Validating a new patient reported outcome measure for adults with intellectual disabilities: the Mini MANS-LD

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Our Vision:
To lead out-of-hospital community healthcare
• Human rights approach to service provision for people with intellectual disabilities (ID) e.g. Valuing People (2001), Valuing People Now (2009)

• However, health inequalities and inequalities in quality of life for people with ID still exist (Emerson & Hatton, 2008)

• Increased pressure on all NHS services to monitor outcomes, including quality of life (DoH, 2010)

• Limited measures of subjective (self-reported) quality of life appropriate for use by people with ID (Townsend-White, Pharm & Vassos, 2012)
Phase 1: Finding appropriate measures

- BPS DCP Faculty ID (2012) described some measures in use with adults with ID who also exhibit behaviours that challenge

- No universally accepted quality of life outcome measure for adults with ID

- NHS-Trust preferred measure = EQ-5D:
  - 5 item health based measure with overall health measure (VAS)

- Phase 1: short pilot (18 adults) in LBHF in autumn 2012 compared this (accessible language version, EQ-5D-Y) with measures recommended by the BPS DCP Faculty ID
  - MANS-LD: 19 items based on Maslow’s hierarchy of needs
  - World Health Organisation Quality of Life Measure (WHOQOL-8): 8 items

- Administrators also completed a form capturing information on:
  - Time taken to complete
  - Ease of use
  - Accessibility of measure to Service user
Phase 1: Developing accessible items

- Pre-pilot consultation with service users to develop acceptable accessible items
- Pictures used to illustrate content
- Traffic light colour coded smiley faces to elucidate scale

Original MANS-LD item

1) I feel my **basic needs, such as the food I eat, how I sleep and keeping warm are being met...**

<table>
<thead>
<tr>
<th>Nearly always</th>
<th>Most of the time</th>
<th>About medium</th>
<th>Not very often</th>
<th>Hardly ever</th>
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Accessible MANS-LD item

1) **My basic needs, such as the food I eat, how I sleep and keeping warm are being met.**

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Measures:

- Only significant association between the WHOQOL-8 and the MANS-LD (rho=.70, p<.001), monotonic with scores on the two increasing together
- No other associations, including within the EQ-5D-Y i.e. between the MVH (EQ-5D-Y single score) and Visual Analogue Scale

Administrators feedback - Quantitative

- **Time**: EQ-5D-Y was quickest to complete
- **Ease of use**: EQ-5D-Y and the WHOQOL-8 were rated as easier to administer than the MANS-LD.
- **Acceptability to service users**: MANS-LD was rated as less acceptable to service users than EQ-5D-Y and the WHOQOL-8

Administrators feedback - Qualitative

- **EQ-5D-Y**: confusion about how to use the VAS
- **WHOQOL-8**: two problematic concepts
- **MANS-LD**: nine problematic concepts
• Adapted EQ-5D-Y was quickest, easiest to administer and the most acceptable to service users.
• **BUT** predominantly physical/health based so lacks sufficient breadth to assess outcomes across diverse range of ID services
• **SO** use EQ-5D-Y, with amended VAS, as one outcome measure for adults with LDs = EQ-5D-LD (beta)

**Amended EQ-5D-Y VAS**

• **AND** develop a second, broader, measure combining limited number of non-health concepts of the WHOQOL-8 and the MANS-LD to use in conjunction with EQ-5D-LD (beta)
Phase 2: Mini MANS-LD

• Development of Mini MANS-LD
  – 9 accessible items, chosen from pilot feedback
  – Reflect 4 of 5 levels of Maslow hierarchy (Basic Needs excluded for brevity)

• Design: Within-groups design used to assess validity

• Ethical Review: proportionate review by North of Scotland NRES

• Participants:
  – 30 adults with mild/moderate ID eligible to receive and currently accessing services:
  – Community LD Service & independent sector residential LD care service

• Administered:
  – Mini MANS LD
  – EQ-5D-LD (beta)
  – Personal Well Being Index (PWI-ID) – as a validated comparison measure, to test concurrent validity

Baseline administration and 3 months later
Phase 2: Materials & Measures

• All measures adapted in same way as original pilot following consultation with small group of service users:
  1. Accessible ‘prompts’ developed for each measure, with photo symbols to illustrate content and colour coded ‘smiley faces’ to increase accessibility
  2. Additional written prompts developed for administrators to ensure consistent clarification (for Mini MANS-LD & PWI-ID)

• *Scaling and acquiescence assessment*: procedures taken from the PWI-ID to test whether participants can understand three and five point scales, and a tendency to agree with the interviewer (acquiescence)

• Demographic data and administrators’ ratings of time taken (minutes), ease of use (0-10) and acceptability (0-10) were collected
Phase 2: Measures
Mini MANS-LD

- Mini MANS-LD:
  - Adapted from Maslow Assessment of Needs Scales – Learning Disabilities (MANS-LD) (Skirrow & Perry, 2009)
  - Individual 9 items scored summed to give overall score
Phase 2: Measures
EQ-5D-LD (beta)

EQ-5D-LD (beta), based on EQ-5D-Y (Willie et al, 2010):

- 5 health related questions
- A single score (Modelling Valuations for health; MHV) calculated using the model developed by Dolan (1997) and as recommended by NICE (2008)

- Visual Analogue Scale (VAS): developed to look like a stair case to aid understanding, and based on 10 point rather than 100 point scale
Phase 2: Measures

PWI-ID

- Personal Wellbeing Index (PWI-ID; Cummins & Lau, 2005):
- Individual 7 items scored summed to give an overall score
Participants:
- n=30
- 43.3% (13) male
- Average age = 40.5 years (sd=15.3)
- 87% (26) considered to have mild ID
- All passed the acquiescence testing
- All except one able to understand 5-point scale
Phase 2: Results: Mini MANS-LD

- **Concurrent Validity**: correlations of Mini MANS-LD & PWI-ID:
  - Mini MANS-LD significantly correlated with PWI-ID ($r(30)=0.67$, $p<0.01$), suggesting good concurrent validity with an already validated measure

- **Reliability (internal consistency)**: Cronbach’s alpha:
  - Cronbach’s alpha for the Mini MANS-LD was .76, indicating acceptable internal reliability (Kline, 1999)
  - None of the individual items would increase the overall alpha if deleted
  - Item-total correlations ranged from .28 to .60.

- **Relationship between Mini MANS-LD & EQ-5D-LD (beta)**: designed to be used in conjunction:
  - significantly correlated with the MVH ($r(30)=.52$, $p<.005$)
  - but not with the VAS ($r(30)=-.01$, $p>.05$) (Bonferroni corrected to .025).
• **Face validity**: quantitative (repeated measures ANOVA):

• **Ease of use**: Overall significant main effect ($F(2,27)=4.12, p<.05$)
  – Mini MANS-LD ($M=9.00, SD=1.11$) rated significantly **easier to administer** than the PWI-ID ($M=8.22, SD=8.22, p<.05$, using a Bonferroni adjustment for multiple comparisons).
  – No significant difference between the EQ-5D-LD (beta) ($M=8.85, SD=1.56$) and the Mini MANS-LD or the PWI-ID (both $p>.05$, using a Bonferroni adjustment for multiple comparisons)

• **Reported Acceptability to Service Users**: Overall significant main effect ($F(2,27)=4.12, p<.05$)
  – Mini MANS-LD ($M=9.19, SD=1.04$) rated as significantly **more acceptable to service users** than the PWI-ID ($M=8.41, SD=2.17, p<.05$)
  – no significant difference between the EQ-5D-LD (beta) ($M=9.22, SD=1.42$) and the Mini MANS-LD or the PWI-ID (both $p>.05$, using a Bonferroni adjustment for multiple comparisons)
Phase 2: Results: Mini MANS-LD

• **Face validity:** quantitative (repeated measures ANOVA):
  - **Time Taken to Administer:** Overall significant main effect \((F(2,27)=14.00, p<.001)\)
    - Mini MANS-LD \((M=6.15, SD=2.84)\) took significantly longer to administer than the PWI-ID \((M=5.93, SD=3.15)\)
    - PWI-ID took significantly longer to administer than the EQ-5D-LD (beta) \((M=4.70, SD=2.35)\)
    - all \(ps<.05\), using a Bonferroni adjustment for multiple comparisons

• This is perhaps to be expected as the Mini MANS-LD has the highest number of items (9), followed by the PWI-ID (7) and the EQ-5D-LD (beta) (6, including the VAS).
• Looking at a time per item repeated measures analysis, the Mini MANS-LD was significantly quicker to administer per item \((M=.68, SD=.39)\) than the PWI-ID \((M=.85, SD=.39, p<.001)\)
**EQ-5D-LD (beta): MVH (single score) and Visual Analogue Scale**

- No significant association between the EQ-5D-LD (beta) MVH score and the VAS ($\rho=0.08, p>0.05$)
- Also, Cronbach’s alpha for the EQ-5D-Ld (beta) would increase (from 0.71 to 0.75) if the VAS was deleted, suggesting the EQ-5D-LD (beta) would be **more** internally consistent **without** the VAS (although designed as separate scales)

**Administrators’ qualitative feedback:**

- **Mini MANS-LD:** no reported qualitative issues with the items
- **PWI-ID:** 3 administrators (out of a total of 7) suggested that the ‘How happy are you about…’ precursor added a level of complexity to the PWI-ID making it harder to administer than the other two measures and that overall the language was more difficult and required significant prompting
- **EQ-5D-LD (beta):** Qualitative feedback from 13% of administrations suggested some difficulties among participants in understanding how to use the VAS and the stairs analogy used
Phase 2: Results: Mini MANS-LD

- **Sensitivity Data:** \(n=19\) so far
- Comparison of Mini MANS-LD & PWI-ID at t1 & t2 using repeated measures t-test (Wilcoxon):
  - PWI-ID showed a significant change in scores from t1 (Median=15.0) to t2 (Median=13.0), \(T=11, p=0.016\), with a large effect size (Cohen’s d=0.72)
  - Mini MANS-LD did not show a significant change in scores from t1 (Median=18.0) to t2 (Median=16.0), \(T=36, p=0.30\), with a small effect size (Cohen’s d=0.25)
- However:
  - Possibly 2 outliers on Mini MANS-LD – when these were removed a significant change in scores was seen from t1 (Median=18.0) to t2 (Median=16.0), \(T=10, p=0.22\), with a large effect size (Cohen’s d=0.65)
  - To review with complete dataset…
Mini MANS-LD
Conclusions & Next Steps

• EQ-5D-LD (beta) – available to use by services who have a licence to use EQ-5D (EuroQol)

• EQ-5D-LD (beta) Visual Analogue Scale - problematic?
  – Similar lack of association between original EQ-5D and VAS (Feng, Parkin & Devlin, 2012)
  – Further work to make the Visual Analogue Scale accessible/acceptable to PwID?

• Mini MANS-LD appears to have good psychometric properties:
  – Good concurrent validity against a previously validated measure (PWI-ID)
  – Acceptable internal consistency
  – Rated by administrators as easier to use and more acceptable to service users than PWI-ID
  – Took longer to administer than PWI-ID and EQ-5D-LD (beta) – but per item analysis suggests may be quicker than PWI-ID
  – Used together with EQ-5D-LD (beta) = <12 minutes to administer on average
  – Sensitivity to detecting change over time is still to be established

• Mini MANS-LD appears to have the potential to be an easy to administer, accessible and validated measure - available for services to use
Thank you!

Questions?

Feedback?

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With thanks to Dr Paul Skirrow & EuroQol
Key References