



Mini MANS-LD

Accessible quality of life outcome measure for people
with learning disabilities

USER GUIDE December 2013

Developed by Dr Roman Raczka, Dr Kate Theodore, Janice Williams

Hammersmith & Fulham Learning Disability Service and Central London Community
Healthcare NHS Trust

Developed from the Maslow Assessment of Needs Scale – Learning Disabilities
(MANS-LD; Dr Paul Skirrow & Dr Ewan Perry, Mersey Care NHS Trust)

Background and introduction

The use of patient-reported outcomes measures with adults with learning disabilities is necessary to support the human rights based approach encapsulated in Valuing People (2001) and Valuing People Now (2009). Alongside this, there has been growing acceptance of the need to use outcome measures routinely to assess the effectiveness of interventions. Gathering such data is vital to inform what is being done at the individual, service, population and policy level.

However, to date there has been a dearth of validated outcome measures for this population. The Mini MANS-LD is a validated, accessible quality of life outcomes measure for use with people with learning disabilities.

Why the 'Mini' MANS-LD?

The Mini MANS-LD is based on an existing measure, the Maslow Assessment of Needs Scale – Learning Disability (MANS-LD; Skirrow & Perry, Mersey Care NHS Trust, 2009) and was developed following a small scale pilot of a number of outcomes measures (Raczka, Williams, Theodore, in press). The MANS-LD is designed to reflect Maslow's hierarchy of human needs, and is based on the premise that people with learning disabilities have the same rights to have these common human needs met as everyone else. The full MANS-LD consists of 19 items, covering the five levels of Maslow's hierarchy.

The pilot found the full MANS-LD to only be suitable for adults with very mild LD, who were able to understand and discriminate between its higher level concepts. The Mini MANS-LD was therefore designed for a broader range of abilities of adults with LD, including those with more significant learning impairments and more complex communications needs. The Mini MANS-LD is shorter (hence 'Mini') and has enhanced accessibility. Both are based on the theoretical constructs underpinning Maslow's hierarchy of needs, therefore both should be able to measure whether the services delivered have the desired socially valid outcomes. The mini MANS-LD was designed with a service user reference group advising on the suitability and accessibility of items.

The Mini MANS-LD is designed to be used to assess quality of life for people with learning disabilities and the outcomes and therefore effectiveness of interventions.

Who is the Mini MANS-LD for?

Research has shown that people with severe or profound and multiple learning disabilities are not able to reliably use self-report measures (ref). The Mini MANS-

LD is therefore most appropriate for use with people with mild to moderate learning disabilities.

Psychometric properties

A full validation study for the Mini MANS-LD is currently being undertaken and is due for completion in April 2014. However, interim results are available, based on the measures being used a single time with a sample of 30 adults with mild/moderate learning disabilities. These showed that the measure has good reliability (Cronbach's $\alpha = .76$). None of the individual items would increase the overall alpha if deleted, suggesting the individual items are also reliable. It also has good congruent validity, being significantly correlated with a previously validated quality of life measure, the Personal Wellbeing Index – Intellectual Disability (PWI-ID) ($r(30) = .67$, $p < .001$). In terms of face validity, feedback from administrators suggested that the Mini MANS-LD is quick to use, taking on average just over 6 minutes, easy to use (rated on average 9/10) and acceptable to people with learning disabilities (rated 9.2/10).

The full validation study will have a total sample size of 40 and will also include a sensitivity measure, by taking a second measure three months after the first and analysing changes in scores.

Further details of the interim analysis are available on request.

What does the Mini MANS-LD consist of?

The Mini MANS-LD consists of nine items, eight based on MANS-LD items and an introductory one, designed as a general rapport-builder, scored on a five point Likert-type scale. Each item is illustrated with photographs from Photosymbols to better explain the subject matter of the question. To facilitate understanding of the scale, each response option has a colour coded cartoon face as well as wording. Both of these adaptations have been shown to improve response rate and accuracy of self-report with adults with learning disabilities (ref).

The items were selected using pilot feedback to:

- Be understood by the widest range of service users, with minimal additional clarification
- Have no conceptual overlap
- Be quick to administer

How to use the Mini MANS-LD

The Mini MANS-LD pack consists of three documents:

- The accessible prompts
- A script for administrators
- Word version of the Mini MANS-LD (without Photosymbols or cartoon prompts)






The **accessible prompts** are designed to be used with the individual. They are not designed for the individual to fill in; either the administrator should go through the questions with the individual, taking care to check understanding of the concept and accuracy of response, or, for the more able, the individual can go through it independently. The relevant score should then be recorded on a separate scoring sheet, either by the administrator or the individual if capable. The suggested **script for administrators** is there to ensure consistent clarification of concepts and also to help administrators ensure that participants consider all response options on the scale, increasing the accuracy of responses. The **word version** contains no pictures and is designed for individuals with very mild/borderline learning disabilities who may be unwilling to use the accessible version. This version also has tick boxes so the individual can fill it in directly.

For the validation study, we incorporated scaling testing to ascertain whether participants could understand the five-point scale before commencing using the measures. We also tested for acquiescence (a researched tendency for adults with learning disabilities to agree with the interviewer). Both of these were adapted from adapted from Cummins and Lau (2009) and, while it is not necessary as a matter of course to use these when administering the Mini MANS-LD, they are available on request.

Scoring the Mini MANS-LD

The Mini MANS-LD should be scored at two levels, the individual item level and a total score, summing the individual scores. In this way it is possible to use the Mini MANS-LD to identify areas for interventions and then to investigate both changes in overall scores over time and also in individual items and relate any shifts back to the interventions.

Scoring is as follows:

				
1 point	2 points	3 points	4 points	5 points

Mini MANS-LD and EQ-5D

The Mini MANS-LD can be used as a stand-alone but can also be used alongside an accessible version of the EQ-5D. The EQ-5D is used with people with wide ranging health needs. It is widely used within the NHS. It consist of five questions about different aspects of health, measured on a three-point Likert-type scale. The EQ-5D-LD (Beta) has been specifically adapted for use by adults with learning disabilities. It uses more accessible language and the same combination of images and colour coded cartoon faces as the Mini MANS-LD. Using the EQ-5D-LD (Beta) alongside the Mini MANS-LD as patient reported outcomes measures for adults with LD also covers the main areas of Valuing People Now (2009): reducing health inequalities, increasing choice about where people live, opportunities for employment/education, and life experiences (relationships, friendships, leisure), and being safe.

The EQ-5D-LD (Beta) is available on request in draft from pending approval from Euroqol. Please note, it is necessary to have a license from Euroqol to use it (see www.euroqol.org for more details).

For further information contact:

Dr Roman Raczka
Consultant Lead Clinical Psychologist
Hammersmith & Fulham Learning Disability Service
Stamford Brook Centre
14-16 Stamford Brook Avenue
London W6 0YD

Tel: 020 8383 6464

E-mail: roman.raczka@lbhf.gov.uk