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Psychometric properties of a brief self-reported health-related quality of life measure (HRQoL-IDD) for persons with intellectual and developmental disabilities

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Abstract

Background: To encourage self-determination and address health disparities among persons with intellectual and developmental disabilities, clinicians and researchers rely on self-reported measures like health-related quality of life (HRQoL). This study evaluated the psychometric properties of a theory-driven self-reported HRQoL measure for adults requiring mild to moderate support related to intellectual and developmental disabilities.

Method: 224 volunteers completed 42 quality of life items developed with extensive input from persons with intellectual and developmental disabilities, family members/caregivers, and providers. The 5-point Likert scale format with visual images of fluid-filled cups represented the range of responses.

Results: Exploratory and Unrestricted Factor Analyses yielded 16 HRQoL items with 4 subscales: *Functional Well-Being*, *Emotional Well-Being*, *Social Well-Being*, and *Healthy Decision-making*. The HRQoL-IDD explained 62.8% of variance, had satisfactory internal consistency (0.73–0.83), stability of responses, and reading level (2nd grade, ages 7–8).

Conclusions: The HRQoL-IDD is a promising measure of self-reported HRQoL for use in community-based settings for persons requiring mild to moderate support related to intellectual and developmental disabilities.

KEYWORDS

generalizability theory, health-related quality of life, intellectual and developmental disability, quality of life, scale development

1 | INTRODUCTION

An estimated 5.1 million persons, or approximately 1.5% of the US population, live with intellectual and developmental disabilities (IDD) with similar prevalence estimates reported internationally (Braddock et al., 2015; Maulik et al., 2011). The estimated worldwide prevalence of intellectual disability (ID) is 10.4/1000 population (Tomlinson et al., 2014).

Adults with intellectual disabilities experience a 'cascade of health disparities' greater than the general population: earlier onset of age-related debilitating conditions, higher rates of chronic conditions, poorer participation in preventive screening, worse overall health and higher medical expenses (Boat & Wu, 2015; Butler et al. 2012; Davis et al., 2014; Krahn & Fox, 2014; Krahn et al., 2015; Reichard et al., 2011). Compared to those with other disabilities, they are also more likely to report co-morbid health outcomes,

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greater social isolation and more days with poor mental health (Hall & Kurth, 2019).

Researchers and clinicians aim to address functional impairments and symptoms associated with IDD through individual therapy (Hronis et al., 2017), group-based health and wellness projects (Taggart et al., 2018), and pharmacologic interventions (Hart et al., 2017). Yet their ability to assess intervention efficacy is limited due to the lack of suitable self-report outcome measures for this heterogeneous population. An important priority, therefore, is the development of valid and reliable outcome measures designed specifically for adults with intellectual and developmental disabilities (NIH, 2017). The purpose of this research was to assess the psychometric properties of a self-reported health-related quality of life (HRQoL) measure for this population.

1.1 | Health-related quality of life (HRQoL)

Self-reported HRQoL is an important indicator used to assess the effectiveness of health care interventions (Alcañiz & Solé-Auró, 2018; Pinhas-Hamiel et al., 2006; Ramerman et al., 2018; Schallock et al., 2008; Schallock & Keith, 2016; Schwimmer et al., 2003). HRQoL refers to peoples' subjective evaluations of the relationship between their current health status and health-promoting activities and their perceived ability to maintain a satisfactory level of overall functioning and well-being (Shumaker & Naughton, 1995).

The World Health Organization (WHO, 2001) recommends that HRQoL measures be multi-faceted and reflect not only the absence of disease or infirmity but include assessments of a person's physical and emotional health, social functioning and general well-being (Andresen & Meyers, 2000; Clark et al., 2017; DHHS, 2012; Fujiura, 2012). However, there is little consensus regarding items to include in a HRQoL measure or whether the measure should have a general focus or be specific to a given disabling condition. Furthermore, little distinction is made between a person's health-related quality of life (HRQoL) and his/her quality of life (QoL).

1.2 | Relationship between HRQoL and QoL

The two constructs, HRQoL and QoL, are often used interchangeably (Post, 2014; Spitzer, 1987). *Do these two constructs merely reflect semantic preferences or are there substantive differences between HRQoL and QoL as experienced by both the general public and the IDD community?* Like Revicki et al. (2000), we posit that there are meaningful differences in dimensionality and scope between the broader construct, QoL, and its more specific subset, HRQoL.

Most QoL investigators agree that QoL is multidimensional and incorporates a broad spectrum of a person's self-reported life satisfaction including social, cultural, ethnic, psychological, interpersonal, spiritual and financial issues (CQL, 2017; Padilla & Kagawa-Singer, 2003). Schallock and colleagues proposed 8 core domains of QoL: *emotional well-being, interpersonal relations, material well-being,*

personal development, physical well-being, self-determination, social inclusion and rights (Claes et al., 2010; Schallock et al., 2008; Schallock & Keith, 2016). These 8 domains formed the content of the *Personal Outcomes Scale* (POS), an interviewer-based assessment of QoL for adults with intellectual disabilities. Two additional QoL measures for adults with intellectual disabilities include the *Personal Outcomes Measure* (POM) (CQL, 2017; Friedman & Rizzolo, 2018) and the *WHOQOL-BREF* (Power et al. 2010). Like the POS, these measures use structured interviews which can be labour-intensive, costly and subject to social desirability bias.

Rosenquist et al. (2006) argue that HRQoL is a subset of QoL that specifically addresses health domains. Unlike QoL, HRQoL does not address some aspects of living, for example spirituality, standard of living, education, housing, employment, cultural and recreational amenities and public services but recognizes that these elements impact HRQoL and vice versa. The critical domains of HRQoL include social, emotional, physical and cognitive functioning, mobility and self-care, overall life satisfaction and perceptions of health status. These factors typically are the purview of health care providers and are likely to be the focus of health care interventions. It is this definition of HRQoL that serves as the conceptual model for this research.

1.3 | HRQoL Measures for adults with disabilities

For adults with intellectual and developmental disabilities, the challenge is to identify accessible measures that incorporate critical HRQoL domains. Given the heterogeneity of the IDD population, some HRQoL measures developed for the general population (e.g. the SF-36) (Ware, 2004) may be best suited for persons with fewer physical and cognitive challenges (Andresen, 2000; Andresen & Meyers, 2000; Fujiura, 2012; Hays et al., 2002; Taggart & Cousins, 2013). While adults with intellectual and developmental disabilities can often navigate paper-pencil measures and use Likert scales with or without support, those with physical challenges or poor reading skills may find such measures difficult to use without verbal/visual cues, computer-based interfaces and assistance.

The FuNHRQOL (Krahn et al., 2014) was designed to be 'function-neutral' for adults with and without functional limitations. It recognizes that a person could be in 'excellent' health yet not able to climb steps because s/he is in a wheelchair. Unfortunately, the target population excludes adults with intellectual or other cognitive impairments (Krahn et al., 2014). The scale also assesses respondents' perceived experiences during the previous month, a duration too long for some persons with cognitive challenges to recall and aggregate. Although the Flesch-Kincaid readability statistic for the total 42-item scale was at a 4th grade reading level (ages 9–10), some individual items present comprehension challenges, for example *Did you quickly recover your energy after you did things that took physical energy?* Other measures (e.g. the CAHPS and the CDC HRQoL-14) assume 7–9th grade reading levels (ages 12–15) (Darby et al., 2005; Darby et al., 2006).

1.4 | Importance of self-report

To avoid accessibility concerns, the temptation may be to use proxies (e.g. family members or care providers) to answer HRQoL questions for adults with intellectual and developmental disabilities. Yet this group has identified 'speaking for oneself' as critical to healthy decision-making (Calkins et al., 2011; Keith & Schalock, 2016; Mostert, 2016; Schwartz et al., 2015; Shogren et al., 2006; Wehmeyer & Abery, 2013). Positive relationships have been found between the extent to which persons with intellectual and developmental disabilities report having control over their health and medical care and their perceived QoL (Shogren et al., 2006; Wehmeyer & Schwartz, 1998).

Engaging proxies to provide subjective health information and QoL can produce invalid results. Proxies may knowingly or unwittingly distort respondents' perceived experiences. Their opinions are often incongruent with, and less positive than, self-evaluation of the health challenges, behaviours and feelings of people with intellectual and developmental disabilities (Addington-Hall & Kalra, 2001; Butler et al. 2012; Claes et al., 2012; Cummins, 2002; Knüppell et al., 2018; Schmidt et al., 2010).

1.5 | Objectives

There is a compelling need to develop a succinct and robust self-report measure of HRQoL for adults with intellectual and developmental disabilities that is grounded in a conceptual model of HRQoL. Such a measure should minimize potential bias introduced by proxies. This report summarizes our efforts to develop such a HRQoL measure that could be used in community settings that serve this population.

Our preliminary goal was to undertake a psychometric assessment of a 42-item bank of QoL items that had been generated from input and feedback from adults with intellectual and developmental disabilities, their caregivers and providers (Clark et al., 2017) and completed by a second sample of 224 adults with intellectual and developmental disabilities. Our ultimate goal was to determine which items and factors generated from this bank of 42 QoL items comprised a succinct and robust measure of HRQoL.

1.6 | Conceptual development of the 42 quality of life (QoL) items

The conceptual development of the 42-item bank of QoL items included in this psychometric assessment has been reported in detail elsewhere (Clark et al., 2017).

The pool of 42 items reflected the larger construct of QoL described by Schalock and colleagues (Schalock et al., 2008; Schalock & Keith, 2016; Verdugo et al., 2012). The items' reading grade level was 2.9 (ages 7 – 8) with no passive sentences per the Flesch-Kincaid readability statistic (Word, 2019).

Following a review of the use of Likert-type scales for adults with intellectual and developmental disabilities (Chachamovich et al.,

2009; Cuskelly et al., 2013; Fang et al., 2011; Hartley & MacLean, 2006; Williams & Swanson, 2001; Wuang et al., 2009) and much discussion with our community partners, we adopted a 5-option format (e.g. 1 = Never to 5 = Always) with visual images of fluid-filled cups representing the range of responses. Respondents also identified areas that they might want to work on with their health care providers. Figure 1 presents examples of physical well-being items included in the 42-item bank of QoL items.

In order to assess the psychometric properties of a HRQoL measure generated from these 42 items, 224 adults with intellectual and developmental disabilities were recruited for this second phase. Exploratory Factor Analysis (EFA) followed by Unrestricted Factor Analysis (UFA) (Ferrando & Lorenzo-Seva, 2000; Lorenzo-Seva & Ferrando, 2020) was used to determine which items and factors best reflected our theoretical premise that HRQoL is a subset of the larger QoL domain, the content of which specifically addresses health domains.

2 | METHODS

2.1 | Participants

A convenience sample of 224 volunteers was recruited from community-based events, service settings, group homes and provider clinics located in Utah and Colorado. Participants who met the inclusion criteria were English-speaking, ages 18 and over, with intellectual and developmental disabilities (IDD) requiring mild to moderate support for success.

Since the service providers from whom we recruited participants had already established eligibility for services using IDD diagnostic criteria, the research team did not administer cognitive or adaptive assessments critical to a formal IDD diagnosis. Front-line service providers familiar with the participants identified the level of support needed for the participant to successfully work towards goals and complete daily tasks. These levels of support were based on the *Instrument for the Classification and Assessment of Support Needs (I-CAN)* (Arnold et al., 2014). *Mild level of support* was defined as accessing natural supports that would be available to all people in the community along with occasional supervision, support or mentoring from another person that occurs once or up to a few times daily. *Moderate level of support* was defined as several hours of daily direct support from another person in addition to accessing natural community supports. Informed consent was obtained per University of Utah Institutional Review Board (IRB) approved protocol.

2.2 | Assessment of acquiescence bias

Acquiescence bias is the tendency for respondents to respond positively to questions regardless of content, often based on their desire to please the interviewer (Clark, et al., 2017; Finlay &




		
P4. How often do you feel tired?	<input type="radio"/> Never <input type="radio"/> Rarely <input type="radio"/> Sometimes <input type="radio"/> Most of the time <input type="radio"/> Always	
		
P5. Would you say you are a healthy person?	<input type="radio"/> Never <input type="radio"/> Rarely <input type="radio"/> Sometimes <input type="radio"/> Most of the time <input type="radio"/> Always	
		
P6. How often do you exercise?	<input type="radio"/> Never <input type="radio"/> Rarely <input type="radio"/> Sometimes <input type="radio"/> Most of the time <input type="radio"/> Always	
We just talked about things that make you feel healthier. Please check the boxes for the areas you would like to work on.	Getting better sleep	<input type="checkbox"/>
	Being healthy enough to do things you like to do	<input type="checkbox"/>
	Getting out in the community	<input type="checkbox"/>
	Feeling tired	<input type="checkbox"/>
	Being a healthy person	<input type="checkbox"/>
	Exercising	<input type="checkbox"/>
	None of these	<input type="checkbox"/>

FIGURE 1 Example of Physical Well-Being items from the 42-items assessed.

Lyons, 2001, 2002). It is important to evaluate this phenomenon when interviewing adults with intellectual and developmental disabilities since lower cognitive ability is significantly associated with greater acquiescence bias (Lechner & Rammstedt, 2015).

Following the format suggested by Cummins (1997), we asked the respondents four acquiescence questions, two of which required a 'no' answer (*Do you make all of your own clothes and shoes?* and *Can you drive a car to the moon?*). In order for their data to be retained in the analyses, the respondents needed to answer 'no' to both questions. The remaining two questions (*Do you like ice cream?* and *Can you choose who lives next door to you?*) could be answered 'yes' or 'no'.

Of the 224 eligible respondents who completed the 42 items, 37 (16.5%) did not pass the two required acquiescence questions leaving 187 persons potentially eligible for the EFA analysis (Figure 2). The 37 excluded persons were more likely to require moderate support related to IDD ($\chi^2_1 = 9.53$, Std. Res. = 2.4) and ≤ 8 th grade education ($\chi^2_2 = 4.31$, $p = 0.04$, Std. Res. = 1.9).

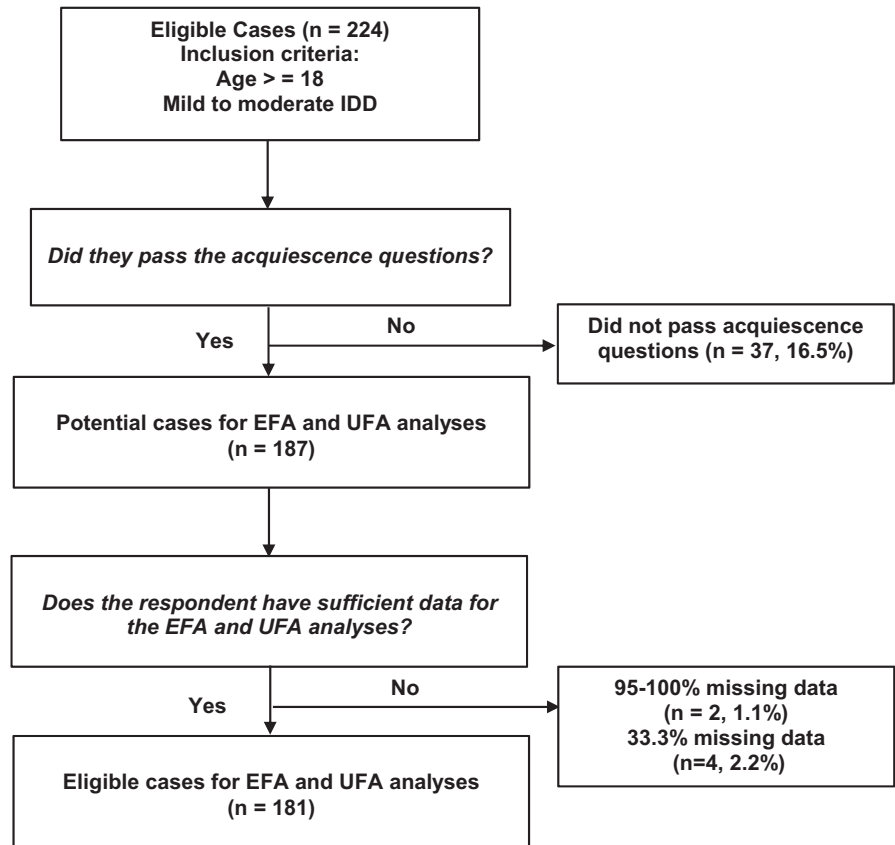
2.3 | Instruments

The respondents initially completed the IRB consent/assent forms, a short demographic questionnaire, and the acquiescence questions. The 42-item measure was completed both initially and approximately 5–10 minutes following the first completion. Agency personnel completed a brief form regarding the respondent's need for support relative to his/her disability and the extent to which they aided the participants in completing the measure. Participants received \$10 gift cards for completing the questionnaires.

2.4 | Procedures

Participants completed the study measures at agency sites, community venues, or, in rare circumstances, at their places of residence. Data collection was completed either through paper-pencil questionnaires or via laptop computer and overseen by persons trained in protocol administration.

FIGURE 2 Flow diagram outlining eligibility assessment.



2.5 | Data entry and analysis

Data were entered into the Research Electronic Data Capture (REDCap) (Harris et al., 2009) and subsequently downloaded into IBM SPSS v. 26 (SPSS, 2018) for data analysis. A multi-step approach to conducting EFA (Lorenzo-Seva & Ferrando, 2020; Norris & Lecavalier, 2010; Pett et al., 2003) was used to assess the psychometric properties of the HRQoL-IDD measure generated from the 42 items.

2.5.1 | Missing data analysis

Missing Values Analysis (MVA) was used to evaluate the patterns of missingness for the 42 items and to assess whether the data were missing at random (MAR) (Graham, 2009, 2012; Lorenzo-Seva & Van Ginkel, 2016; Schafer & Graham, 2002). Two of the 187 potential respondents had more than 95% of their data missing from the 42 items and were excluded from further analyses. Four persons had missing data for the same 14 items located at the end of the 42-item measure. Because these data were missing not at random (MNAR) (possibly owing to data collection error or respondent fatigue), these 4 respondents were also excluded, leaving a final sample of 181 participants (Figure 2).

While 159 (87.8%) of the 181 respondents had complete data, 22 respondents (12.2%) had at least one item missing. Ten of the 42 items (23.8%) had complete data. The frequency of missing values for the remaining 32 items ranged from 1 (18 items, 42.9%) to 4 (1 item, 2.4%): *How many friends do you have?*. The distribution of these

missing values appeared to be MAR (Little's MCAR $\chi^2_{834} = 872.30$. The Expectation and Maximization (EM) algorithm was used to impute missing values for the 22 persons (Graham, 2009, 2012).

2.5.2 | Exploratory factor analyses (EFA)

Because the bank of 42 QoL items had not been previously evaluated psychometrically, we began our initial examination using Exploratory Factor Analysis (EFA). Principal axis factoring (PAF) (Oblimin rotation) and the factor pattern matrix were used initially to determine model fit. A Kaiser-Meyer-Olkin (KMO) of 0.80 and a significant ($p < 0.001$) Bartlett's Test of Sphericity indicated that the sample size ($n = 181$) was adequate for the initial EFA. Items were considered for deletion if their correlations with other items within a potential factor were either too high ($> |0.80|$) or too low ($< |0.20|$) or the items' factor loadings were greater than $|0.35|$ on more than one factor. All items loading on a factor needed to make intuitive sense. Following removal of an item, a new EFA model was generated to determine its theoretical and statistical fit.

2.5.3 | Refining the structure

Although the original 42-item QoL assessment was projected to have 8 potential subscales (Clark, et al., 2017), the initial EFA

analysis revealed that many items had high loadings (> 0.35) on multiple factors. Parallel Analysis (Baglin, 2014; Timmerman & Lorenzo-Seva, 2011) for the 42-item data set identified 4 factors, implying the need for refining the factor structure. Using our criteria for removal, we iteratively removed items that either loaded poorly or cross-loaded on multiple factors. This resulted in a 4-factor solution containing 16 items that reflected HRQoL, a subset of the larger QoL construct.

2.5.4 | The polychoric correlation matrix and unrestricted factor analysis (UFA)

Traditionally, EFA analyses are based on the Pearson correlation matrix which assumes that the data are at least interval level of measurement and normally distributed. Since persons with intellectual and developmental disabilities tend to report their perceived QoL very positively, the distributions for the 16 ordinal level 5-point Likert scale items demonstrated significant kurtosis ($p < 0.001$). Therefore, we re-assessed the viability of this 16-item EFA solution using the polychoric correlation matrix generated in the computer program FACTOR (Baglin, 2014; Ferrando & Lorenzo-Seva, 2017; Lorenzo-Seva & Ferrando, 2006, 2013). The polychoric correlation is appropriate with ordinal level data that show significant skewness or kurtosis (Timmerman & Lorenzo-Seva, 2011). We also evaluated the entire set of 42 QoL items using the polychoric correlation matrix, but the solution failed to converge.

Unrestricted Factor Analysis (UFA) (Ferrando & Lorenzo-Seva, 2000; Lorenzo-Seva & Ferrando, 2020) is an approach available in FACTOR that is conceptually situated between EFA and the more restrictive Confirmatory Factor Analysis (CFA). We used the polychoric correlation matrix with UFA, including the Robust Diagonally Weighted Least Squares (RDWLS) solution for factor extraction and Robust Promin oblique factor rotation to achieve factor simplicity (Lorenzo-Seva, 2003; Lorenzo-Seva & Ferrando, 2019). UFA provides goodness-of-fit statistics unavailable in traditional EFA, for example Root Mean Square Error of Approximation (RMSEA) and various goodness-of-fit indices, for example the Adjusted Goodness-of-Fit Index (AGFI).

2.5.5 | Scale readability

Following recommendations to assess readability using multiple programs (Perez et al., 2017), the 16-item HRQoL-IDD was evaluated using the Flesch-Kincaid Reading Ease statistic (Word, 2019) and two statistics offered by Readability Studio 2019: the Harris-Jacobsen Wide Range Formula and the New Dale-Chall readability statistics (OleanderSoftware, 2019). These statistics were selected because their identified grade levels reflected the potential skills of persons with intellectual and developmental disabilities requiring mild to moderate daily support.

2.5.6 | Internal consistency reliability and generalizability theory analyses

Because of the non-normal distributions of the 16 ordinal level HRQoL-IDD items, internal consistency reliability was first assessed using McDonald's coefficient Omega (McDonald, 1999; Viladrich et al., 2017). Coefficients ≥ 0.60 were acceptable.

Next, Generalizability theory (G-theory) analyses were undertaken within the SPSS 'Matrix-End Matrix' environment (Mushquash & O'Connor, 2006) to assess the size of the variance components associated with potential sources of measurement error (the HRQoL items, the two occasions and their interactions) (Brennan, 2001; Vispoel et al., 2018a, 2018b). G-coefficients evaluated the internal consistency reliability of the subscales and total scale across the two occasions of measurement.

Typically, assessments of test-retest reliability are undertaken two or more weeks apart under conditions similar to those in which the data were initially collected. Because it was impossible to place the community-based participants in similar situations several weeks following their initial participation (e.g. in a camp or health fair), we elected to assess the stability of the participants' responses a second time in the same session. The goal was to determine whether the participants could respond consistently to the items presented. Since missing values are not permitted in G-theory analyses, only those respondents who completed both occasions of measurement ($n = 174$) were included in this analysis.

3 | RESULTS

3.1 | Participants

Table 1 summarizes the demographic characteristics of 181 eligible participants (96 males, 84 females and 1 transgender). Participants ranged in age from 18 to 78 years ($M = 36.7$, $SD = 13.5$), 85.1% were Caucasian, 11.4% being Hispanic. The majority of the respondents had at least a high school education (91.0%). While 43.1% of the 181 respondents were not employed, 49.7% were employed part-time, and 7.2% were employed full-time outside the home. Regarding level of support needed, 77.3% of respondents were reported as needing intermittent or mild support and 22.7% required moderate support related to their intellectual and developmental disabilities. The demographic characteristics of the study sample reflected the Utah and Colorado population of adults with intellectual and developmental disabilities with whom the participating agencies worked.

3.2 | Assistance needed to complete the HRQoL-IDD

Administrators completed information regarding assistance needed for 127 participants. Eighty-two (64.6%) of the 127 respondents

TABLE 1 Demographic characteristics of the participants (n = 181)

Demographic Characteristics	n ^a	%
Gender (n = 181)		
Male	96	53
Female	84	46.4
Transgender	1	0.6
Ethnicity (n = 176)		
Hispanic	20	11.4
Non-Hispanic	156	88.6
Race (n = 175)		
Caucasian	149	85.1
African American	7	4
African American (5)		
African American/Caucasian (1)		
African American/Native American (1)		
Native American	11	6.3
Native American (2)		
Native American/Caucasian (9)		
Pacific Islander		
Pacific Islander/Caucasian (1)	1	0.6
Asian	1	0.6
Asian/Caucasian (1)		
Other (unspecified)	6	3.4
Education (n = 177)		
≤8 th Grade	6	3.4
Some high school	10	5.6
High school graduate	126	71.2
Some college/technical school/college degree	35	19.8
Employment (n = 181)		
Not employed	78	43.1
Employed part-time	90	49.7
Employed full-time	13	7.2
Disability check (n = 173)		
Receives disability	142	82.1
Does not receive disability	31	17.9
Living arrangements (n = 178)		
Lives alone	28	15.7
Lives with others	150	84.3
Family members	57	32
Roommate	29	16.3
Group home, living facility, host home, foster care	27	15.2
Husband/wife	5	2.8
Girlfriend/boyfriend	3	1.7
Other (unspecified)	29	16.3

(Continues)

Table 1 (Continued)

Demographic Characteristics	n ^a	%
Functional ability (n = 172)		
Mild support related to IDD	133	77.3
Moderate support related to IDD	39	22.7
Age (n = 176)		
	Mean (SD)	Range
	36.7 (13.5)	18–78

^aNot all total n's add up to 181 owing to missing data.

completed the 42 items without assistance (Table 2). When needed, the main types of assistance involved reading the items to the respondent (58.0%) and helping the person to maintain focus (33.3%). Other assistance included marking the form given verbal input from the participants (4.3%), item clarification (2.9%) and use of sign language (1.5%). Persons who required moderate daily support were more likely to need help completing the 42 items ($\chi^2_1 = 27.8$, $p < .001$, Std. Res. = 3.8).

3.3 | Results of the UFA analysis

The determinant of the polychoric matrix (.001), Bartlett's test = 1071.7 (df = 120, $p < 0.0001$), the KMO test (0.81), RMSEA (.000, 95% CI: 0.00 – 0.02) and AGFI (1.00) indicated that the 4-factor solution generated from the polychoric correlation matrix had an excellent model fit (Table 3). The 4 subscales containing 16 items included *Social Well-Being (SWB)* (5 items), *Healthy Decision-Making (HD)* (2 items), *Emotional Well-Being (EWB)* (4 items) and *Functional Well-Being (FWB)* (5 items). For the SWB, HD and FWB subscales, higher scores reflected more positive HRQoL. The EWB items were reverse-coded to reflect a similar direction. Since the subscales contained different numbers of items, subscale means were generated.

The results indicated that the 181 respondents viewed their HRQoL positively. They reported themselves to be healthy, able to go to the doctor when they needed to, had someone to talk to when feeling sad, were able to make choices regarding eating, and, in general, were happy with their lives. Their lowest HRQoL scores were in the areas of frequency of exercise, feelings of anger, being lonely, feeling tired and anxious (Table 3).

All HRQoL items loaded $\geq |.35|$ on only one factor (Table 3). The eigenvalues ranged from 5.3 to 1.1 and explained 62.8% of the variance among the items (Table 4). The four subscales had acceptable internal consistency reliability with Omega coefficients ranging from 0.73 (*Functional Well-Being*) to 0.83 (*Healthy Decision-Making*). Inter-scale correlations were low to moderate (range: 0.30 to 0.66).

3.4 | Results of the G-theory analyses

Table 5 presents the G-theory analyses of the sources of potential measurement error and G-coefficients for the HRQoL subscales and

total scale. The variance component for *participant* represents the estimated variation in scores on the 16-item HRQoL-IDD when the score for each respondent represents his/her mean score across all items and the two occasions of measurement. Larger values for the *participant* variance component indicate systematic individual differences among the respondents. The magnitude of variance components associated with item and occasion and their interaction reveal their importance as potential sources of error (Mushquash & O'Connor, 2006).

The moderate-sized variance components for *participant* (30.5%, 48.6% and 34.6%) for the three subscales, SWB, HD and EWB, indicate that, across both occasions, the respondents differed substantially from one another with regard to their subscale scores. These differences were less evident for the FWB scale (22.6%) and the overall scale (13.5%).

The variance component for *item* indicates how well the items within the subscales and total scale fit together. Lower percentages indicate greater internal consistency in a given subscale. The low percentage variances (1.7 – 4.6%) for the HD, SWB and EWB subscales demonstrate that, across both occasions, these subscales showed strong internal consistency. This is reflected in their G-coefficients (0.756, 0.756 and 0.723) (Table 5). Internal consistency was lower for the FWB subscale (11.1%) as evidenced by its G-coefficient (0.661). The larger *item* variance component for the total HRQoL scale (20.6%) suggests that HRQoL may not be a univariate construct but one whose subscales reflect different aspects of HRQoL. Nevertheless, the internal consistency of the total scale was strong (G-coefficient = 0.790).

The variance component for *participant*item interaction (p*i)* assesses whether the rank-ordering of scores for the participants differed across the items within the four subscales and total scale given the two occasions of measurement. Higher percentages indicate more differentiation among the participants. Except for the HD subscale which had two items, the variance components for *participant*item interaction* demonstrated strong participant

differentiation (20.5%–42.0%). More than 50% of the variance in scores on both the subscales and total HRQoL scale was a function of the *participant (p)* and the participant interacting with items (*p*i*) (Table 5).

The variance components accounted by *occasion (o)* (0.0% - 0.3%) and its interaction with *item (i*o)* (0.0% - 0.1%) were consistently negligible. The variance component for *occasion*participant interaction* was a bit stronger (0.8% - 9.0%) but still minimal. This suggests that the respondents were consistent in their responses to the items when the two occasions were compared.

The large variance component for the three-way interaction of *participant*item*occasion (22.2%–37.7%)* represents unexplained variance after having considered *participant, item, occasion* and their interactions. This component could be influenced by factors not controlled for in the research design, for example the varied data collection situations.

The G-coefficients for the HRQoL subscales and total scale represent the reliabilities of the subscales and the 16-item HRQoL-IDD when considering the two occasions. These reliabilities ranged from 0.661 (FWB) to 0.790 (Total scale), slightly more conservative than the Omega coefficients (0.73 to 0.80) which were based only on the first occasion of measurement.

3.5 | Readability statistics

Readability of the 16-item HRQoL-IDD measure was appropriate for adults with intellectual and developmental disabilities. Its Flesch-Kincaid ease of reading score was 93 out of 100 (higher scores indicate greater ease of reading). Both the New Dale-Chall and Harris Jacobsen wide range tests concluded that the scale items were appropriate for readers in the 2nd grade (ages 7–8). Five unfamiliar words identified by the Harris Jacobsen formula included 'community', 'exercise', 'tired', 'anxious' and 'lonely'.

TABLE 2 Assistance needed to complete the HRQoL ($n = 131$)

Respondent needed assistance?	<i>n</i>	%
No assistance needed	82	62.6
Completed HRQoL without administrator present	10	7.6
Administrator present but completed on own	72	55
Assistance needed	49	37.4
Types of assistance ($n = 67$)^a	<i>n</i>	%
Sat next to respondent helped to focus	22	32.8
Read the HRQoL to respondent	39	58.2
Completed form for person	3	4.5
Item clarification	2	3.0
Used sign language	1	1.5
Total	67	100.0

^aMore than one type of assistance could apply.

TABLE 3 Factor Pattern Matrix for the 16 item HRQoL-IDD (n = 181)

Subscales and Items			M (f)	SWB	HD	EWB	FWB
				Factor loadings			
Social Well-Being (SWB) (k = 5)							
SW1.	Do you spend time with your friends?	3.8 (1.2)	0.78	-0.18	0.03	-0.09	
SW2.	When you are feeling sad, do you have someone to talk to?	4.1 (1.1)	0.98	-0.05	-0.11	-0.20	
SW3.	How often do you get out in the community to do things like eating out or going shopping?	3.9 (1.1)	0.58	-0.04	-0.20	0.32	
SW4.	Are you able to go to the doctor when you need to?	4.4 (0.9)	0.39	0.14	0.18	0.07	
SW5.	Are you happy with your life?	4.3 (0.9)	0.66	0.02	0.14	0.09	
	Total SWB:	4.1 (0.7)					
Healthy Decision-making (HD) (k = 2)							
HD1.	Do you get to choose what to eat?	4.3 (1.0)	0.07	0.78	0.00	0.11	
HD2.	Do you get to choose how much to eat?	4.0 (1.2)	0.06	0.87	0.01	-0.10	
	Total HD:	4.1 (1.0)					
Emotional Well-Being (EWB) (k = 4)							
EW1.	How often do you feel worried or anxious? (r) ^a	2.7 (1.1)	-0.01	-0.013	0.65	0.08	
EW2.	How often do you feel lonely? (r)	3.2 (1.2)	0.19	0.04	0.62	-0.13	
EW3.	How often do you get really mad? (r)	3.1 (1.0)	-0.02	0.03	0.77	-0.13	
EW4.	How often do you feel tired? (r)	2.7 (1.1)	-0.25	0.07	0.65	0.22	
	Total EWB:	2.9 (0.8)					
Functional Well-Being (FWB) (k = 5)							
FW1.	Do you sleep well at night?	3.9 (1.1)	0.28	-0.16	0.21	0.37	
FW2.	Are you healthy enough to get out in your community?	4.5 (0.8)	0.07	0.11	-0.05	0.56	
FW3.	Would you say you are a healthy person?	4.2 (1.0)	-0.10	-0.05	-0.06	0.96	
FW4.	How often do you exercise?	3.5 (1.3)	0.06	-0.08	0.07	0.52	
FW5.	Do you have enough money to buy what you need?	4.1 (1.0)	0.25	0.21	-0.03	0.38	
	Total FWB:	4.0 (0.7)					

Note:: Extraction Method: Unrestricted Factor Analysis; Dispersion matrix: Polychoric correlations; Rotation Method: Robust Promin. FWB, Functional Well-Being; EWB, Emotional Well-Being; HD, Healthy Decision-making. Range for FWB (FW1 – FW3, FW5), HD, & SWB items: 1 = Never to 5 = Always; FW4: 1 = Never to 5 = Everyday; ^a(r) = reverse-coded; Recoded Range for EWB items: 1 = Always to 5 = Never. The bolded factor loadings in the Factor Pattern Matrix indicate the subscale on which a given item loaded.

4 | DISCUSSION

The aim of this study was to generate and determine the psychometric properties of a theory-driven self-report measure of HRQoL for adults with intellectual and developmental disabilities. The resulting 16 HRQoL-IDD items and their subscales reflect the multidimensional construct of HRQoL identified by Shumaker and Naughton (1995) and Rosenquist et al. (2006). Four subscales (and total scale) with strong internal consistency were identified: a person's subjective evaluation of his/her social, emotional and functional well-being and healthy decision-making.

While the participants were consistent in their responses across the two occasions, they differed substantially from each other with

regard to their scores. The HRQoL-IDD also demonstrated appropriate readability and independent completion by the majority of respondents. For those needing assistance to complete the measure, the primary mode of assistance was reading the items to the participant.

4.1 | Implications for practice and policy

With the introduction of new pharmacologic, behavioural and other therapeutic interventions for people with intellectual and developmental disabilities, readily available and succinct measures of self-reported HRQoL are essential for determining which interventions

contribute to positive HRQoL. Until now, researchers have lamented the absence of such measures and have defaulted to pragmatic substitutes without success (Ramerman et al. 2018). Using 'hand-me down' measures developed and tested with other populations (e.g. adults without disability) raises serious ethical and scientific issues (Clark et al. 2017; Driessnack & Furukawa, 2012). Establishing scientific evidence to guide practice decisions for the benefit of people with intellectual and developmental disabilities requires validated measures that are accessible and specific to the experience of this marginalized and heterogeneous population. The 16-item HRQoL-IDD is a promising measure to add to the repertoire.

The HRQoL-IDD offers advantages to researchers, clinicians, and people with intellectual and developmental disabilities. Researchers and clinicians are likely to appreciate the utility of a succinct 16-item HRQoL measure that is readily available at no cost (<https://hrqolidd.com>). Compared to measures with more items, the 16-item HRQoL-IDD reduces subject burden which may enhance completion rates. The 26 excluded items, which potentially address QoL, are available on our website, should the clinician/researcher desire to include them in future QoL studies.

TABLE 4 HRQoL-IDD eigenvalues, % of variance, inter-scale correlations, and McDonald's omega

	Total	SWB	HD	EWB	FWB
Eigenvalues		5.3	2.1	1.5	1.1
% of Variance	62.8	33.2	13.0	9.6	7.0
Inter-scale correlations (Omega on diagonal) ^a					
SWB		(0.80)			
HD		0.32*	(0.83)		
EWB		0.43**	0.30*	(0.75)	
FWB		0.66**	0.38**	0.32*	(0.73)

Note.: *: $p < 0.05$. **: $p < 0.01$.

^aOmega instead of Cronbach's alpha was used to assess internal consistency of these ordinal 5-point Likert scales.

TABLE 5 Generalizability (G-Theory) assessment of sources of variance and reliability estimates: HRQoL-IDD subscales and total scale ($n = 174$)

Sources of Variance	Social Well-Being (SWB)		Healthy Decision-making (HD)		Emotional Well-Being (EWB)		Functional Well-Being (FWB)		Total Scale (HRQoL-IDD)	
	Estimate	%	Estimate	%	Estimate	%	Estimate	%	Estimate	%
Number of items	5		2		4		5		16	
Participant (p)	0.359	30.5	0.669	48.6	0.485	34.6	0.282	22.6	0.204	13.5
Item (i)	0.054	4.6	0.024	1.7	0.059	4.2	0.139	11.1	0.312	20.6
Occasion (o)	0.003	0.2	0.000	0.0	0.004	0.3	0.000	0.0	0.000	0.0
Participant*item (p*i)	0.387	32.8	0.057	4.1	0.288	20.5	0.524	42.0	0.565	37.3
Participant*Occasion (p*o)	0.057	4.8	0.124	9.0	0.037	2.6	0.025	2.0	0.012	0.8
Item*Occasion (i*o)	0.000	0.0	0.000	0.0	0.000	0.0	0.000	0.0	0.001	0.1
Participant*Item*Occasion (p*i*o)	0.318	27.0	0.504	36.6	0.529	37.7	0.277	22.2	0.420	27.7
G-Theory reliability estimate	0.723		0.756		0.756		0.661		0.790	

An advantage of the 16-item HRQoL-IDD is the holistic, theory-based conceptualization of health upon which the measure was structured. Across IDD diagnoses and spanning different levels of impairment, the HRQoL-IDD probes respondents' functional well-being, emotional well-being, social well-being and healthy decision-making. These factors align with noted health disparities in this group and map key areas of comprehensive health experience beyond disease or impairment (CDC 2016).

Study results indicated that overall and item-specific HRQoL scores were clustered in the higher ranges, suggesting potential ceiling effects. These relatively high HRQoL scores align with the observed 'disability paradox' (Albrecht & Devlieger, 1999; Drum et al., 2008), namely, self-report of good or excellent QoL among adults with disability who may be rated to have lower QoL from an external vantage point (Hays et al., 2002; Nord, 2001; Skotko et al., 2011). The self-reported ratings of HRQoL supplied by study participants may be viewed as a valid experience, albeit non-normally distributed.

4.2 | Study limitations

Study participants were recruited from a variety of community-based services for adults with intellectual and developmental disabilities (e.g. health fairs, day camps, clinics and group homes). Because we relied upon providers' assessments of their clients' need for support, we did not administer formal cognitive or adaptive IDD assessments. A goal for future research would be to evaluate the sensitivity of the HRQoL-IDD measure in more controlled settings in which functional ability and level of support could be readily verified.

Given the impossibility of repeating the data collection protocol under similar circumstances several weeks later, we reduced the interval between successive HRQoL-IDD administrations and assessed the short-term stability of participant responses. We recommend assessing test-retest reliability of the 16 HRQoL items in

future studies in which there is greater control over the data collection environment.

The HRQoL-IDD readability statistics indicated the measure is suitable for adults with low-literacy. Persons with more limited literacy may require someone to read the items and orient the participant to the response format. In this study, the persons who assisted the participant by reading or marking responses could easily view the results. While these 'helpers' were not related to the participants and were instructed not to comment on item responses, their mere presence as a source of potential bias is unknown.

The factor structure of the HRQoL-IDD was determined after excluding individuals who were unable to successfully complete the acquiescence screening items. Since acquiescence is a red flag for validity, an important future contribution would be the development of approaches that enhance the validity of responses given by persons with intellectual and developmental disabilities who tend to offer acquiescent responses. Supported decision-making (Shogren et al., 2018) in scale completion may provide a middle ground between independent completion and proxy reports.

4.3 | Recommendations

The HD subscale features two healthy decision-making items addressing food intake. While the items' dietary content resonated with the daily experiences of participants, other items with a healthy decision-making focus did not emerge from the factor analyses. Perhaps obesogenic environments and personal risk factors may heighten the value of choices related to food. We recommend additional items reflective of this domain be developed for healthy decision-making in preventive care (e.g. vaccinations and health screenings) and safety (e.g. seatbelt and helmet use).

Our experiences in developing the 16-item HRQoL-IDD underscore the importance of inductive measure development and collaboration with people with intellectual and developmental disabilities at every step in the process, from concept specification, to item refinement, and outcome participation. The application of universal design principles in digital display and administration of self-administered HRQoL scales is critical. For example, branching logic algorithms may be employed to reduce the multiple-choice response format into a series of more discrete choices. Administering a digitized version of the measure via tablet with adaptive touch-screen technology and verbal cues could facilitate participation of users with visual and motor impairments, result in faster response times and may increase access for persons with more severe challenges.

Development of a reliable and valid instrument is an ongoing process. In this study, the assessment of the HRQoL-IDD focused on conceptual clarity of the HRQoL focus, internal consistency, response stability and face validity of the measure. Additional validity assessments need to be undertaken in the future. Key to any 'good' measure is the extent to which it is 'useful' not only to researchers and clinicians but also to persons with intellectual and

developmental disabilities. By ensuring participation in research and healthcare using technology-enhanced and psychometrically-sound measures, person-centered planning is possible. At both the individual and population level, better measurement is a step towards greater health equity.

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