Journal of Policy and Practice in Intellectual Disabilities

Journal of Policy and Practice in Intellectual Disabilities doi: 10.1111/jppi.12386

State of the Field: The Need for Self-Report Measures of Health and Quality of Life for People With Intellectual and Developmental Disabilities

Karrie A. Shogren*, Alexandra Bonardi†, Chelsea Cobranchi‡, Gloria Krahn§, Alexa Murray‡, Ann Robinson‡, and Susan M. Havercamp,‡ The Nisonger RRTC on Health and Function

*Kansas University Center on Developmental Disabilities, University of Kansas, Lawrence, Kansas, USA; †Human Services Research Institute, Cambridge, Massachusetts, USA; ‡Nisonger Center, The Ohio State University Nisonger Center, Columbus, Ohio, USA; and §Oregon State University, Corvallis, Oregon, USA

Abstract

Background: Collecting self-reported health and quality of life (QoL) outcomes is increasingly considered best practice, but people with intellectual and developmental disabilities (IDD) are often excluded from patient-reported outcome measures.

Objective: This article provides a literature-informed overview of the state of the field of self-reporting of physical health and QoL in research with adults with IDD.

Approach: We first identified and synthesized definitions of key constructs related to the self-reporting of health. Next, we summarize literature on existing and emerging practices focused on health and QoL assessment, discussing the frequent and sometimes overly broad use of proxy-respondents in the IDD field. We then highlight emerging directions focused on cognitive accessibility and universal design. Finally, we provide conclusions and recommendations for the field.

Conclusions: Informed by the literature, we provide action steps to guide the field in considering how to incorporate self-reporting of health outcomes by people with IDD in research, policy, and practice.

Keywords: health, intellectual and developmental disabilities, patient-reported outcomes, quality of life, self-reporting

Introduction

Engaging people with intellectual and developmental disabilities (IDD) in research about their lives is central to understanding their experiences. Participation in research and quality monitoring drives health and societal improvements and promotes meaningful participation and self-determination (McDonald, Conroy, Olick, & The Project ETHICS Expert Panel, 2017). Collecting self-reported health outcome data (i.e., one's self-perceptions of their health status) has become standard practice in the general population but is practiced much less frequently with people with IDD (Fujiura & the RRTC Expert Panel on Health Measurement, 2012). Self-reported health and quality of life (QoL) are critical to assess given the relationship established in research between self-reported health and mortality (Idler & Benyamini, 1997) and indicators of health risk, healthcare access, and lifestyle factors (Gallagher et al., 2016). Best practice recommendations indicate that self-reported indicators or patient-reported outcome (PRO) measures should be considered in conjunction with more traditional, objective, and externally verifiable measures of health (e.g., laboratory tests, diagnostic tests) (Cella et al., 2010). However, the assessment of self-reported health outcomes among people with IDD poses unique issues that have not been adequately addressed to date.

The National Quality Forum (NQF), an organization dedicated to the science of monitoring quality healthcare and long-term supports in the United States, defines patient reported outcomes (PRO) as "any report of the status of a patient's (or person's) health condition, health behavior, or experience with healthcare that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else" (National Quality Forum, 2013). NQF notes that the word "patient" is intended to be inclusive of all persons, including patients, families, caregivers, and all persons receiving support services, including those with disabilities. While this definition has been used internationally in a broad range of research and health monitoring settings, people with IDD have had very limited participation in self-reported measures of health (Fujiura & the RRTC Expert Panel on Health Measurement, 2012).

Many factors contribute to under-utilization of self-reported health outcomes measures in people with IDD including concerns about (1) the reliability and validity of self-reporting and (2) the burden of participation in this population (Broomfield, Harrop, Judge, Jones, & Sage, 2019; Felce & Perry, 1995; Finlay &

Received April 8, 2020; accepted June 2, 2021
Correspondence: Karrie A. Shogren, Kansas University Center on Developmental Disabilities, University of Kansas, 1200 Sunnyside Ave., Rm. 3134, Lawrence, KS 66045, USA.
E-mail: shogren@ku.edu

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Lyons, 2001; Fujiura & the RRTC Expert Panel on Health Measurement, 2012). A common strategy to address these challenges has involved the use of proxy-reporting by supporters to assess the health and QoL of people with IDD (Cella et al., 2012). Proxy-reporting creates its own challenges, however. For example, concrete rules for when proxy-reporting are necessary and appropriate do not exist for the majority of current assessments. Nor are there standard methods for aggregating information from self-report and proxy-report to generate population level statistics on health outcomes. Further, cognitive accessibility and universal design (further elaborated on subsequently) are rarely considered in the development of health and QoL outcome measures, which may artificially limit participation in self-report by the population of respondents with IDD. Assumptions about risk and complexity, rather than feasibility of self-reporting, can shape methodological decisions (Broomfield et al., 2019).

There are compelling reasons to focus on self-reported health and QoL outcomes in people with IDD. First, a focus on PRO in the domains of health and QoL would enable the health needs of people with IDD to be more fully recognized and addressed (Fujiura & the RRTC Expert Panel on Health Measurement, 2012). Self-reporting of people with IDD provides a more complete picture of their health status, which can guide healthcare and health promotion program and policy decisions. Second, self-report by people with IDD allows them to become active participants in health research and to have a voice in the studies being conducted and the programs, policies, and products informed by the research (Krahn, Hammond, & Turner, 2006). Third, research on self-reported health by people with IDD is needed to address the question of "for whom and under what circumstances is self-reported health assessment feasible?" This information can identify opportunities that advance the accessibility and engagement of people with IDD in self-reported health assessment. Overall, self-reporting by people with IDD promotes ethical practice, self-determination, and equality in a population that has been historically marginalized and dismissed (Beart, Hardy, & Buchan, 2004).

The purpose of this article is to provide a literature-informed overview of the state of the field of self-reporting of physical health and QoL in research with adults with IDD. We did not engage in a systematic review of the literature that typically addresses a narrow research question with bounded outcomes. Instead, the authors first identified and synthesized definitions of key constructs related to the self-reporting of health. As we will note, the reliability and validity of measures depend on clarity of the construct being assessed, which necessitates conceptual clarity of key constructs including disability, health, and QoL. For this reason, we define and provide a framework for integrating these constructs. Second, we use current existing research and practice to summarize the status of health and QoL assessment in the field, describing the frequent and sometimes overly broad use of proxy-responding. Third, we highlight emerging research directions focused on cognitive accessibility and universal design. The principles of these practices can inform ongoing research and assessment development to promote greater use of self-reported outcomes and encourage conceptualizations of what self-report can look like for all respondents, including those with IDD. We end with recommended action steps derived from our literature-informed overview to guide the field in considering how to incorporate self-reporting of health outcomes by people with IDD in research, policy, and practice.

Definitions of Key Health and QoL Constructs: Toward Disentangling Health, Disability, and Function

Health, function, and disability are related but distinct constructs. Until recently, disability was presumed to be equivalent to illness, with expectations of dependence, inactivity, and exclusion from community life. However, many people with disabilities are healthy and enjoy a good QoL (Albrecht & Devlieger, 1999; Krahn et al., 2006). The International Classification of Functioning, Disability and Health (ICF) (World Health Organization, 2001) provided an integrative framework that conceptually differentiates health from disability and function, thereby permitting exploration of factors that contribute to the health of people with disabilities. In the ICF framework, *functioning* refers to all body functions, activities and participation, while *disability* is an umbrella term for impairments in body function and structure, limitations in activity, and restrictions in participation. Functioning and disability are reciprocally influenced by the interaction of a person's health conditions (e.g., Down syndrome, cerebral palsy), environment (e.g., negative attitudes, inaccessible transportation, inadequate supports), and personal factors (e.g., age, sex, race, education level). The ICF facilitated a conceptual shift that encourages healthcare professionals to broaden the focus from rehabilitation to promoting the health of people with disabilities. By expanding the focus beyond bodily functions and structures, ICF enabled a greater focus on the role of multidimensional factors, including activity limitations and participation restrictions, in shaping health across the life course (United States Public Health Service, 2002; Drum, Krahn, Culley, & Hammond, 2005).

This distinction between disability and health has not fully pervaded health research, where measures of functional limitations continue to be equated with measures of health and QoL (Krahn et al., 2009). Many popular measures of health-related quality of life (HRQoL) confound measurement of health by including items that assess functional ability (Hall, Krahn, Horner-Johnson, & Lamb, 2011). When completed by people with disabilities, these measures yield lower health scores, known as a "functional penalty" of unknown magnitude (Krahn et al., 2009). Function items also cause confusion in respondents with functional limitations who wonder whether to answer as if using their assistive devices or not. When respondents with spinal cord injuries were questioned after completing a self-report measure of health, 51% always considered their spinal cord injury in assessing their health, 21% never did, and the remainder sometimes did (Tate, Kalpakjian & Forchheimer, 2002). This variability in interpretation leads to measurement noise leading to a lack of clarity of the construct that is being assessed, particularly in the context of self-reporting of health and QoL.

Proposed Definitions of Health and QoL Constructs

Despite the wide acknowledgment of the importance of self-perceived health, a lack of consensus persists on the construct

that is being measured when assessing self-perceptions of health. Existing literature uses the terms health, health outcomes, HRQoL, and QoL somewhat interchangeably (Karimi & Brazier, 2016; Krahn et al., 2009). This lack of conceptual clarity is evidenced by the Measurement Outcomes Survey Short Form (SF-36) and the Europol (EQ-5D), which have been used in different studies to measure health status, HRQoL, and QoL (Karimi & Brazier, 2016). The indiscriminate use of these terms has created confusion in the literature about the meaning of these constructs and the interpretation of research findings. The authors of this article collaborated to identify and synthesize definitions of each of these constructs in the existing literature to develop the framework presented here and guide our ongoing work related to advancing the self-reporting of health. The following sections highlight these definitions with the intent to advance communication and advance the field by drawing attention to limitations and suggesting solutions. We advocate for ongoing research to further elucidate these constructs and their complex interrelationships and to develop standards that can be adopted across researchers and fields to promote clarity in the operationalization and measurement of self-reported health outcomes.

Health

We propose a definition of health as the dynamic balance of physical, mental, social, and spiritual/existential dimensions of wellness in adapting to conditions of life and the environment (Krahn, Robinson,, & Havercamp, 2019). This definition is grounded in the World Health Organization's 1948 definition of health, distinguishes health from functioning and disability as indicated in the International Classification of Functioning, Disability and Health (World Health Organization, 2001) and explicitly incorporates key changes to the WHO definition that have been recommended in the 70 years since its introduction.

Health Outcomes

A health outcome is a change in the health status of an individual, group, or population, which is attributable to a planned intervention or series of interventions, regardless of whether the intervention was designed to change health status (Nutbeam, 1998). Health outcomes are typically the dependent variable in an analysis and are usually measured using health indicators. Recognizing the importance of patient perceptions, the National Institute of Health developed the Patient-Reported Outcomes Measurement Information System (PROMISE), a set of publicly available, efficient, PRO measures. The Global Health Scale (Cella et al., 2010) includes 10 items that measure physical, mental, and social aspects of health including global health appraisals, physical functioning, pain, fatigue, mental health, and satisfaction with social life. Proxy reporting has been adopted in some measures, such as to allow for parent reporting for children who cannot self-report (Broderick, DeWitt, Rothrock, Crane, & Forrest, 2013); however, issues related to engaging people with IDD have not been robustly considered.

Perceived Health

Perceived health is sometimes called self-perceived health, self-rated health, or health status. Self-rated health is usually measured by a single question having the individual rate his or her overall health on a 5-point scale from "excellent" to "poor." Other measures of self-perceived health ask respondents to rate the extent to which they were bothered by recent health problems, the extent to which they were worried about their health (Farmer & Ferraro, 1997) or to estimate the number of days in the past month that they experienced poor health (Barile et al., 2013). In this article, we use the term perceived health to mean self-reported health by adults with IDD.

Health-Related Quality of Life

HRQoL has been defined in multiple ways that vary in their breadth of focus. For example, definitions of HRQoL include: "only those factors that are part of an individual's health" (Torrance, 1987), "those aspects of quality of life that are affected by health, or how well a person functions in their life, fulfills valued social roles, and his or her perceived well-being in physical, mental, and social domains of health" (Naughton & Shumaker, 2003). Economic studies commonly use utility-based approaches to measure HRQoL, attempting to quantity the extent of loss of QoL due to living with disability (Hays & Morales, 2001; Wilson & Cleary, 1995), as in Quality Adjusted Life Years and Disability Adjusted Life Years. The premise that disability diminishes life value is refuted by many disability researchers (Smith, Brown, & Ubel, 2008) and may itself negatively impact the health of people with disabilities (National Quality Forum, 2013). HRQoL is typically assessed with a longer set of questions (e.g., MOS SF-36; FuNHRQOL) compared to perceived health, which has frequently been assessed with a single item. However, in reviewing popular HRQoL measures, Karimi and Brazier (2016) concluded that the scores on HRQoL measures are more reflective of perceived health status than QoL.

Quality of Life

Further compounding the conceptual confusion is the separate definition framework for QoL, generally. The World Health Organization Quality of Life (WHOQOL) Group asserted that QoL is the person's global evaluations of behaviors, states, and capacities in terms of satisfaction/dissatisfaction (WHOQOLGroup, 1995). The WHOQOL assessment is organized into the following six broad domains: physical, psychological, level of independence, social relationships, environment, and spirituality/religion/personal beliefs. As such, there is conceptual overlap with some definitions of HRQoL. A growing consensus conceptualizes QoL as a purely subjective experience (Moons, Budts, & De Geest, 2006), but externally

observable indicators such as socio-economic status and housing conditions are sometimes also included in QoL assessment. The question of whether objective indicators reflect or merely contribute to QoL depends on how QoL is defined (Meeberg, 1993) and there is variability in approaches to the use of subjective and objective indicators in the IDD field (Brown, Hatton, & Emerson, 2013).

Understanding Quality of Life in the Context of Disability

It is often assumed that QoL would be significantly and negatively impacted by disability. However, people with disabilities typically self-report a higher level of happiness than what is expected by nondisabled people (Ubel, Loewenstein, Schwarz, & Smith, 2005). This apparent contradiction is known as the disability paradox (Albrecht & Devlieger, 1999). The contradiction is particularly troubling in healthcare settings where underestimated QoL by professionals may negatively influence healthcare decisions for people with disabilities (Gerhart, Koziol-McLain, Lowenstein, & Whiteneck, 1994).

Schwartz and colleagues explored possible mechanisms for the disability paradox. First, people with disabilities may experience response shift (Schwartz, 2010; Schwartz et al., 2007) when they change their internal standards of measurement for QoL (scale recalibration). They may compare themselves to other people with the same disability when rating QOL rather than with an "ideal." This phenomenon of scale recalibration has been documented for aging respondents (e.g., "for an 85 year old, my health is pretty good") and across multiple clinical groups (e.g., colon cancer, bone metastasis, childhood cancer, colonoscopies) (Bernhard et al., 1999; Oort, Van Der Linden, Sprangers, & Leer, 2005; Schwartz, Feinberg, Jilinskaia, & Applegate, 1999). Another explanation is that respondents may change the value they place on certain abilities (reprioritization), whereby some limitations considered hypothetically are not nearly as important to QoL when one lives with them. A third possibility is that the understanding of the construct of QoL changes (reconceptualization) for people with disabilities, whereby what "healthy" means may change (e.g., "my friendships are an important part of feeling well") (Schwartz et al., 2007). These differences in appraisal processes raise concerns about ambiguity in measurement for research and clinical purposes, particularly when using proxy measures of QoL. Strategies to manage response shift require careful attention to the constructs being measured and the context of measurement (Schwartz et al., 2007; Ubel, Loewenstein, & Jepson, 2005).

There is an emerging agreement that the disability paradox is not merely a result of people with disabilities misreporting or exaggerating their QoL. The preponderance of evidence suggests that people with disabilities adapt to their circumstances and that self-reported QoL and HRQoL are largely accurate and provide unique and meaningful information (Ubel, Jankovic, Smith, Langa, & Fagerlin, 2005; Ubel, Loewenstein, & Jepson, 2005). Based on this literature, we conclude—as have multiple researchers in the health and disability field—that promoting self-report of health and QoL is critical as self-report reflects the perceptions of the individual, and it is these perceptions that drive behavior and health. Further, greater clarity and universal frameworks are needed to define, distinguish, and measure QoL and HRQoL constructs. Addressing this issue is central to meaningfully assessing and communicating self-reported health outcomes, and ensuring the role of QoL in health and the complex interrelationships between health and QoL are measured. However, in order to engage in such work, it is necessary to enable self-reporting by those with IDD to allow for the integration of objective and self-reported health and QoL outcome data. The next challenge, then, is how to navigate through the challenges to develop best practices for promoting self-report in people with IDD.

Current Status and Challenges in Assessing Health and QoL in People With IDD: A Literature-Informed Overview

Self-reported health and QoL in the general population has been shown to predict objective health outcomes including mental health measures, serological measures, and mortality (Gallagher et al., 2016; Nicolaidis et al., 2015). However, for people with IDD and other cognitive limitations, concerns are frequently raised about the reliability and validity of self-reported health and QoL, leading to less research on the relationship between PRO and objective outcomes in this population. Interpreting and responding to PRO questions typically require several rapid and concurrent demands that include: considering the question structure and delivery mode, interpreting the meaning of the question, formulating a response that describes a steady state (e.g., overall physical health) versus the immediate experience (e.g., I'm sore right now), and generating a response either verbally or using technology (e.g., computer-based assessments). Responding to Likert-types scales introduces additional cognitive demands (Finlay & Lyons, 2001). Responding often requires comparing current or past experiences to optimal experiences. All this cognitive processing must also occur within a timeline dictated by the interviewer or survey format. Self-report measures often used in health-related research are not typically designed with cognitive accessibility in mind and, as a result, are unintelligible to people with IDD (Feldman, Bosett, Collet, & Burnham-Riosa, 2014; Loewenson, Laurell, Hogstedt, D'Ambruoso, & Shroff, 2014; Nicolaidis et al., 2015; O'Keeffe, Guerin, McEvoy, Lockhart, & Dodd, 2019; Schwartz, Kramer, & Longo, 2018). This accounts for the reliance on proxy-reporting evident in the literature.

QoL Assessment in IDD

Reporting on QoL is also a highly subjective and cognitively complex process. Self-reporting on QoL requires introspection and aggregating evaluations of personal satisfaction across many situations and abstract life domains (Cummings, 1997; Stancliffe, Wilson, Bigby, Balandin, & Craig, 2014). A systematic review of self-reported QoL measures for people with IDD identified nine measures developed across four global locations (Li, Tsoi, Zhang, Chen, & Wang, 2013). Proxy reporting by people familiar with the person with IDD has been favored by some, but not all, IDD researchers. Unique to the IDD population, QoL measures are used to characterize satisfaction with and to

evaluate IDD services. It may be assumed that better services and supports would result in higher QoL. For this purpose, some scholars reasoned that proxies without IDD would have a better appreciation of various life conditions, such as community inclusion, that were denied to people with IDD (Ager & Hatton, 1999; Felce & Perry, 1995; Hatton & Ager, 2002). Some QoL researchers expressed the concern that people with IDD may not recognize the unacceptability of their living conditions (Ager & Hatton, 1999; Felce & Perry, 1995; Hatton & Ager, 2002) and therefore may not have an adequate basis for reporting on their own QoL. Felce and Perry (1995) observed that people with IDD are likely to adapt to even the least favorable conditions including segregated living arrangements. We argue, as do other QoL researchers (Emerson, Felce, & Stancliffe, 2013), that proxy reporting of many QoL domains is problematic as it reflects the proxy's perception of the person's experiences. Further, it fails to recognize the capacity for adaptation and resilience that contributes to positive health and QoL outcomes. We suggest that the remarkable ability to adapt bodes well for health and QoL outcomes in people with IDD. However, work is needed to disentangle subjective assessment of QoL from the evaluation of services and supports. With these constructs decoupled, the QoL framework developed for the general population may be relevant to people with IDD allowing the inclusion of people with IDD in population QoL research.

Lack of Guidelines for Proxy Reporting

Despite its widespread use, there are currently no widely accepted guidelines for when and how proxy-reporting should be used instead of self-report. Without guidance, there is often a proxy-reporting default in broad health and QoL research. However, proxy responding on subjective measures of health and QoL introduces its own set of challenges. First, the proxy may be directed to respond with how they *think* the person would respond, or to provide their *own* perspective on the person's physical health, creating the opportunity for confusion. Second, researchers have identified an inter-rater gap between the person's self-perception and the proxy's ability to comprehend the person's view, leading to variability in reporting on multiple health and quality of life-related constructs (Pickard & Knight, 2005). The limited research on the level of agreement between self- and proxy-report suggests wide variability. Li et al. (2013) suggested concordance across self- and proxy-reports on QoL measures and subscales ranged from negligible to strong (−-0.08 to 0.80). We hypothesize that this gap is influenced by the disability paradox and the inherent challenges of reporting on another person's internal experiences.

Examples from large-scale survey protocols in the IDD field provide some guidance. It is important to note, however, that these surveys were developed to evaluate the quality of supports and services not health or HRQoL. For example, the National Core Indicators adult survey includes both self-report items and proxy-report items. For certain items, proxy reporting is not allowed. If obtaining self-report is determined not feasible, those items are not asked as it is assumed a proxy cannot provide valid responses. Trained surveyors use the first three to four items as a pre-test to determine whether it is possible to complete the self-report-only section of the survey. The surveyor training and protocols are designed to provide accommodations to promote a self-reported response. A follow-up question for surveyors asks for their impression of whether the person responding understood the questions and could self-report their answers. The authors note, however, that these determinations are based on interviewer judgment and are not absolute. Similarly, Li et al. (2013) recommend the use of pretest protocols, but there is not broad agreement on the characteristics of such protocols. Frameworks to determine the feasibility of gaining informed consent for research from participants with intellectual disability (Schwartz, Kramer, Cohn, & McDonald, 2019; Stack & McDonald, 2018) also suggest factors to consider. Ultimately, there are multiple personal and environmental factors that shape self-reporting and its reliability and validity in people with IDD across a range of health and QoL constructs.

Implications: Emerging Directions in Self-Reporting of Health in IDD

The limited data collected from people from people with IDD in population health and QoL research have major implications for describing health characteristics and needed supports in this population (Broomfield et al., 2019). We believe that concerns about the reliability and validity of self-report in IDD are also shaped by expectations resulting from the disability paradox and beliefs about the ability of people with IDD to meaningfully report on their health and QoL outcomes. These expectations can contribute to researchers defaulting to proxy-reporting and not promoting cognitive accessibility in the design of measures of health and QoL outcomes. We assert that creative efforts to increase the cognitive accessibility of established and new instruments is sorely needed to create opportunities for people with IDD to be involved in research on their own health (McDonald, 2012). New technologies offer opportunities to design cognitively accessible assessments to maximize the opportunities for people with IDD to speak to their own health and QoL.

What Is Cognitive Accessibility?

There is not one universally accepted definition of accessibility or cognitive accessibility (Johansson, 2016; Persson, Åhman, Yngling, & Gulliksen, 2015). However, there are a key set of design principles that can promote access to people with a broad range of support needs (Schwartz et al., 2018; Tanis et al., 2012; White et al., 2015). For example, providing multiple means of representation (e.g., present content in multiple formats), multiple means of engagement (e.g., provide different ways to connect with content), and multiple means of expression (e.g., create multiple options for how to respond) are key principles of universal design for learning (Rappolt-Schlichtmann, Daley, & Rose, 2012). These principles encourage consideration of the vast heterogeneity of support needs in a population of potential users and suggest that design can minimize barriers to use (Johansson, 2016). Truly accessible, universal design works

to meet the needs of the broadest number of end-users, consistent with the diversity present in society (Lewis & Seeman, 2019). Health researchers typically lack the tools and strategies needed to design or modify standardized instruments to promote cognitive accessibility, particularly for people with IDD and other cognitive support needs (Loewenson et al., 2014; Nicolaidis et al., 2015). We assert that support needs should not preclude participation; rather instrument design should strive to meet a range of respondents' needs. This necessitates ongoing collaborations between disability and health researchers.

Cognitively Accessible Measurement Design

A growing body of research suggests that many adults with IDD can provide reliable and valid reports of complex constructs such as depression and well-being when presented with appropriately adapted, cognitively accessible measurement instruments (Esbensen, Seltzer, Greenberg, & Benson, 2005; Lindsay & Skene, 2007). Using cognitively accessible self-report measures can also significantly increase the response rate among people with IDD. For instance, Stancliffe et al. (2014) compared two self-report measures of loneliness: one used for the general population which used more difficult question wording and a more complex response scale, and the other designed for respondents with intellectual disability with simpler wording and response options. Among adults with mild to moderate deficits in intellectual functioning, the researchers found a higher response rate for the instrument designed with cognitive supports (83%) in comparison to the one that was not (25%). This finding exemplifies the benefit of designing cognitively accessible self-report measures (e.g., simplified wording, reduced complexity of rating scale, picture-based supports, exemplars, and definitions of complex terms) so that many more people with intellectual disability can actively respond and engage in health-related research (Emerson et al., 2013). Such modifications may benefit other groups as well (e.g., aging adults, adults with low literacy) promoting greater inclusion of those populations.

ATLAS (Accessible, Testing, Learning & Assessment System) (Davies, Stock, King, Wehmeyer, & Shogren, 2017) provides an example of universal design in assessment delivery. The tool was designed to provide a cognitively accessible platform, within which any survey can be programmed. It has been used to measure self-reported satisfaction with healthcare and engagement in health promotion (Schwartz et al., 2013; White et al., 2015). The ATLAS digital platform allows questions to be read aloud, repeated, and rephrased; pictures are embedded that can be turned on and off; and cognitive demands are reduced through displaying only one item on the screen at a time. Such design features promote cognitive accessibility and minimize factors that can limit reliability and validity of responses on self-reported measures by people with IDD and other support needs. By providing read-aloud and re-phrasing supports, difficulties with reading and understanding the meaning of questions can be reduced. Cognitive demands are further reduced by the option to use different rating scales and different means of responding. The ability to repeat questions and use pictures can support people with language or literacy needs to contextualize words and content. Considering these needs can play a significant role in designing effective, cognitively accessible instruments for persons with IDD and other populations (Finlay & Lyons, 2001; Hartley & MacLean Jr, 2006; Lewis & Seeman, 2019).

We propose that developing self-reported health measures for people with IDD should be undertaken with the following assumptions: (1) applying universal design principles to the instrument design process will increase accessibility and usability of an instrument for many, or even most, people with IDD; (2) the diversity in types and levels of functioning among people with IDD means that some people will be able to respond to a measure without any modifications while others may need extensive supports for cognitive accessibility in order to respond; and (3) in some cases, supports may include other modalities (e.g., observations, proxy reporting). However, our premise is that measurement can be accessible to more people with IDD with appropriate planning for cognitive accessibility.

Likert-type scales. One issue with many self-report measures of health and QoL has been the use of Likert-type scales. These scales require distinctions among discrete response options (e.g., "strongly disagree" from "somewhat disagree") (Finlay & Lyons, 2001) and distinctions ranging from dichotomous choices to 11 or more options (Li et al., 2013). Hartley and MacLean Jr (2006) reviewed the empirical literature on Likert-type self-report measures with respondents with ID and found low response rates among participants with severe and profound deficits in intellectual functioning. This work has not explored how use of accommodations to reduce cognitive demands could increase response rates. However, innovative solutions are emerging. One is the use of visual analog scales, where response options are provided on a slider scale whereby respondents identify the degree to which they disagree or agree with a given statement along a continuum that is scored by the computer software. Researchers have found that using slider scales can reduce discrimination errors (Ahearn, 1997; Rausch & Zehetleitner, 2014) and can promote access and greater variance in responses for people with IDD (Raley, Shogren, Rifenbark, Anderson, & Shaw, 2019).

Prescreening and clinical judgment. Hartley and MacLean Jr (2006) among others suggest using pretests (pre-interviews) to evaluate respondent ability to understand and communicate using the self-report assessment as designed; and to determine the most appropriate cognitive supports for the person's needs (e.g., pictures, different response scale) when such supports have been created for the assessment. Others have suggested the use of standardized verbal and auditory comprehension measures as part of the pretest (Feldman et al., 2014; Finlay & Lyons, 2001). Future research should evaluate frameworks that guide clinical judgment by researchers administering self-report measures and planning for accommodations and supports for participants with IDD.

Recommendations for the Field

Overall, there has been limited focus, particularly in the general health literature, on engaging people with IDD in the movement toward PROs or self-reported indicators of health. There has been even less attention to the inclusion of people with IDD

who have highly complex communication or support needs (Broomfield et al., 2019). The existing literature suggests a compelling need for greater focus on promoting (1) clarity of the construct being assessed, with clear and operationalizable definitions of health, function, disability, and QoL; (2) instrument design for cognitive accessibility to maximize accessibility for all, inclusive of people with IDD; and (3) thoughtful consideration of how to address situations where self-report is not feasible despite the best efforts to provide an accessible experience. Such in-depth consideration should include clear protocols for integrating data from multiple sources and options to ensure that the most relevant information is included in research on health and health outcomes across the life course. We believe future work should explore ways to minimize the use of proxy-reports by focusing on the development of assessments that are flexible, integrate universal design principles to achieve reliability and validity, particularly for population research. Given constantly emerging technological innovation, increased attention should also be devoted to integrating these innovations in the development of valid measures of self-reported health in this population to broaden participation, including the use of multiple modalities of responding.

We suggest the following action steps to guide the field in moving forward:

1. Involve persons with IDD directly in developing and testing measures.
2. Adopt a framework of health that recognizes its dynamic and multidimensional nature and use this framework to guide the assessment of health and QoL.
3. Acknowledge that health is not static, but changes over the life course and is directly related to adaptation and resilience as well as to personal, social, and environmental factors. There are complex interrelationships between health, disability, and QoL across the life course.
4. Promote clarity in the health outcome being measured and align assessment with the operational definition of the outcome construct. Ensure that measures do not conflate constructs (e.g., health with function, or QoLwith services and supports).
5. Approach self-reported health assessment design and development with the goal of maximizing accessibility for all stakeholders, including people with IDD, by leveraging technological advances and universal design principles. Consider how definitions or modalities of self-reporting can change with emerging technologies.
6. Acknowledge the vast heterogeneity of people with IDD across the life course, and the need to individualize assessments based on the person and the purpose of the data collection. Report the accommodations provided to inform other researchers.
7. Take care to not assign blanket priority to objective (externally verifiable) data over subjective data, particularly for people with IDD in health and QoL measures.
8. Conduct research that examines the effectiveness of instrument design that maximizes cognitive accessibility, including research to assess construct-similarity for persons with and without IDD on the instruments.
9. Consider developing and systematically evaluating guidelines or strategies to support clinical judgment in determining the need for proxy-reporting. Test the degree to which self- and proxy-report is measuring the same construct and explore ways to integrate these data from different sources into population-level research.
10. Hold high expectations on the ability and desire of people with IDD to meaningfully communicate information about their health and QoL.

Conclusions

Clinical judgment and expertise are needed in the design, administration, and interpretation of self-reported health and quality of life data to ensure that the best data are available from as many people with IDD as possible. Changes in technology as well as potential advances in how to conceptualize "responding" (e.g., scored recording of behavioral expressions using technology, alternative ways of responding) are anticipated to increase the degree to which cognitive accessibility and challenges with self-report can be addressed. Such approaches have the potential to further reduce the reliance on proxy-responses and to increase understanding of the health and quality of life of people with IDD from their point of view. People with IDD should be directly engaged in the development and testing of accessible research instrumentation (Feldman et al., 2014). This can help establish the impact of designing for cognitive accessibility and the relationship between participant characteristics and engagement with the assessment. Consistent with participatory research, ongoing work is needed to explore ways to use the knowledge and experience of people with IDD to promote participation in research on self-reported health and QoL outcomes (Fujiura & the RRTC Expert Panel on Health Measurement, 2012).

We conclude with a quote from then Surgeon General David Satcher (United States Public Health Service, 2002) that is as relevant today as it was in 2002 when he called for improving the health and QoL of people with IDD:

> This dedicated community can teach us a great deal. They can help us all to better understand and face their unmet needs, which are significant and all too common. Perhaps the greatest lesson is that as a society we have not really been listening and paying attention to them. We have been too likely to expect others, without [intellectual disability], to speak to their needs. We have found it too easy to ignore even their most obvious and common health conditions. Just as important, we have not found ways to empower them to improve and protect their own health. No one who cares would suggest that this is acceptable. Nothing, however, will follow from this effort unless we help our society better understand and appreciate that these persons are an integral part of the American people, with much to give if they, too, enjoy proper health."

ACKNOWLEDGMENTS

This article was developed as part of a Rehabilitation Research and Training Center (RRTC) on Health and Function

awarded to The Ohio State University (OSU) Nisonger Center through a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR grant number 90RTHF0002-01-00). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). The contents of this Commentary do not necessarily represent the policy of NIDILRR, ACL, or HHS and should not assume endorsement by the Federal Government.

Conflicts of Interest

The authors have no conflicts of interest to declare.

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Appendix A.

Collaborators of Nisonger Center RRTC on Health and Function

The Ohio State University Nisonger Center RRTC on Health and Function (90RTHF0002-01-00) consists of the following collaborators in alphabetical order by last name: Susan Havercamp, Rebecca Andridge, L. Eugene Arnold, Jarrett Barnhill, Shawn Bodle, Ethan Boerner, Alixe Bonardi, Mary Lou Bourne, Christine Brown, Andrew Buck, Sarah Burkett, Richard Chapman, Chelsea Cobranchi, Christopher Cole, Dan Davies, Travis Dresbach, Jeanne Farr, Robert Fletcher, Braden Gertz, Jill Hollway, Margo Izzo, Gloria Krahn, Rosie Lawrence-Slater, Luc Lecavalier, Alexa Murray, Kristin Page, Samantha Perry, Ashley Poling, Paula Rabidoux, Robert Rice, Ann Robinson, Megan Ryan, Christopher Sanford, Colin Schaeffer, John Seeley, Karrie Shogren, Annie Song, Kristy Stepp, Marci Straughter, Lara Sucheston-Campbell, Marc Tasse', Christopher Taylor, Katherine Walton, Michael Wehmeyer, Craig Williams, Andrea Witwer.