch the limits of valid self-report of individuals with intellectual disability. Lessons learned from participatory action research with individuals with intellectual disability may guide future research in this area.

## 5.1 | Participatory action research

As part of the research team, individuals with intellectual disability offer a unique skill set to develop more accessible research procedures and assessment measures. In the past, researchers have excluded individuals with intellectual disability from clinical studies because of practical challenges and ethical concerns. In addition to being excluded from research participation, individuals with intellectual disability have rarely contributed to research activities, such as measurement development, data analysis, and disseminating findings (Nicolaidis et al., 2015; Powers, 2017). Partnering with individuals with intellectual disability can improve the accessibility of self-report measures (O'Keeffe et al., 2019) including questions about abstract and sensitive topics (Dagnan et al., 2008). O'Keeffe and colleagues were guided by adults with intellectual disability through a series of focus groups and pilot testing (O'Keeffe et al., 2019) to adapt items and visuals used on a scale measuring grief. She concluded that it was essential to include members of the target population in the development and pilot testing of the questionnaire in order to ensure the use of appropriate language. While participatory action research offers opportunities for individuals with intellectual disability to learn, to contribute to research, and to develop leadership skills (Stack & McDonald, 2014), it may also be essential to advancing the science of health research in this population (McDonald & Raymaker, 2013). Using methods such as participatory action research not only empowers individuals with intellectual and developmental disabilities, but will improve the quality of information that is gathered in mental health treatment of individuals with intellectual and developmental disabilities.

## 5.2 | Recasting Tim Jones' example mental health appointment

Tim Jones came to an appointment with his psychiatrist accompanied by his support staff, who had worked for Tim during the evening shift for the past 3 months. This was Tim's third visit to the psychiatrist this year; his support staff members were concerned that he was not responsive to staff during routine activities and panicked easily during the day. *Before the visit, evening and day staff met to discuss and document Tim's behaviours of concern.* The psychiatrist interviewed Tim privately about how he was doing. She used simple, clear vocabulary and

short sentences, allowing Tim extra time to reply. *During the interview, his psychiatrist re-framed questions so they were easier to understand. She asked follow up questions to understand and clarify Tim's responses and summarised what she thought Tim said.* The doctor gave Tim a form to complete about his feelings. *The form had been adapted to be cognitively accessible to individuals with intellectual disability. She used situational anchors to help Tim understand the time frame of her questions (Were you sad around Easter?) and included picture representations of questions and response options, which made the questions easier for Tim to understand. This format was also clear to his support staff, who helped him complete the form, allowing them to paraphrase and/or expand upon questions and responses.* Tim put forth his best effort to answer all the questions. *Tim left the appointment thinking that his voice had been heard and that his input was valued.*

In conclusion, it is not always easy, but it is certainly always important to get self-reported information about the wellbeing of individuals with intellectual disability. This is especially true in mental health assessment because many psychiatric symptoms are internal and can only be understood with direct input from the individual. This article highlights the need to develop better tools to more reliably obtain self-reported health and mental health information in research and clinical practice. We argue that including individuals with intellectual disability may be a critical component to achieving this goal.

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## CONFLICT OF INTEREST

The authors declare that there is no conflict of interest..

## DATA AVAILABILITY STATEMENT

Data sharing not applicable - no new data generated

## ORCID

Susan M. Havercamp  <https://orcid.org/0000-0002-8764-7987>

Chelsea Cobranchi  <https://orcid.org/0000-0001-9806-7614>

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