**Validating a new quality of life measure for adults with intellectual disabilities: the Mini-MANS-LD**

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**An initial validation of a new quality of life measure for adults with intellectual disability: the Mini-MANS-LD**

**Abstract**

There is an appropriate increasing focus on the need to ensure the voices of people with intellectual disability are captured as part of assessing individuals’ quality of life, however there remains a lack of a consensus on ways to achieve this. This article describes the development of a self-report measure of quality of life for people with intellectual disability, the ‘Mini-MANS-LD’, based on the concepts of Maslow’s hierarchy of needs. Following use with 33 individuals with intellectual disability, the Mini-MANS-LD was found to have acceptable psychometric properties, including moderate congruent validity and acceptable internal consistency. Administrators’ feedback suggested good acceptability and feasibility, and that the measure was relatively quick to administer, easy to use, and acceptable to service users. Despite a small sample size, this initial study suggests the Mini-MANS-LD may present a conceptually relevant, feasible and acceptable self-report measure of quality of life for people with intellectual disability.

**Keywords**

People with intellectual / learning disability, quality of life, outcome measures.

**Introduction**

Valuing People (Department of Health; DoH, 2001), and the subsequent policy update, Valuing People Now (DoH, 2009), firmly established a human-rights based approach to service provision for people with intellectual disability. People with intellectual disability are entitled to be treated with dignity and respect, and to be afforded the same aspirations and life chances as other citizens (DoH, 2001). The range of health and social care support provided should be focused on giving people with intellectual disability the opportunity to enjoy a similar quality of life and life happiness to those without.

Within the general population, there has been increasing interest in studying quality of life, life satisfaction and happiness in the psychological literature, moving away from a focus on investigating psychopathology (Seligman and Csikszentmihalyi, 2000). Diener and Seligman (2002) suggested that one of the key factors that emerged in people who were described as consistently very happy was that they had positive and fulfilling social relationships. There is no reason to expect that the factors that make people in the general population very happy and satisfied with their lives would be different for people with intellectual disability, but there has been much less direct research. Haigh and colleagues (2013) co-facilitated an inclusive research project with people with intellectual disability, using a qualitative methodology to attempt to find out what makes people with intellectual disability happy and satisfied with their lives. Factors identified included having choice and independence, access to activities, as well as positive relationships with others, and positive support from others. What is striking about these findings are the similarities with studies of factors that are important for happiness in the general population. Haigh et al. (2013) also reflect on how these important factors for happiness also mirror O’Brien’s (1989) ‘five accomplishments’. These ‘five accomplishments’ represent what are considered to be vital aspects of human experience, namely the rights of individuals to community presence, valued relationships with others, to make one’s own choices, to learn new skills and participate in meaningful activities, and the right to be valued and respected by others. The ‘five accomplishments’ are also very much linked with the principles of normalisation, social role valorisation and empowerment (Wolfensberger, 1972), which have guided the ethos of service provision for people with intellectual disability over the past 40 years.

The World Health Organisation (1998) defined ‘quality of life’ as more than simply ‘absence of pathology’, but “as an individual’s perception of their position in life in the context of the culture and value systems in which they live” (p. 3). This “broad ranging concept” (WHO, 1998, p. 3) therefore is not simply captured by narrower terms such as ‘life satisfaction’, ‘health related quality of life’ or ‘well-being’. Various potential domains of quality of life have been identified in the literature, with Simoes, Santos and Claes (2015) suggesting that arguably “the number of domains is less important than the acknowledgment that any proposed structure must recognize the need for a multi-element framework and the idea that domains must represent, in the aggregate, the complete quality of life construct” (p. 172, Simoes et al., 2015). Representing the work of the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSID) when attempting to further conceptualise the concept of quality of life for individuals with intellectual disability, Schalock et al. (2002), describe the core domains that affect quality of life for both people with and without intellectual disability as physical, psychological, personal beliefs, social relationships, and environmental factors. It has been reported that measuring quality of life should incorporate both subjective and objective means. The relationship however between objective (e.g. economic status) and subjective measures is modest, and in their core principles for conceptualising quality of life, Schalock et al. (2002) purport that that it “is primarily the perception of the individual that reflects the quality of life he/she experiences” (p. 460).

With the importance of quality of life as a construct within intellectual disability evolving since the 1980s (Verdugo et al. 2005), a number of measures have been developed (Townsend-White, Pham and Vassos, 2012). To date there has been a focus in intellectual disability services on measuring objective and external conditions (such as employment and environment) alongside self-reported quality of life, although as aforementioned, relationship between the two may be limited (Schalock et al. 2002). Proxy measurement (i.e. measurement by another person on behalf of a person with intellectual disability) may be useful when people are unable to speak up for themselves at all. However, both objective and proxy measures may not capture important aspects of an individual’s own perception of their life quality, and their subjective quality of life. Schalock et al. (2002) state that “proxy measurement is not valid as an indication of a person’s own perception of his or her life” (p. 462). In intellectual disability services, emphasis is placed on the importance of enabling service users to speak up directly about their own lives, rather than relying solely on external and proxy measures. However, despite the helpful core principles in quality of life measurement provided by the work of the IASSID group (Schalock et al, 2002), there is still no agreement on a ‘gold standard’ measure of self-reported quality of life for people with intellectual disability (Townsend-White et al., 2012).

Relatively recently, the British Psychological Society, Division of Clinical Psychology Faculty for People with Intellectual Disabilities (2012) conducted a review of available measures of outcomes of services for people with behaviour that presents challenges. This recommended the use of two service user rated quality of life measures: the Maslow Assessment of Needs Scale-Learning Disabilities (MANS-LD; Skirrow and Perry, 2009) and the Adapted World Health Organisation Quality of Life Measure (WHOQOL-8; Schmidt et al. 2006). The MANS-LD (Skirrow and Perry, 2009) is a measure that attempts to capture aspects of quality of life for people with intellectual disability based on Maslow’s (1943) seminal hierarchy of needs. Items reflect the five motivational needs, namely basic physiological, safety, social (love and belonging), esteem (feeling of accomplishment) and self-actualisation (achieving one’s full potential). The MANS-LD therefore applies this important psychological theory directly to people with intellectual disability, to measure whether services are demonstrating socially valid outcomes for the individuals they serve. Whist the British Psychological Society (2012) report specifically addressed measures for use with adults with intellectual disability who also exhibit behaviours challenging to services, it concluded that these two measures may also be useful for broader service level outcome reporting. For example, although psychological therapies interventions have largely focused on outcomes at a symptom level, there is some evidence that changes made during psychological interventions may also have an impact on broader quality of life factors, such as community engagement (e.g. Skelly, 2016).

Within the National Health Service (NHS) in the UK, targets are being set for all NHS Trust services to develop and implement relevant patient-reported outcome measures (PROMS) to measure clinical effectiveness. There is a lack of accessible patient-reported (i.e. self-report) outcome measures available for people who may find standardised measures inaccessible, including people with intellectual disability. It is necessary to ensure that measures are developed that meet the needs of this population. As outlined above, it seems essential that this is taken as an opportunity to empower service users to give direct feedback on outcomes, including how they rate their own quality of life.

This current study aimed to further develop a self-report measure of quality of life that would be acceptable, accessible and valuable in measuring the self-perceived quality of life of people with intellectual disability.

**Method**

*Piloting and involvement of experts by experience*

Prior to the current study, a pilot study had been conducted (Raczka et al. 2014), to investigate the use of routine outcome measures with people with intellectual disability. Within this study, the self-report measures recommended by the British Psychological Society (2012), namely the MANS-LD (Skirrow and Perry, 2009) which consists of 19 items, and the WHOQOL-8 (Schmidt et al. 2006) which consists of 8 items, were reviewed alongside another measure widely used in the NHS (but not adapted specifically for use with people with intellectual disability) the EQ-5D-Y (Willie et al., 2010), developed by the Euroqol group. This pilot study collaborated with Speech and Language Therapy and with a small group of experts by experience (peoplewith intellectual disability) to review and adapt the measures to ensure they were accessible. Accessible prompts, using Photosymbols® to illustrate content and ‘traffic light’ colour-coded ‘smiley faces’ to elucidate the response scales, were developed with input from the Speech and Language Therapists and experts by experience. Through this piloting, it emerged that a number of items within the MANS-LD and WHOQOL-8 in particular required further clarification to ensure they were clearly understood by people with intellectual disability. Additionally, the 5-point scale (e.g. *Overall do you feel your life is… Very Good, Good, OK – neither good or bad, Bad, Very Bad?)* often required a two-stage presentation; namely, an initial break-down into 3-points (e.g. *Overall do you feel your life is… Good, Bad, or just OK?*), and a subsequent further clarification to use the full scale (e.g. *If good, do you feel your life is Very Good or just Good?* Or *If bad, do you feel your life is Very Bad or just Bad?*). Furthermore, developing scripts for the items of the MANS-LD and WHOQOL-8 in this way enhanced standardisation, ensuring administrators always used the same prompts in the same way to support people with intellectual disability to give their responses.

The piloting, conducted with 18 people with mild or moderate intellectual disability, revealed that both the MANS-LD and WHOQOL-8 were somewhat lengthy and repetitive to be used as a regularly administered outcome measures. The EQ-5D-Y (with accessible prompts) appeared acceptable to service users and was quick to administer. However, with its focus only on physical health based constructs (health-related quality of life), meant that it lacked the breadth to capture all important aspects of subjective quality of life for people with intellectual disability, as conceptualised by Schalock et al.(2002). This therefore led to the development of the ‘Mini-MANS-LD’ (described in more detail below), which included the most important items of the MANS-LD together with one introductory item adapted from the WHOQOL-8. This was designed to be used in conjunction with the health-related quality of life measure, the EQ-5D-Y to, capture all the important aspects of self-reported quality of life of people with intellectual disability, and incorporating Maslow’s hierarchy of needs.

The current study describes the validation of this emergent measure, the ‘Mini-MANS-LD’.

*Ethical Review*

Ethical approval for this study was received following proportionate review from the North of Scotland National Research Ethics Service Committee of the NHS Health Research Authority. Local approvals to conduct the research within an inner London NHS service were granted.

*Measures*

Three quality of life measures were administered for the current study:

*Mini-MANS-LD.* As described above, this measure was adapted from the Maslow Assessment of Needs Scales – Learning Disabilities (MANS-LD)(Skirrow and Perry, 2009), with one item derived from the WHOQOL-8 (Schmidt et al. 2006), following a pilot development study (Raczka et al. 2014). The Mini-MANS-LD is a 9-item accessible assessment instrument to be completed with support as required. The full items and corresponding rating scale can be seen in Table 1. It uses a five-point Likert-type scale, using a pictorial as well as verbal scale. An example of an item with the pictorial scale can be seen in Figure 1.

[insert table 1 about here]

[insert figure 1 about here]

The nine items included in the Mini-MANS-LD cover factors including self-reported satisfaction with environment, safety, social relationships, esteem and self-actualisation, as well as an item of overall life satisfaction. A script for administrators was also developed, as described above, to enhance the overall standardisation of the measure by ensuring administrators followed a two-stage presentation of each item, following standardised prompts, to make the 5-point scale accessible for service users, alongside the use of the pictorial scale. For example, for item 2: *‘Do you get on well with other people you know, like friends, family and other people who support you? Yes or no?* [stage 1] *If yes, do you always get on well with them? Most of the time? Some of the time? If no, do you never get on well with them, or not very often?* [stage 2]*’*

In total, eight items adapted from the original 19 items of the MANS-LD (Skirrow and Perry, 2009) were included in the Mini-MANS-LD. These eight items broadly represent the theoretical constructs underpinning Maslow’s (1943) hierarchy of needs. Table 2 shows how the original MANS-LD items, and the subsequently chosen Mini-MANS-LD items, map onto Maslow’s hierarchy of needs. A number of items can be conceptualised as representing more than one need as described by Maslow, and so have been included in more than one domain. Each of Maslow’s needs is therefore represented by at least two items on the Mini-MANS-LD.

[insert table 2 about here]

Physiological needs are described in Maslow’s (1943) Hierarchy as basic requirements for human survival. Theoretically it is purported that if any needs are met higher on the hierarchy, such as safety needs, then basic needs must have also been met. During the initial pilot and development phase, it became clear that participants did not interpret the original MANS-LD item on physiological needs at the level of Maslow’s basic needs, but from a quality of life perspective, for example talking about healthy eating, rather than having enough food to survive. For the purposes of developing a clear and abbreviated assessment of quality of life, the decision was taken to omit the item relating to physiological needs.

Within items chosen for the Mini-MANS-LD, there is a focus on safety needs, which also seem to relate to a range of individual concerns (i.e. safety in relation to others, self and living environment) that were important to include individually within the quality of life measure. One item within the safety domain from the original MANS-LD regarding to health status (*‘I am happy with my health’)* is not included, as the Mini-MANS-LD has been developed to be used jointly with the EQ-5D (see below), which would then include additional aspects of health related quality of life.

Maslow’s other needs of social (love and belonging), self-esteem and self-actualisation are represented by two items each. In the piloting that took place prior to this study, other items within these domains were found to be repetitive or difficult to rate by a number of service users. For example, *‘I feel accepted by other people’* was particularly difficult for service users with more significant learning disabilities to answer. There was also overlap between items within these domains and indeed across other constructs, for example, ‘*I feel I am achieving what I want to’* and ‘*I feel I am being everything that I can be’.* Therefore, for the purposes of developing the Mini-MANS-LD as a brief and accessible measure, particularly for individuals who may have struggled to access a more detailed or complex measure, a reduced number of the most simplified items was chosen to represent each of these domains.

In addition, one item adapted from the WHOQOL-8 (Schmidt et al. 2006) was included as an introductory question. The WHOQOL-8 was developed as an abbreviated version of the 26-item measure, the WHOQOL-BREF (The WHOQOL Group, 1998), with two items from each of the four domains (physical, psychological, environmental, social) of the original WHOQOL-BREF. The WHOQOL-8 was found to have good internal consistency, acceptable convergent and discriminant validity (Schmidt et al. 2006), although has not been validated for use with people with intellectual disability. The item derived from the WHOQOL-8 to be included as an introductory question in the Mini-MANS-LD, ‘*Overall, [how] do you feel your life is…’* also taps into Maslow’s concept of self-actualisation, and as such provides a useful introduction to the Mini-MANS-LD quality of life items overall.

The chosen items included in the Mini-MANS-LD overall also relate well to the eight core domains of quality of life proposed by Schalock et al. (2002); namely emotional well-being (safety, stable and predictable environments, positive feedback), interpersonal relations (affiliations, affection, intimacy, friendships, interactions), material well-being (ownership, possessions, employment), personal development (education and habilitation, purposive activities, assistive technology), physical well-being (health care, mobility, wellness, nutrition), self-determination (choices, personal control, decisions, personal goals), social inclusion (natural supports, integrated environments, participation), and rights (privacy, ownership, due process, barrier-free environments). Specifically, Table 2 shows how the ultimately chosen Mini-MANS-LD items map onto seven of these eight domains. The domain not felt to be covered by the Mini-MANS-LD, namely physical well-being, is felt to be adequately addressed by EQ-5D-Y (see below) which focuses on health-related quality of life (including subjective health status and mobility), and which the Mini-MANS-LD has been developed to be used alongside. Therefore, the Mini-MANS-LD, particularly when used together with the EQ-5D-Y, is thought to represent the broad concept of quality of life, as this is defined and proposed by Schalock et al. (2002).

*EQ-5D-LD (Beta)*: This measure is developed from the EQ-5D (Power, 2003), a more specific health-related quality of life measure, originally developed by the EuroQol group and currently used extensively within the NHS. It consists of five questions related to health status using a three-point scale, plus a visual analogue scale (VAS) for people to rate their health state on the day of the assessment, from 0 (worst imaginable) to 100 (best imaginable). The EQ-5D-Y (Willie et al., 2010), is an adaptation of the EQ-5D for young people. It askes the same five questions as the EQ-5D using the same three-point scale with a visual analogue scale to measure current health state, but uses more accessible language. For example, the EQ-5D standard version item *‘I am a moderately anxious or depressed’,* is adapted for the EQ-5D-Y to the less complex, *‘I am a bit worried, sad or unhappy’.* As the constructs underpinning the items themselves do not change from the EQ-5D to the EQ-5D-Y, it was considered the EQ-5D-Y with its simpler language would be a better starting point for the development of a more accessible version for people with intellectual disability. Following a similar structure to that described for the Mini-MANS-LD above, a pictorial prompt sheet was developed to be used alongside the EQ-5D-Y, to support its accessibility for people with learning disabilities.

The EQ-5D-Y includes the visual analogue scale for respondents to rate their overall health from 0 (worst imaginable health state) to 100 (best imaginable health state). Following feedback from the pilot evaluation study, this was reduced to a ten-point rather than a 100-point scale, given the difficulties people with intellectual disability faced with rating on a 100-point scale. The 10-point visual analogue scale was developed to look like a staircase or steps, a concept that has been used successfully with adults with intellectual disability to clarify other analogue scales (e.g. Cummins and Lau, 2005).

These adaptations made to the EQ-5D-Y (excluding the visual analogue scale), to make it accessible for adults with intellectual disability, have been discussed with the measure’s developers, EuroQol. It has been agreed to call this accessible version ‘EQ-5D-LD (Beta)’ whilst additional data on its psychometric properties was collated.

*Personal Well-Being Index – Intellectual Disability (PWI-ID; Cummins and Lau, 2005)*. This is a seven-item questionnaire that assesses individuals with intellectual disability’s self-reported quality of life, to be completed with support as appropriate using a five-point Likert-type scale (with options to also use a two-point or three-point scale if the person is unable to understand the five-point scale). It is one of the only self-report quality of life measures that has a version designed specifically for people with intellectual disability. The measure asks individuals ‘How happy do you feel about…?’ then lists seven areas reflecting broad areas that are thought to make up the construct of quality of life. It was included in this study to evaluate congruent validity of the Mini-MANS-LD as it has been previously validated and reported to have acceptable internal consistency (Cronbach alpha coefficient of 0.76, McGillivray et al. 2009). Despite being a measure developed for use with individuals with intellectual disability, the PWI-ID does not include visual prompts for its items. For consistency with the other measures, the five-point scale of the PWI-ID was used for this study, but with an accessible prompt sheet with visual prompts for each item, and pictorial scale consistent with the other scales used in this study.

*Scale and acquiescence assessment.* Procedures were included at the start of each administration, adapted from the PWI-ID (Cummins and Lau, 2005), to test whether participants could understand three and five point scales, and to assess for a tendency for acquiescence.

*Materials*

As described above, all measures were adapted in two ways in line with the adaptations made for the original pilot evaluation study (Raczka et al., 2014) following consultation with a small group of experts by experience. Firstly, a set of accessible prompts was developed for each measure to use with participants, using Photosymbols® and colour coded ‘smiley faces’ to enhance accessibility. Secondly, for the Mini-MANS-LD and the PWI-ID additional written scripts were developed for administrators to use to ensure consistent clarification of potentially problematic concepts and the five point scale.

*Design*

A number of within groups designs were used for the quality assessment of the measures. Congruent validity was assessed using a correlational design, with total scores on the PWI-ID and Mini MANS-LD as the variables. Reliability used a within groups design with scores on individual items on the Mini MANS-LD as the dependent variable. Acceptability and feasibility used a within groups design with measure as the independent variable (three levels: EQ-5D-Y, Mini MANS-LD, PWI-D) and administrator ratings as the dependent variable. Finally, responsiveness and sensitivity were explored in a preliminary way using a within groups design with time point as the independent variable (two levels: baseline and approximately three months later) and scores on the three measures as the dependent variables.

*Participants*

Given the target use of the measure, participants were people with intellectual disability (namely ‘significant’ impairments of both intellectual and adaptive behaviour evident before adulthood) that did not have severe levels of intellectual disability (British Psychological Society, 2015). A convenience sample of 33 adults with intellectual disability eligible to receive and currently accessing support at services for people with intellectual disability within inner London were administered the measures between June and November 2013. Fourteen (42.44%) were male. The mean age of participants was 39.11 years (*SD=*14.63) and the range was 22 to 69 years. As all participants were known to a clinical service, a clinical opinion of level of intellectual disability was elicited from the clinical team, rather than administering further intellectual functioning assessments. Of the participants, 87.89% were considered to have ‘mild’ intellectual disability by their clinical team, and the remaining ‘moderate’ intellectual disability. See Table 3 for demographic characteristics.

The measures were administrated by either qualified clinical psychologists (n=3), trainee clinical psychologist (n=1), or assistant psychologists (n=3) who worked within the services, all of whom were trained in administration of the measures.

[insert table 3 about here]

It was planned to repeat administration approximately three months after baseline to allow a preliminary exploratory analysis of the sensitivity of the new measure to detect changes in outcomes over time. This was achieved for twenty-five participants. It was not possible to repeat the administration with eight participants; two had died, one declined to have the measures again and six were no longer being seen at the service at the time of the re-administration.

*Procedure*

An accessible information sheet was produced, outlining the research study and detailing what was required from the participant, to ensure that participants were supported to to provide informed consent to take part in the research. Participants signed or initialled the form to provide written informed consent.

Acquiescence and testing of understanding of scales were assessed first. If a participant was assessed as having a tendency to acquiesce, the protocol was that the measures were not administered. However, if the participant did not pass any of the scale tests (i.e. participant did not appear to fully understand the scales), the protocol was to still administer the measures. All measures were administered to all participants. Measures were administered in one of two orders, randomised within the sample. Participants were either administered the Mini-MANS-LD and EQ-5D-Y, which had been designed to be used together, first (‘block 1’), or they were administered the PWI-ID first (‘block 2’). The same order was used at the second administration as at the first administration. Demographic data and administrators’ ratings of time taken (minutes), ease of use (0-10) and acceptability (0-10) were also collected.

*Scoring*

For the EQ-5D-Y, a single score (known as ‘modelling valuations for health’) was calculated using the model developed by Dolan (1997) and as recommended by NICE (2008). For the Mini-MANS-LD and PWI-ID, individual item scores were summed to give an overall score. Both the single score and the visual analogue scale were reversed prior to analysis so they were in line with the direction of scoring of the Mini-MANS-LD and the PWI-ID.

*Statistical Analysis*

Fitzpatrick et al. (1998) suggest quality assessment of outcome measures should look at validity, reliability, responsiveness, acceptability and feasibility. In line with these principles, the current study reviewed the following to assess whether the Mini MAND-LD was a valid outcome measure for adults with intellectual disability:

* Congruent validity: Pearson’s correlation of Mini-MANS-LD with a pre-existing measure, namely PWI-ID
* Reliability (internal consistency): Cronbach’s alpha
* Acceptability and feasibility: quantitative (repeated measures ANOVA e.g. administrators’ ratings of ease of use, acceptability to service users, and time taken to administer, for each of the measures) and qualitative analysis of administrators’ feedback.
* Exploratory Analysis: Responsiveness and sensitivity: difference between scores at the first and second administration points (repeated measures t-test) allowed a preliminary exploratory analysis into this aspect of the measure.

All data were analysed using SPSS 21.0. Prior to analysis, data were checked to confirm they satisfied parametric test assumptions. The relationship between the EQ-5D-Y’s single score calculated (known as ‘modelling valuations for health’, Dolan 1997) and its visual analogue scale was non-linear so a non-parametric test was used to assess this. Because of the smaller sample size for the sensitivity test, this was also assessed using a non-parametric test.

**Results**

*Scale and acquiescence testing*

All participants passed the acquiescence testing (i.e. were not found to have a tendency to agree with the interviewer). All except one of the participants were able to understand the five-point scale. This participant was able to understand the three-point scale. Subsequent (five-point) test measures were still administered for this individual as per the study protocol.

*Mini-MANS-LD: congruent validity*

Other research in this field which has investigated congruent validity of quality of life measures has suggested that a Pearson correlation coefficient between 0.40 – 0.69 is deemed moderate, between 0.70 – 0.89 is deemed high, and above 0.90 is very high (Simoes et al. 2002). The Mini-MANS-LD was significantly correlated with the PWI-ID (*r(*33*)*=0.67, *p*<.001), suggesting it has moderate congruent validity with an already validated measure.

*Mini-MANS-LD: reliability (internal consistency)*

Cronbach’s alpha for the Mini-MANS-LD was 0.74, indicating acceptable internal consistency (Kline, 2000). None of the individual items would increase the overall alpha if deleted and the item-total correlations ranged from 0.29 to 0.58.

*Relationship between Mini-MANS-LD and EQ-5D-Y*

The Mini-MANS-LD has been designed to use in conjunction with the EQ-5D-Y. It was significantly correlated with the overall single health state score, (*r*(33)=0.51, *p<*0*.*005), but not with the visual analogue scale (*r(*33)=-0.02, *p*>0.05) (Bonferroni corrected to 0.025).

*Acceptability and feasibility: administrators’ feedback (n=27)*

Mauchley’s test of sphericity was significant and so a Greenhouse-Geisser correction was used. There was an overall significant main effect of ease of use (*F(*1.46,29)=5.90, *p*<0.05). The Mini-MANS-LD (*M=*9.10, *SD=*1.09) was rated as significantly ***easier to administer*** than the PWI-ID, using a Bonferroni corrected significance level of 0.017 *(M=*8.40, *SD=1.96, t(*29)=0.78, *p*<0.017)*.* There was no significant difference between the EQ-5D-Y (*M=*8.96, *SD=*1.52) and the Mini-MANS-LD (*t(*29)*=*.78, *p*>0.017) or the PWI-ID (*t(*29*)=*1.79, *p>*0.017).

The same pattern was found for ratings of acceptability to service users**.** Once again, Mauchley’s test of sphericity was significant and so a Greenhouse-Geisser correction was used. There was an overall significant main effect of ease of use (*F(*1.38,29)=5.29, *p*<0.05). The Mini-MANS-LD (*M=*9.27, *SD=*1.01) was rated as significantly ***more acceptable to service users*** than the PWI-ID, using a Bonferroni corrected significance level of 0.017 (*M=*8.57, *SD=*2.11, *p<*0.017). Again, there was no significant difference between the EQ-5D-Y (*M=*9.30, *SD=*1.37) and the Mini-MANS-LD (*t(*29)=.22, *p*>0.017) or the PWI-ID (*t*(29)=2.33, p>0.017).

Considering the time taken to administer, once more there was an overall significant main effect (*F*(2,28)=15.84, *p*<.001). Both the Mini-MANS-LD (*M=*5.83, *SD=*2.89; *t*(28)=5.05, *p<*.001) and the PWI-ID (*M=*5.62, *SD=*3.16; *t*(28)=*4.07,* p<.001) took ***significantly longer*** to administer than the EQ-5D-Y (*M=*4.31, *SD=*2.45) at a Bonferroni corrected significance level of 0.017. There was no significant difference in the time taken to administer the Mini-MANS-LD and the PWI-ID (*t*(28)=.83, *p*>0.017).

Administrators’ qualitative feedbackreported no qualitative issues with the items of the Mini-MANS-LD. Three administrators (out of a total of 7) suggested that the language of the PWI-ID was more difficult and required significant prompting. In particular the precursor, ‘How happy do you feel about…’, was considered to add a level of complexity to the PWI-ID which made it harder to administer than the other two measures. Qualitative feedback from 13% of administrations suggested some difficulties among participants in understanding how to use the visual analogue scale and the stairs analogy of the EQ-5D-Y, however the majority (87%) did not report difficulty with this.

*EQ-5D-Y:* single overall score *and visual analogue scale*

There was no significant association between the EQ-5D-Y’s single overall total health state reported score (score known as ‘modelling valuations for health’, Dolan 1997), and the visual analogue scale (*rho*(33)=.10, *p>*0*.*05).

*Exploratory Analysis: Sensitivity*

Re-administering the measures after a period of time allowed a preliminary exploratory analysis of the potential sensitivity of the measures to change over time, following service intervention. The mean length of time between the first and second administration was just less than 4 months (115.43 days; *SD=*13.47, range 98-133 days). Using a non-parametric repeated measures t-test (Wilcoxon signed ranks test), there was no significant difference in scores on the Mini-MANS-LD from the first administration (Median = 17.0) and the second (Median = 16.0; *Z=*1.71, *p*=0.087). The same pattern was observed for the PWI-ID (T1 Median = 13.0, T2 Median =13.0; *Z=*1.14, *p*>0.05) and the both the EQ-5D-Y single score (T1 Median = 0.66, T2 Median = 0.73; *Z=*1.38*, p>*0.05) and the visual analogue scale (T1 Median = 8, T2 Median = 8; Z=0.29, *p>*0.05) of the EQ-5D-Y.

There was, however, a significant correlation between the number of days between T1 and T2 and the difference in Mini-MANS-LD scores (*r*(21)=0.45, *p*<0.05). For the EQ5D-Y’s single overall score (*r(*21) = -0.12, *p>*0.05) and its visual analogue scale (*r*(21) = 0.10, p>0.05) and the PWI-ID (*r(*21) = -0.002, *p*>0.05), the correlations were not significant.

**Discussion**

Whilst there already exist a number of potential measures, there is no agreement regarding a ‘good standard’ self-reported quality of life measure designed for use with adult intellectual disability populations (Townsend-White et al. 2012); furthermore, the authors’ experience was that those that do exist are not always wholly accessible for adults with intellectual disability, to support self-report of subjective, rather than proxy, quality of life. The Mini-MANS-LD was developed to provide such an accessible measure. Although it must be acknowledged that this study represents only an initial validation study, and as such the sample size is small, the results suggest that the Mini-MANS-LD has potential to demonstrate adequate psychometric properties. It has acceptable internal consistency and moderate congruent validity against a previously validated measure. It was rated by administrators (using a 10-point likert scale) as easier to use and more acceptable to service users than the previously validated PWI-ID comparison measure, and took the same amount of time to administer. Designed to be used with the EQ-5D-Y, the two measures together took, on average, less than 12 minutes to administer. This suggests that they could be appropriate measures to be used fairly routinely within clinical health and social care services for people with intellectual disability.

Within the EQ-5D-LD (Beta), a lack of association was found between the visual analogue scale and the single overall score (known as ‘modelling valuations for health’, Dolan 1997). One possible reason is the difficulties reported by some administrators of the experiences of some of the participants in understanding the stairs analogy. However, a similar lack of association between the (non-adapted) visual analogue scale and the single overall score was found in another assessment of the main EQ-5D (Feng et al. 2012). This suggests there may be a wider challenge with correlating the standard (e.g. thermometer style) visual analogue scale and the single overall score of the EQ-5D scales, irrespective of how the visual analogue scale is adapted. Furthermore, the majority of administrators did not report difficulties with the accessible stairs analogy of the visual analogue scale. It is therefore challenging to draw a conclusion from this data and thus it requires further investigation.

The preliminary exploratory analysis suggested none of the measures detected a significant change in scores over a three-month period. However, the Mini-MANS-LD did show a difference in the median scores between the two time points approaching significance. There was also a significant correlation between the number of days between first and second administration and the difference in Mini-MANS-LD scores (but not for the PWI-ID nor the EQ-5D-Y’s single overall score or its visual analogue scale). This may suggest a significant change in Mini-MANS-LD scores may have been seen with a greater length of time between T1 and T2 than the mean 115 days (just short of four months), which may be less likely with the PWI-ID or the EQ-5D-Y. Given the limitations of the preliminary exploratory analysis into sensitivity of the measure to change over time, this should be interpreted with caution. The current study followed up participants after a period of just under four months and re-administered the measures at that time. However, participants were recruited as service users receiving a range of health and social care interventions, and as such, the theoretical links between the different interventions being provided and the expected impact on self-reported quality of life in line with Maslow’s hierarchy of needs, is not established. Therefore, to follow up the preliminary exploratory investigation into sensitivity of the Mini-MANS-LD, further repeated measures research would be necessary, using a more specific intervention aimed to improve subjective quality of life for service users, to assess whether the Mini-MANS-LD was responsive and sensitive to change over time.

This was a small scale initial validation study utilising a convenience sample within inner London intellectual disability services. It may, therefore, not be representative of all UK services. It is also important to note that the majority of administrators were in some way involved in the development of the measures, potentially biasing their reporting of acceptability and ease of use. It should also be noted that the PWI-ID, despite purporting to be a subjective quality of life measure appropriate for use with people with intellectual disability, required some additional prompts (such as visual prompts to support each item) to make it more accessible to the individuals in this study. This also means that the version of the PWI-ID used in this study deviated slightly from the previously validated version. Similarly, this was the first study to develop more accessible prompts to make the EQ-5D-Y easier to understand for individuals with intellectual disability, and the resulting measure, the EQ-5D-LD (Beta) requires additional research to establish its psychometric properties.

Finally, the study aimed to develop a self-report tool to measure subjective quality of life of individuals with intellectual disability, and whilst it succeeded to a certain extent in doing this within this initial validation study, it is the case that even an ‘accessible’ measure such as this will still only be ‘accessible’ and meaningful to people with intellectual disability that are not severe. For those with severe intellectual disability, who are not able to speak up for themselves even with support of a more accessible measure, services may still need to rely on proxy or objective means of assessing quality of life.

Despite these limitations, this study has led to the development of a measure, the Mini-MANS-LD, that has the potential to support many people with intellectual disability to provide their self-report on the broad concept of subjective quality of life when used in conjunction with an established measure of health-related quality of life, i.e. the EQ-5D-LD (Beta). The Mini-MANS-LD has been found to be acceptable to a sample of people with intellectual disability, and is based on established theoretical constructs (Maslow’s hierarchy of needs) that may underpin important concepts to be measured, which also relate to Schalock et al’s (2002) core domains of quality of life. The Learning Disability Professional Senate (2016) has recently produced a document to support clinicians to choose and develop appropriate outcome measures with a human rights and equality framework. This document outlines seven principles derived from the Human Rights Act, the Equalities Act, and current NHS and Document of Health policy documents among others. The Mini-MANS-LD items (as shown in Table 1), have the potential to support services’ aims to assess and to demonstrate clinical evaluation against these principles for individuals to be respected, safe, make choices, have a place of their own, be active, have fulfilling relationships, and be supported to access appropriate services.

Recurring concerns about ill-treatment of individuals with intellectual disability such as Winterbourne in the UK and the resulting commitment to transforming the commissioning of services for people with intellectual disability (NHS England, 2015), demonstrate how fundamental it is to find a meaningful way to ask service users directly about their life experiences and the quality of the lives they are living. It is progressively recognised that clinician rated outcomes or proxy reports by carers, whilst important in their own right, cannot be a replacement for service users’ own voices. The availability of a measure such as the Mini-MANS-LD, and its ability to be administered relatively quickly, is essential in a health service context which is, appropriately, placing increasing importance on individuals’ subjective quality of life, in line with principles of human rights and equality.

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Table 1: Mini-MANS-LD items and rating scale:

|  |  |
| --- | --- |
| **Item** | **Rating scale** |
| *1* | *2* | *3* | *4* | *5* |
| 1. Overall do you feel your life is…? | *Very good* | *Good* | *OK – neither good or bad* | *Bad* | *Very bad* |
| 2. Do you get on well with people you know? | *Always* | *Most of the time* | *Some of the time* | *Not very often* | *Never* |
| 3. Are you happy with where you live? | *Very happy* | *Happy* | *OK – neither happy or sad* | *Sad* | *Very sad* |
| 4. Are you happy with how you spend your time? | *Very happy* | *Happy* | *OK – neither happy or sad* | *Sad* | *Very sad* |
| 5. Do other people try to hurt you? | *Never*  | *Not very often* | *Some of the time* | *Most of the time* | *Always* |
| 6. Do you feel like hurting other people? | *Never* | *Not very often* | *Some of the time* | *Most of the time* | *Always* |
| 7. Do you try to hurt yourself? | *Never* | *Not very often* | *Some of the time* | *Most of the time* | *Always* |
| 8. Can you speak up for yourself? | *Always* | *Most of the time* | *Some of the time* | *Not very often* | *Never* |
| 9. Are you doing the best you can in life? | *Always* | *Most of the time* | *Some of the time* | *Not very often* | *Never* |

|  |  |  |  |
| --- | --- | --- | --- |
| **Maslow’s Hierarchy of Needs (1943)** | **Original MANS-LD Items** | **Mini-MANS-LD Items** | **Schalock et al, 2002 recommended core domains of quality of life** |
| Physiological *(breathing, food, water, sex, sleep, hoemostatis, excretion)* | * I feel my basic needs, such as the food I eat, how I sleep and keeping warm, are being met
 |  |  |
| Safety *(security of: body, employment, resources, morality, the family, health, property)* | * I am happy with where I live
* I am happy with how I spend my time
* Other people try to hurt me
* I feel like hurting other people
* I feel like deliberately hurting myself or trying to kill myself
* I am happy with my health
 | * Item 3: Are you happy where you live?
* Item 4: Are you happy with how you spend your time?
* Item 5: Do other people try to hurt you?
* Item 6: Do you feel like hurting other people?
* Item 7: Do you try to hurt yourself?
 | * *Material well-being / Rights*
* *Personal development / Social inclusion*
* *Emotional well-being / Rights*
* *Emotional well-being*
* *Emotional well-being*
 |
| Social i.e. Love and Belonging *(friendship, family, sexual intimacy)* | * I get on well with the people I know well (e.g. my family, the staff who support me).
* I can make and keep friends.
* I feel accepted by other people
* I feel happy about boyfriends and girlfriends
 | * Item 2: Do you get on well with people you know?
* Item 3: Are you happy where you live?
 | * *Interpersonal relations*
 |
| Esteem *(self-esteem, confidence, achievement, respect of others, respect by others)* | * I feel good about myself.
* I feel confident.
* I feel I am achieving what I want to.
* I feel other people respect me.
* I feel I respect other people.
 | * Item 8: Can you speak up for yourself?
* Item 4: Are you happy with how you spend your time?
 | * *Self-determination*
 |
| Self-actualisation *(morality, creativity, spontaneity, problem solving, lack of prejudice, accpetance of facts)* | * I feel like life is worthwhile.
* I feel I accept who I am.
* I feel I am being everything that I can be.
 | * Item 1: Overall, do you feel your life is… *(from WHOQOL-8)*
* Item 9: Are you doing the best you can in life?
 | * *Self-determination*
 |

Table 2: MANS-LD and Mini-MANS-LD items as related to concepts of Maslow’s hierarchy of needs (Maslow, 1943) and recommended core domains quality of life (Schalock et al, 2002)

**Table 3: Demographic characteristics of participants**

|  |  |
| --- | --- |
|  | n(%) |
| *Gender* |  |
| Male | 14 (42.42) |
| Female | 19 (57.58) |
| *Ethnicity* |  |
| White | 26 (77.78) |
| Black | 4 (12.12) |
| Asian | 2 (6.06) |
| Other | 1 (3.03) |
| *Intellectual disability* |  |
| Mild | 29 (87.89) |
| Moderate | 4 (12.11) |

Figure 1: Example Items and rating scale from the Mini-MANS-LD





Pictures by Photosymbols