

**Personal Wellbeing Index –
Intellectual Disability
(English)**

3rd Edition

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MANUAL

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1. Introduction

1.1. Measuring and defining quality of life

The quality of life (QOL) construct has a complex composition, so it is perhaps not surprising that there is neither an agreed definition nor a standard form of measurement. This is not due to a lack of ideas. Cummins' web-site Directory of Instruments (<http://acqol.deakin.edu.au/instruments/instrument.php>) describes some 800 instruments which purport to measure life quality in some form, but each one contains an idiosyncratic mixture of dependent variables.

It is also notable that many QOL instruments have been developed for highly selected groups in the population; particularly in regard to scales devised to monitor medical conditions or disability types. Such scales are unsuitable for use with the general population. On the other hand, most scales devised for use with general population samples cannot be used with all sectors of the population, such as people with cognitive impairment and children. These are important limitations since it means that the QOL experienced by minority groups cannot be norm-referenced back to the general population.

In order to remedy this situation, the Comprehensive Quality of Life Scale (ComQol), and now the Personal Wellbeing Index (PWI) have been developed. Parallel forms are available for any population sub-group. These forms are (see Reference List):

PWI-A: designed for use with the general adult population.

PWI-ID: designed for use with people who have an intellectual disability or other form of cognitive impairment.

PWI- SC: designed for use with children and adolescents who are attending school.

PWI-PS: designed for use with children of pre-school age.

The scale also contains features of construction which reflect contemporary understanding of the QOL construct. The details of ComQol test development have been published (Cummins, 1991; Cummins, McCabe, Romeo & Gullone, 1994). The PWI represents the satisfaction sub-scale of the Com-Qol. The original scales of Importance, and the objective ComQol Scale have been abandoned for reasons described in the document 'Caveats to using the Comprehensive Quality of Life Scale' (<http://acqol.deakin.edu.au/instruments/index.htm>). The PWI differs from the ComQol satisfaction scale in substituting 'Satisfaction with future security' for the original 'satisfaction with own happiness'.

Definition

The PWI is designed as the first level of deconstruction of the global, abstract question 'How satisfied are you with your life as a whole?'

1.2. The Personal Wellbeing Index (PWI) Scale

There are eight items in the adult PWI scale, each one corresponding to a quality of life domain as: standard of living, health, life achievement, personal relationships, personal safety, community-connectedness, future security and spirituality-religion. Evidence for the adoption of these eight domains has been presented by Cummins 1996, Cummins 1997, Cummins, McCabe, Romeo, Reid, & Waters 1997 and The International Wellbeing Group, 2006).

The PWI scale can be used with any section of the population. Three parallel versions of the adult PWI have been developed. Unlike the original PWI adult version however, these parallel versions contain seven items as spirituality-religion is under investigation for determination of its inclusion. Its current exclusion does not yield psychometrically different data from the PWI-adult version (e.g. Lau, 2006; Lau, Cummins, Chan, McGillivray & Li, 2006; Lau, Cummins, Lam, Li, McGillivray, J., & Chan 2006.) PWI-PS is for use with children and adolescents attending school, PWI-PS is for pre-school age children, while PWI-ID is designed for people who have an intellectual disability or other form of cognitive impairment.

1.3. Psychometric Characteristics

The basic psychometric characteristics of the PWI-A have been described (Cummins, Eckersley, Pallant, Van Vugt & Misajon, 2002) and detailed data concerning scale composition, reliability, validity, and sensitivity are provided in the many Reports on the Australian Unity Wellbeing Index (<http://acqol.deakin.edu.au/index.htm>) and other countries (e.g. Lau, Cummins & McPherson, 2005; Tiliouine, Cummins & Davern, 2004).

The cumulative psychometric characteristics of the adult scale are published in Cummins, R.A., Eckersley, R., Lo, S.K., Okerstrom, E., Hunter, B., & Davern, M. (2003).

1.4. The PWI-ID Scale

The PWI-ID scale differs from the PWI-A in that it incorporates a pre-testing protocol to determine whether, and to what level of complexity, respondents are able to use the scale. Questions on ‘satisfaction’ from the PWI-A are substituted by the term ‘happiness’. While it is recognized that these two terms are not equivalent, they yield very similar data (Cummins, Eckersley, Pallant, Misajon & Davern, 2001a; Cummins, et al., 2001b; Lau, Cummins & McPherson, 2004). The ID version also uses more simple and concrete wordings. An additional question which asks how happy or sad the respondent is with life as a whole is included. A reduced choice format, illustrated as a series of outline faces, from very sad to happy, is provided to enhance comprehension and substitutes for the Likert scale used in the PWI-A version for people who cannot cope with the latter format.

1.4.1. The test item: Domain on “Feeling Part of the Community”

With regards to the above-mentioned section 1.4, a noteworthy item is the sixth question of the PWI which taps subjective wellbeing (subjective QOL) of “community-connectedness”. When compared with the other items of the PWI, this item carries high abstractness and complexity which has required more rigor and trials of many different question formats to

identify the optimal substitute, which will be easily understood by the less cognitively competent groups, while fulfilling still, as an item representing the first (i.e. broadest) level deconstruction of life quality.

In the current PWI-ID scale, the question “How happy do you feel about doing things outside your home?” replaces “How satisfied are you with feeling part of your community?” in the PWI-A version. The aim of this item is to tap the extent to which a person is happy or satisfied with their sense of ‘connectedness’ or ‘belonging’ with their community. The term ‘community’ may take the form of a distinct group (e.g. school) or the larger community (e.g. district-based), which is to be left at the discretion of the respondents’ personal interpretation. This “sense of connectedness” or “belonging” may be derived through either behavioral or non-behavioral acts, with or without other people, outside the home.

The current question format “How happy do you feel about doing things outside your home?”, has been adopted as it is found to be generally inclusive of the above-mentioned considerations. A limitation, however, is that the question does suggest a more dominant behavioral orientation which may not necessarily be the case, as indicated above. Nonetheless, this question is preferred as people who are less cognitively competent e.g. children, intellectual disability are found to relate better to such a context. While the current question may not be an exact substitute for the original question in the PWI-A scale, it will provide as an optimal approximate at this stage, until further empirical evidence suggests an enhanced version.

2. Scale Administration

2.1. General Information

The scale must be administered on an individual basis to the person with an intellectual disability. It is NOT to be answered 'on behalf of the person' by a caregiver or someone who 'knows the person well'. Such Proxy Responses are invalid in relation to subjective measurement (see Cummins 2002 for a review).

It should be emphasised that there is no time limit. The pre-testing and the full scale administration take from 10 to 20 minutes to complete, depending on the extent of pre-testing required.

2.2. The Testing Environment

When using the scale with people who have a suspected intellectual or cognitive disability it is vital to ensure that the information they supply is valid. This requires great care on the part of the interviewer due to the problem of acquiescent responding.

People with an intellectual or cognitive disability are substantially more likely, than members of the general population, to answer in ways they perceive are desired by the interviewer. This problem is exacerbated by a sense of threat or unease. Such a response bias may be generated through the perception of a power differential or being questioned in an unfamiliar environment.

In an attempt to overcome this problem, the interviewer should take special precautions with the interview process. The interviewer should:

- dress in a manner which does not invoke anxiety;
- they should be prepared to engage in simple social rituals, such as having a cup of tea or meeting other members of the household before testing takes place, and
- should be perceived by the interviewee as friendly, or at least neutral.
- Ideally, the interview should be held on home-ground for the person being interviewed, in a quiet place away from the distractions of other people or television.

2.3. The Role of Caregivers

Caregivers MUST NOT be present during testing. The interviewees should be seen alone or, if absolutely necessary, with one supportive friend of their choice.

2.4. Ethics

Prior to conducting the test, it is the responsibility of the test administrator to ensure that:

- (a) appropriate ethics approval has been obtained from the relevant authority under which they are operating, and also
- (b) that approval for such testing has been obtained from the interviewee or when necessary, the interviewee's parent or legal guardian.

Chapter 4 provides a useful protocol for obtaining informed consent from people who are able to process information at a relatively high level.

2.5. Pre-Testing and Test

Without doubt, the most essential aspect of testing people with an intellectual or cognitive disability is to ensure that they understand the nature of the task they are agreeing to perform. Only then can the test administrator have confidence that the responses being provided are valid. Such assurance requires a carefully constructed pre-testing protocol as follows:

2.5.1. Pre-test Step 1: Initial selection of potential respondents

DO NOT attempt to test anyone who has a severe or profound level of intellectual disability on the PWI-ID. It has now been well established that people who have a severe or profound level of intellectual disability cannot respond validly to this, or any other, scale of subjective wellbeing (e.g. Chadsey-Rusch, DeStefano, O'Reilly, Gonzalez, & Collier-Klingenberg 1992). The only known method of measurement for such people is through behavioral observation. Caveats apply. See Cummins (2004) for further discussion on this topic.

2.5.2. Pre-test Step 2: Testing for acquiescent responding

People with intellectual or cognitive disability are particularly prone to acquiescent responding (see Chapter 3 for discussion). Formal testing for acquiescent responding can take place as follows:

1. After checking that the respondent is comfortable and ready to respond, carefully and slowly proceed as follows:
2. Point to the respondent's watch or some item of clothing. Ask them:
 - a) "Does that (e.g. watch) belong to you?"
 - b) "Do you make all your own clothes and shoes?"
 - c) "Where you live, have you seen the people who live next door?"
 - d) "Where you live, did you choose who lives next door to you? "

Scoring:

If a positive response is provided to items b and d, then it is apparent that the respondent is not sufficiently competent to complete the Index. Hence, no further testing should take place.

2.5.3. Pre-test Step 3: Testing for Likert scale competence using 0-10

If the interviewee passed Pre-test Step 2, formal testing for Likert scale competence can take place. This involves two stages, as establishing the respondent's familiarity with a 0 to 10 distribution, and then testing the person's ability to use a 0 to 10 Likert scale.

The optimal response scale for the interviewee to use is the modified version of the normal 0-10 scale employed with PWI-A, which replaces 'satisfaction' with 'happiness'. This allows maximum discrimination of degrees of happiness and is likely to be within the competence of people with a mild level of intellectual disability.

Procedure

Step 3: Stage 1

Provide the following instructions:

- (a) “Can you count from Zero to 10?”

If ‘Yes’: Proceed to next item.

If ‘No’ : Proceed to Pre-test Step 4

- (b) “OK, can you please now count from Zero to 10.”

If successful: Proceed to Stage 2 within this Step.

If failed: Proceed to Pre-test Step 4

Step 3: Stage 2

1. Present the PWI-ID happiness scale in Appendix A.

2. Provide the following instructions.

“Good. Now, here is a measure of happiness. I am going to ask how happy you feel from Zero - 10.

Zero means you feel VERY SAD [Point to the left side of the scale].

10 means you feel VERY HAPPY [Point to the right side of the scale].

And the middle of the scale is 5, which means you are NEITHER HAPPY NOR SAD [Point].”

“Do you understand this?”

If ‘Yes’: Proceed to tasks (a) to (c) below..

If ‘No’: Repeat just once, then add the following:

“So, four to zero [Point from 4 to 0] means feeling sad to very sad,
six to ten [Point from 6 to 10] means feeling happy to very happy. ”

After repeating, if ‘No’ again, proceed to Pre-test Step 4.

Ask the following questions.

- (a) “If you felt VERY HAPPY, where would you point?” (*exaggerate* VERY HAPPY)
[Respondent must point to 10 for a correct response]
- (b) “If you felt VERY SAD, where would you point?” (*exaggerate* VERY SAD)
[Respondent must point to zero]
- (c) “If you felt just A LITTLE BIT HAPPY, where would you point?” (*say* LITTLE BIT *gently*)
[Accept any score from 6-8]

If the person has succeeded in all the above 3 tasks ('a' to 'c'): Proceed to Step 5A to test that person on the 'happiness with life as a whole' question and the PWI-ID scale, using the 0-10 scale.

If the person has failed ANY ONE of the above 3 tasks: Repeat that task just once.

- *If the person succeeded on the re-test of that task and had also succeeded on the other 2 tasks: Proceed to Step 5A, using the 0-10 scale.*
- *If the person failed on the re-test of that task: Proceed to Pre-test Step 4.*

2.5.4. Pre-test Step 4: Testing for Likert scale competence using a reduced-choice format

When the interviewee cannot use the 0-10 scale, the testing moves through three phases which are designed to determine whether the person can use a reduced-choice format via:

Phase (1): identifying items in order of magnitude (test on size discrimination between blocks),

Phase (2): using a scale with a concrete reference (test on size discrimination and matching between blocks and steps),

Phase (3) using a scale with an abstract reference (test on discrimination between facial expressions).

These Pre-test items are found, beginning from page 13. The testing protocol involves moving the respondent from a concrete (Phase 2) to an abstract (Phase 3) reference. Each of the three testing phase comprises three tasks (labeled 'a' to 'c'), with each task progressing in complexity from a binary choice (task 'a') to a choice involving five elements (task 'c'). Diagrams, provided in this manual (see Appendix), are used for the tests.

The following should be noted:

1. It is important that the respondent has a minimal experience of failure. If they cannot do a task, minimise negative feedback and return to a level of task at which they can succeed. Motivation can be enhanced through appropriate praise and encouragement.
2. As with the administration of all psychological tests, it is vital that the tester is completely familiar with the instrument prior to administration. Practice sessions on family, friends and/or volunteers are essential.

Equipment

The diagrams that are provided will need to be printed so that they can be presented to the respondent as single pages.

Procedure

1. The respondent

- a) During testing, the respondent should be seated at a table with the appropriate diagram in front of them.
- b). The person responds by pointing on the diagram.

2. Pretesting

2.1 Which item should testing commence on ?

Testing should start from Phase I and Task a (2 blocks) in that phase.

2.2 How should testing proceed within each phase and between phases ?

- a) In the starting phase, Phase 1 (Order of Magnitude), the respondent will be tested progressively upwards to a more complex task. That is, commence at Task a (2 choices), then Task b (3 choices) and then Task C (5 choices). The aim is to identify the highest level of choice format the respondent succeeds at.
- b) The respondent must be tested progressively on tasks from the simplest phase (Phase 1) to the most complex [Phase 3 (Use of Abstract Reference)]. To be eligible for testing in the next phase, the respondent must have succeeded in the previous phase, at least, on the simplest task [Task a (2 choices)]. E.g. To be tested in Phase 2, the respondent must have succeeded on Task a (2 choices) in Phase 1.
- c) In any phase, if the respondent fails on the simplest task [Task a (2 choices)], terminate testing completely.
- d) For testing in the next phase, this should commence at the task which uses the highest level of choice format the respondent succeeded with in the previous phase. Eg. If the respondent finally succeeded at Task b (3 choices) in Phase 1, commence testing on Task b (3 choices) in Phase 2.

Should the respondent fail at the task their testing commenced on, they must be tested on the next simpler task. E.g. If the respondent failed Task b (3 choices) in Phase 2, test the respondent on Task a (2 choices) in that phase.

The respondent must NOT be tested on a task that is more complex than the one their testing commenced on. E.g. If testing commences at Task b (3 choices) in Phase 2, and they succeed, they will not be tested on Task c (5 choices).

- e) In Phases 2 and 3, regardless of whichever task the testing commenced with, always adopt instructions of Task a (2 choices) to introduce and orientate the respondent to the testing demands of that phase.

2.3. What if the respondent failed to respond correctly to a task ?

If the respondent fails to respond correctly to a task for the first time, retest JUST ONCE on that task.

2.4. How to determine if the respondent has succeeded on a task?

The respondent must respond correctly to ALL items of a task to be considered as having succeeded with that task.

3. Testing on ‘Happiness with Life as a Whole’ and PWI-ID items using Reduced Choice Response Format (Step 5B)

- a) To be eligible for testing in Step 5B (questions on “Happiness with life as a whole” and PWI-ID scale items), the person must have successfully completed the preceding final phase of pre-testing [Phase 3: Use of an Abstract Reference)]. Even if the respondent was to fail in Phase 3 but succeeded in the earlier two pretesting phases (1 and 2), the respondent will not be eligible for testing in Step 5B.
- b) For responding to the test contents of Step 5B, the response choice format to be adopted should be the same as the highest level of choice format the respondent demonstrated competence with in the preceding Phase 3 of pre-testing. E.g. If the respondent’s highest level of performance is succeeding on Task b (3 faces), the three-choice-response scale format should be adopted in Step 5B.

PRE-TEST: STEP 4

PHASE 1: ORDER OF MAGNITUDE

Order of Magnitude Test

(a) Present the 2-Block Diagram

Procedure: Present the 2-block diagram of extreme sizes (Appendix B1) to the respondent.

Instruction: “Here are two blocks. One of them is bigger than the other.”

Record Succeeded (√) or Failed (x)

Q: “Please point to the **BIGGEST** block”

Q: “Please point to the **SMALLEST** block”

[√ in appropriate box]

Overall Succeeded

Overall Failed

Note: If the person Overall SUCCEEDS: Proceed to task (b) (three choices).
If the person Overall FAILS: Repeat the instruction and Re-test this task just once.

On Retesting this task (a):

- If the person Overall SUCCEEDS: Proceed to Phase 2 and attempt just task (a) (binary choice) in that phase.
- If the person Overall FAILS: Do not proceed to Phase 2 and terminate testing completely.

(b) Present the 3-Block Diagram

Procedure: Present the 3-block diagram of differing sizes. (Appendix B2)

Instruction: “Here are three blocks.”

Q: “First, please point to the **BIGGEST** block”

Q: “Now, please point to the **MIDDLE SIZED** block”

Q: “Please point to the **SMALLEST** block”

[√ in appropriate box]

Overall Succeeded

Overall Failed

Note: If the person Overall SUCCEEDS: Proceed to task (c) (five choices).
If the person Overall FAILS: Repeat the instruction and Re-test this task just once.

On Re-testing **this task (b)**:

- If the person Overall SUCCEEDS: Proceed to Phase 2, Task (b).
- If the person Overall FAILS again: Re-test task (a) just **once**.

...On Re-testing task (a)

- If the person Overall SUCCEEDS: Proceed to Phase 2 and attempt just task (a) (binary choice) in that phase.
- If the person Overall FAILS: Do not proceed to Phase 2 and terminate testing completely.

(c) Present the 5-Block Diagram

Procedure: Present the 5-block diagram of differing sizes. (Appendix B3)

Instruction: “Here are five blocks.”

Q: “Please point to the **BIGGEST** block”

Q: “Please point to the **SMALLEST** block”

Q: “Please point to the **MIDDLE SIZED** block”

Q: “Please point to the **SECOND BIGGEST** block”

Q: “Please point to the **SECOND SMALLEST** block”

[√ in appropriate box]

Overall Succeeded

Overall Failed

Note: If the person Overall SUCCEEDS: Proceed to Phase 2-Task (c) (five choices).
If the person Overall FAILS: Repeat the instruction and Re-test just **once** on this task.

On Re-testing **this task (c)**

- If the person Overall SUCCEEDS: Proceed to Phase 2-Task (c) (five choices)
- If the person Overall FAILS again: Re-test task (b) just **once**.

...On Re-testing task (b)

- If the person Overall SUCCEEDS: Proceed to Phase 2-Task (b) (three choices).
- If the person Overall FAILS: Re-test task (a) just **once**.

...On Re-testing task (a)

- If the person Overall SUCCEEDS: Proceed to Phase 2 and attempt just task (a) (binary choice) in that phase.
- If the person Overall FAILS: Do not proceed to Phase 2 and terminate testing completely.

PRE-TEST: STEP 4

PHASE II: MATCHING TO CONCRETE REFERENCE

Scale with a Concrete Reference

NOTE: For testing which commences at Tasks (b) or (c) in this phase, start by using instruction of Task (a) to introduce the respondent to the testing demands. Then proceed to provide the respective instructions of either Task (b) or (c), prior to testing.

(a) Present the 2-Block Diagram and 2-Step Diagram

Procedure: Present the 2-block and the 2-step diagrams. (Appendix B1 and B4)

Instruction: “Here are the some blocks [present the two-block diagram] and some steps [present the two-step diagram].”

“I want you to point to the step that matches the blocks. That is, the big block must match with the big step, while the small block must match with the small step.”

“So, when I point to the big block [point], you point to the big step [point]. OK?” [repeat if the person seems uncertain].”

“When I point to the small block [point], you point to the small step [point]. OK?”

Record Succeeded (✓) or Failed (x)

[Point to the big block]

Q: “Which step does the **BIG** block go on ?”
(person to point to the correct step)

☐

[Point to the small block]

Q: “Which step does the **SMALL** block go on ?”

☐

[✓ in appropriate box]

Overall Succeeded

Overall Failed

Note: If the person Overall SUCCEEDS:

- Proceed to Phase 3 and attempt just Task (a) (binary choice) in that phase.

If the person Overall FAILS:

- Repeat the instruction and Re-test this task just **once**.

On Retesting this task (a):

- If the person Overall SUCCEEDS: Proceed to Phase 3 and attempt just Task (a) (binary choice) in that phase.
- If the person Overall FAILS: Do not proceed to Phase 3 and terminate testing completely.

(b) Present the 3-Block Diagram and 3-Step Diagram

Procedure: Present the 3-block diagram and the 3-step diagram. (Appendix B2 and B5)

Instruction: Here are three blocks and steps. I want you to point to the step that matches each block. OK?

[Point to the big block]

Q: "Which step does the **BIG** block go on?"

☐

(person to point to the correct step)

[Point to the small block]

Q: "Which step does the **SMALL** block go on?"

☐

[Point to the middle-size block]

Q: "Which step does the **MIDDLE-SIZE** block go on?"

☐

[√ in appropriate box]

Overall Succeeded

Overall Failed

☐
☐

Note: If the person Overall SUCCEEDS:

- Proceed to Phase 3 and attempt just Task (b) (three choices) in that phase.

If the person Overall FAILS:

- Repeat the instruction and Re-test this task just **once**.

On Re-testing this task (b):

- If the person Overall SUCCEEDS: Proceed to Phase 3, Task (b) (three choices).
- If the person Overall FAILS again: Re-test Task (a) (binary choice) in this phase just **once**.

...On Re-testing task (a)

- If the person Overall SUCCEEDS: Proceed to Phase 3 and attempt just Task (a) (binary choice) in that phase.

- If the person Overall FAILS: Do not proceed to Phase 3 and terminate testing completely.

(c) Present the 5-Block Diagram and 5-Step Diagram

Procedure: Present the 5-block and the 5-step diagrams. (Appendix B3 and B6)

Instruction: “Here are five blocks and steps. I want you to point to the step that matches each block. OK?”

[Point to the smallest block]

Q: “Which step does the **SMALLEST** block go on ?”

[REPEAT for other blocks in the following sequence]

Q: “...**BIGGEST**-size block”

Q: “...**MIDDLE-SIZE** block”

“...**SECOND BIGGEST** block”

Q: “...**SECOND SMALLEST** block”

[√ in appropriate box]

Overall Succeeded

Overall Failed

Note: If the person Overall SUCCEEDS:

- Proceed to Phase 3 and attempt Task (c) (five choices) in that phase.

If the person Overall FAILS:

- Repeat the instruction and Re-test just **once** on this task.

On Re-testing this task (c)

- If the person Overall SUCCEEDS: Proceed to Phase 3, Task (c) (five choices)
- If the person Overall FAILS again: Re-test task (b) just **once**.

...On Re-testing task (b)

- If the person Overall SUCCEEDS: Proceed to Phase 3, Task (b) (three choices).
- If the person Overall FAILS: Re-test Task (a) in this phase just **once**.

...On Re-testing task (a)

- If the person Overall SUCCEEDS: Proceed to Phase 3 and attempt just Task (a) (binary choice) in that phase.
- If the person Overall FAILS: Do not proceed to Phase 3 and terminate testing completely.

PRE-TEST: STEP 4

PHASE III: USE OF AN ABSTRACT REFERENCE

Scale with a Abstract Reference

NOTE: For testing which commences at Tasks (b) or (c) in this phase, start by using instruction of Task (a) to introduce the respondent to the testing demands. Then proceed to provide the respective instructions of either Task (b) and (c), prior to testing.

a) Present the 2-Face Diagram

Procedure: Present the 2-face diagram. (Appendix C1)

Instruction: “Here are two faces.”

“One is a happy face [point], one is a sad face [point].”

“Tell me something that makes you **HAPPY**?”

[Respondent’s Reply – X (e.g. eating chocolate)]

“Now, when I ask ‘If you felt **HAPPY** about something (like X)...’, I want you to point to the happy face [point], OK?”

“Tell me something that makes you **SAD**?”

[Respondent’s Reply Y (e.g. people teasing me)]

“Alright, when I ask ‘If you felt **SAD** about something (like Y)...’, I want you to point to the sad face [point], OK?”

“Ready ?”

Record Succeeded (✓) or Failed (x)

Q. “If you felt **HAPPY** about something, which face would you point to?”

☐

Q: “If you felt **SAD** about something, which face would you point to?”

☐

[✓ in appropriate box]

Overall Succeeded

Overall Failed

Note: If the person Overall SUCCEEDS:

- Proceed to Step 5B and use the binary choice to respond to the PWI test items

If the person Overall FAILS:

- Repeat the instruction and Re-test this task just **once**.

On Retesting this Task (a):

- If the person Overall SUCCEEDS: Proceed to Step 5B and use the binary choice to respond to the PWI test items
- If the person Overall FAILS: Do not proceed to Step 5B and terminate testing completely.

(b) Present the 3-Face Diagram

Procedure : Present the 3-face diagram. (Appendix C2)

Instruction: “Here are three faces.”

“They are [point to each in turn] ‘sad’, ‘neither happy nor sad’, and ‘happy’.”

Q: “If you felt **HAPPY** about something, which face would you point to?”

Q: “If you felt **SAD** about something, which face would you point to?”

Q: “If you felt **NEITHER HAPPY NOR SAD**, which face would you point to?”

[√ in appropriate box]

Overall Succeeded

Overall Failed

Note: If the person Overall SUCCEEDS:

- Proceed to Step 5B and use the 3-choice format to respond to the PWI test items.

If the person Overall FAILS:

- Repeat the instruction and Re-test this task just **once**.

On Re-testing this task (b):

- If the person Overall SUCCEEDS: Proceed to Step 5B and use the 3-choice format to respond to the PWI test items.
- If the person Overall FAILS again: Re-test Task (a) in this phase just **once**.

...On Re-testing task (a)

- If the person Overall SUCCEEDS: Proceed to Step 5B and use the binary choice to respond to the PWI test items
- If the person Overall FAILS: Do not proceed to Step 5B and terminate testing completely.

(c) Present the 5-Face Diagram

Procedure : Present the 5-face diagram. (Appendix C3)

Instruction: “Here are five faces.

“They are [point to each in turn] ‘very sad’, ‘a little bit sad’, ‘neither happy nor sad’, ‘a little bit happy’, and ‘very happy’.”

Q: If you felt **VERY SAD** about something which face would you point to?

Q: If you felt **A LITTLE BIT HAPPY** about something, which face would you point to?

Q: If you felt **VERY HAPPY** about something, which face would you point to?

Q: If you felt **A LITTLE BIT SAD** about something, which face would you point to?

Q: If you felt **NEITHER HAPPY NOR SAD** about something, which face would you point to?

[√ in appropriate box]

Overall Succeeded

Overall Failed

Note: If the person Overall SUCCEEDS:

- Proceed to Step 5B and use the 5-choice format to respond to the PWI test items.

If the person Overall FAILS:

- Repeat the instruction and Re-test just **once** on this task.

On Re-testing this task (c)

- If the person Overall SUCCEEDS: Proceed to Step 5B and use the 5-choice format to respond to the PWI test items.
- If the person Overall FAILS again: Re-test Task (b) in this phase just **once**.

...On Re-testing Task (b)

- If the person Overall SUCCEEDS: Proceed to Step 5B and use the 3-choice format to respond to the PWI test items
- If the person Overall FAILS: Re-test Task (a) just **once**.

...On Re-testing Task (a)

- If the person Overall SUCCEEDS: Proceed to Step 5B and use binary choice to respond to the PWI test items.
- If the person Overall FAILS: Do not proceed to Step 5B and terminate testing completely.

Test Step 5A: Happy with Life as A Whole and Personal Wellbeing Index-Intellectual Disability (11-point Scale)

Procedure and Instructions:

Procedure: Continue to show the 0-10 happiness scale, which was shown to the respondent in Pre-test Step 3.

Instruction: “Good. Now, I am going to ask you a few questions about how happy you feel, using this Zero to 10 scale.”

“As I said before, Zero means you feel very sad [Point to the left side of the scale].

10 means you feel very happy [Point to the right side of the scale].

And the middle of the scale is 5, which means you are neither happy nor sad [Point].”

“Using this zero to 10 scale.....” [Proceed to ask each test item below]

Test Items: Record the respondent’s ratings in the appropriate boxes below.

Respondent’s Rating

11-pt

(0-10)

Part I: Happy with Life as a Whole [optional]

“How happy do you feel about your life as a whole?”

Part II: Personal Wellbeing Index – Intellectual Disability

“How happy do you feel about...?”

1. the things you have? Like the money you have and the things you own?

2. how healthy you are?

3. the things you make or the things you learn?

4. getting on with the people you know?

5. how safe you feel?

6. doing things outside your home?

7. how things will be later on in your life?

Test Step 5B: Happy with Life as A Whole and Personal Wellbeing Index- Intellectual Disability (Reduced-choice Scale)

Procedure and Instructions:

- Procedure:**
1. Select the faces-scale that corresponds to the respondent's maximum level of discriminative competence in Pre-test Step 4 - Phase 3.
 2. Show this scale to the respondent and continue with the corresponding instruction provided below.

Instruction: “Good. Now, I am going to ask you a few questions about how happy you feel, using these [Point] faces.”

(i) **If ‘2-face’ diagram**

“As you have seen before, this face means you feel happy [Point].

This one means you feel sad [Point]

When I ask you the questions afterwards, point to the face which tells me how happy you feel.”

“Is that ok ?”

If ‘yes’: Proceed to next item.

If ‘no’: Repeat instruction but just once. Then proceed to next statement.

“Using these faces, ...” [Proceed to ask each test item below]

(ii) **If ‘3-face’ diagram**

“As you have seen before, this face means you feel happy [Point].

This one means you feel sad [Point]

The one in the middle means you feel neither happy nor sad [Point]

When I ask you the questions afterwards, point to the face which tells me how happy you feel.”

“Is that ok ?”

If ‘yes’: Proceed to next item.

If ‘no’: Repeat instruction but just once. Then proceed to next statement.

“Using these faces, ...” [Proceed to ask each test item below]

(iii) If '5-face' diagram

"As you have seen before, this face means you feel very happy [Point].

This one means you feel a little bit happy [Point]

This one means you feel very sad [Point]

This one means you feel a little bit sad [Point]

The one in the middle means you feel neither happy nor sad [Point]

When I ask you the questions afterwards, point to the face which tells me how happy you feel."

"Is that ok ?"

If 'yes': Proceed to next item.

If 'no': Repeat instruction but just once. Then proceed to next statement.

"Using these faces, ..." [Proceed to ask each test item below]

Test Items: (Record the respondent's answers according to the following code, in the appropriate boxes below)

Code:	(a) <u>2-faces</u> (2-pt)	(b) <u>3-faces</u> (3-pt)	(c) <u>5-faces</u> (5-pt)
	Sad = 0 Happy = 1	Sad = 0 Neither Happy nor Sad = 1 Happy = 2	Very Sad = 0 A Little Bit Sad = 1 Neither Happy nor Sad = 2 A Little Bit Happy = 3 Very Happy = 4

Respondent's Rating

2-pt **3-pt** **5-pt**
(0-1) (0-2) (0-4)

Part 1: Happy with Life as a Whole [Optional]

"How happy do you feel about your life as a whole?"

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Part 2: Personal Wellbeing Index – Intellectual Disability

"How happy do you feel about...?"

1. the things you have? Like the money you have and the things you own?

--	--	--

2. how healthy you are?

--	--	--

3. the things you make or the things you learn?

--	--	--

4. getting on with the people you know?

--	--	--

2. Scale Administration continued

5. how safe you feel?

--	--	--

6. doing things outside your home?

--	--	--

7. how things will be later on in your life?

--	--	--

3. Analysis of Grouped Data

3.1. Data Cleaning

While acquiescent responding contaminates all survey and interview data to some degree, people with an intellectual or cognitive disability are particularly prone to this form of responding. There are two main reasons. The first is deference to an authority figure (the interviewer) learned as a consequence of institutional living or dependence on caregivers. The second is defence against appearing incompetent when asked questions they do not understand. Agreement with the question, or answering in the affirmative, is the form of response that is least likely to generate a negative consequence for the person being questioned.

In using the original Comprehensive Quality of life Scale with people who have a mild/moderate level of intellectual disability, in the absence of pre-testing we often found up to 25 percent of people consistently answer at the top of the happiness scale. This may be due to the use of low - discrimination scales (2- or 3- point scales), such that the normal negative response-skew forces response consistency. Alternatively, it may represent acquiescent responding. In either case, the data provide no internal variation and should be eliminated prior to analysis to defend the data set from acquiescent responders.

Therefore, is essential that all data are checked for response sets. These are evident when the respondent scores at the top or the bottom of the scale for all seven Personal Wellbeing Index items. No matter the cause, the lack of variation will distort the data analysis. Hence, data sets from individual respondents showing consistently maximum or minimum scores on all 8 domains should be eliminated prior to data analysis.

3.2. Data Analysis of “Happiness with Life as a Whole” and Personal Wellbeing Index Items.

Standardize all data into units of a 0 to 100 point distribution. This is achieved by shifting the decimal point one step to the right. E.g. a value of 6.0 becomes 60 points.

3.3. Data Analysis converting raw scores into the standard 0 – 100 scale format

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For the purpose of creating results that can be simply compared with one another, we convert all data to a standard form, which makes it look as though they had all been rated on a 0 – 100 point scale. The values derived from this process are called ‘percentage of scale maximum’ (%SM). This conversion does not alter the statistical properties of the data, since the process is a simple linear conversion, but it has the advantage that data from the PWI and other scales can be directly compared in terms of their means and standard deviations.

The conversion of PWI scores, which have been derived from a 0 – 10 response scale, is simple. The conversion is achieved by simply shifting the decimal point to the right. For example, a score of 7 becomes 70 %SM, or a mean score of 6.56 becomes 65.6%SM.

When comparisons are to be made with other data that have been derived from different response scales, such as ones that use a 1 – 5 rating, then the values derived from the scale can be converted to the standard 0 – 100 %SM through the use of the formula below.

$$\frac{X - k^{\min}}{k^{\max} - k^{\min}} \times 100$$

X = the score or mean to be converted

$k^{\min}$ = the minimum score possible on the scale
ie If a scale is score from 1 to 5, then $k^{\min} = 1$
If a scale is score from -5 to +5, then $k^{\min} = -5$

$k^{\max}$ = the maximum score possible on the scale
ie If a scale is score from 1 to 5, then $k^{\max} = 5$
If a scale is score from -5 to +5, then $k^{\max} = +5$

Example 1

A mean score of 3.5 on a scale rated from 1 to 5.

$$\frac{3.5 - 1}{5 - 1} \times 100 = 62.5\%SM$$

Example 2

A mean score of +3.5 on a scale rated from -5 to +5.

$$\frac{+3.5 - (-5)}{+5 - (-5)} \times 100 = \frac{+8.5}{+10} \times 100 = 85.0\%SM$$

Standardize all Likert scale data on happiness, into units of Percentage of Scale Maximum (%SM) on a 0 to 100 distribution. This is achieved by the following procedures for data derived from different scale formats:

(a) For 11-point scale

- Convert data derived from a 0 to 10 point scale by shifting the decimal point one step to the right. E.g. a value of 6.0 becomes 60.

(b) For Reduced-choice scale

Step 1: Code the likert scale from 0 to X, where '0' represents the lowest response category and 'X' represents the highest. E.g. a 1–5 scale would become 0–4.

Step 2: Perform calculation using the following formula,

$$[(\text{Score}/X) \times 100]$$

where ‘Score’ refers to the reported group mean value and ‘X’ represents that as previously defined. Eg. A score of 3.0 would become $[(3.0/4) \times 100] = 75$

3.4. Data Interpretation

Data derived on the Personal Wellbeing Index-ID scale items may be used either at the level of individual domains, or the domain scores may be aggregated and averaged to form the Personal Wellbeing Index (PWI).

The item “Happiness with Life as a Whole” **IS NOT** a component of the PWI and hence, should be analysed as a separate variable. This item is used to test the construct validity of the PWI using multiple regression. Each domain should contribute unique variance and the normative data using this technique are shown in Appendix B and C.

The mean of the domain scores derived from the PWI constitutes a measure of Subjective Wellbeing. Such a datum can be referenced to two types of normative data as follows:

- (a) If the datum is the score of an individual person, it can be referenced to the normal distribution of individuals within a population. The Australian normative range for individuals is 50-100 points.
- (b) If the datum is the mean score of a group, it can be referenced to the normal distribution of group means. The normative range for Western means is 70-80 points. The normative range for Australia is 73.4 – 76.4 points.

Note: These values are generally ‘around 10 percentage points lower for Asian populations’ due to a cultural response bias e.g. Chinese (Lau, Cummins & McPherson, 2005).

4. Obtaining Informed Consent

The first formal interaction should be to inform the person about the nature of the evaluation process. This involves two stages as the provision of information, and then testing the person to ensure that they have understood the information provided.

Stage 1

The information provided to the person should include a description of the following (IASSID, 2003):

- a) Why the research is being proposed.
- b) Who is to conduct the research.
- c) How the research is to be conducted and what it involves.
- d) The possible outcomes to the research for the person, including any potential benefits, potential risks or possible adverse consequences.
- e) How individual information will be kept and who could have access to it.
- f) The person's rights with respect to their declining or agreeing to participate and, if they agree to participate, their right to later withdraw at any time.
- g) That there will be no adverse consequences to them if they decline to participate or later withdraw.

Stage 2

In order to test whether the interviewee has understood this information, a set of questions should be asked similar to the following, which have been taken from Arscott, Dagnan & Kroes (1998):

- a) "What will I be talking to you about?"
- b) "How many times will I want to talk to you?"
- c) "Are there any good things about talking to me?"
- d) "Are there any bad things about talking to me?"
- e) "What can you do if you decide you won't want to talk to me any more?"

Obviously, the precise form of these questions will depend on the content of the information that has been previously provided. Arscott et al., (1998) used an acceptability criterion of three or more appropriate responses.

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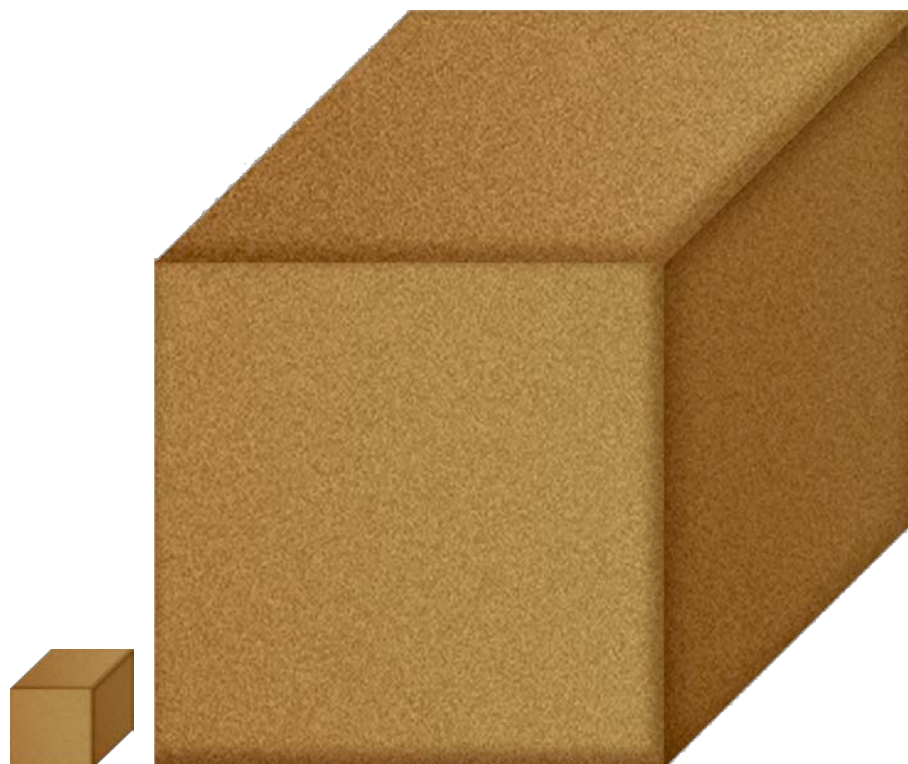
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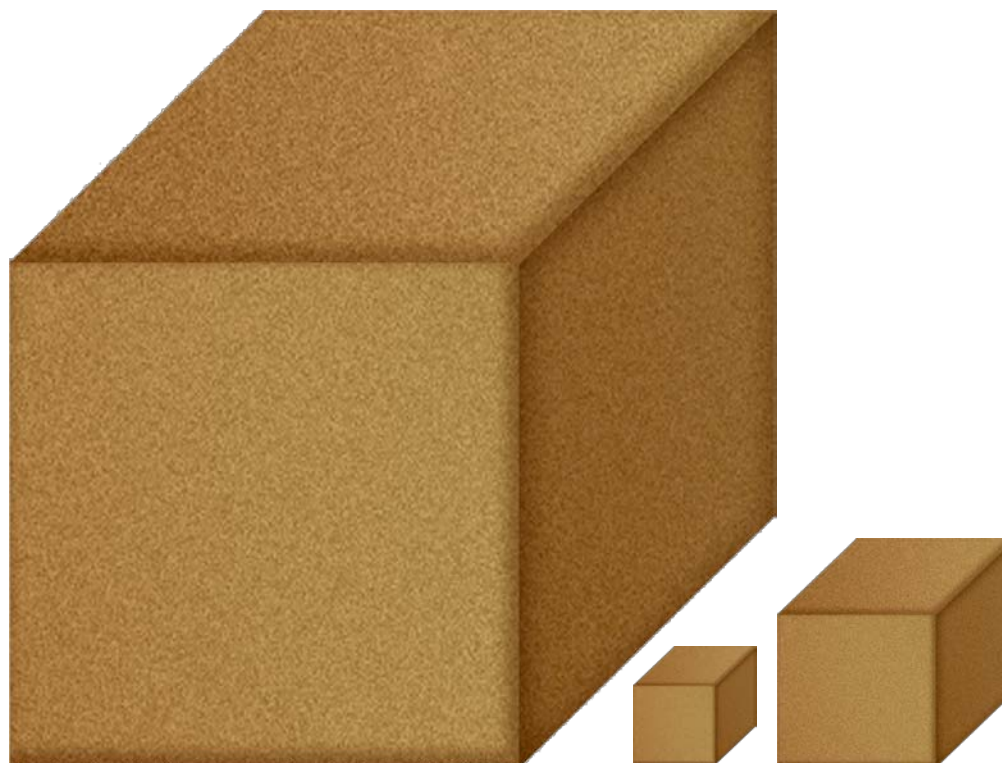
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6. Appendix - Testing Materials

VERY SAD	NEITHER HAPPY NOR SAD								VERY HAPPY	
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	
0	1	2	3	4	5	6	7	8	9	10



TWO BLOCKS



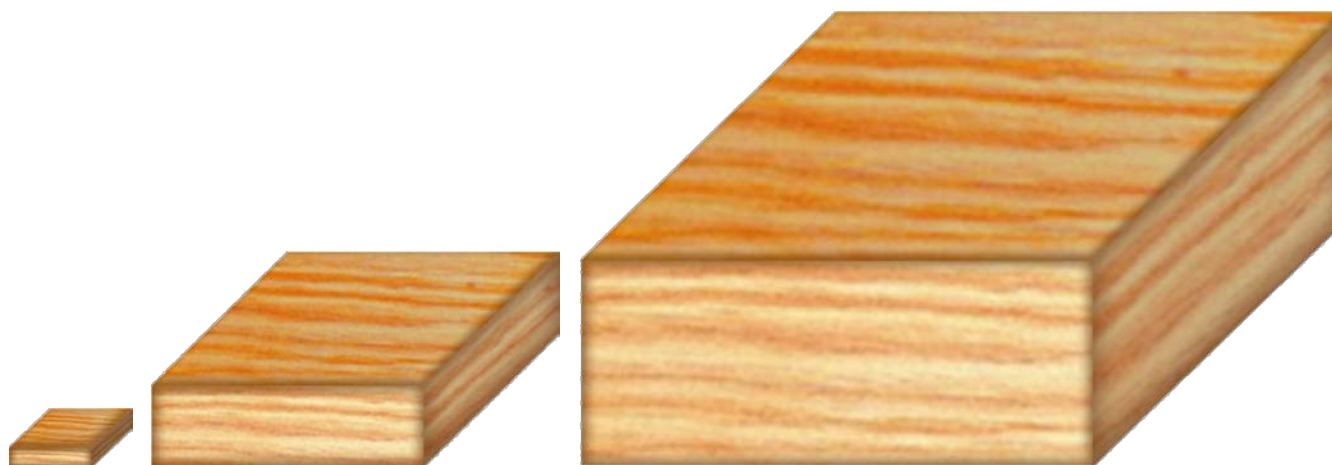
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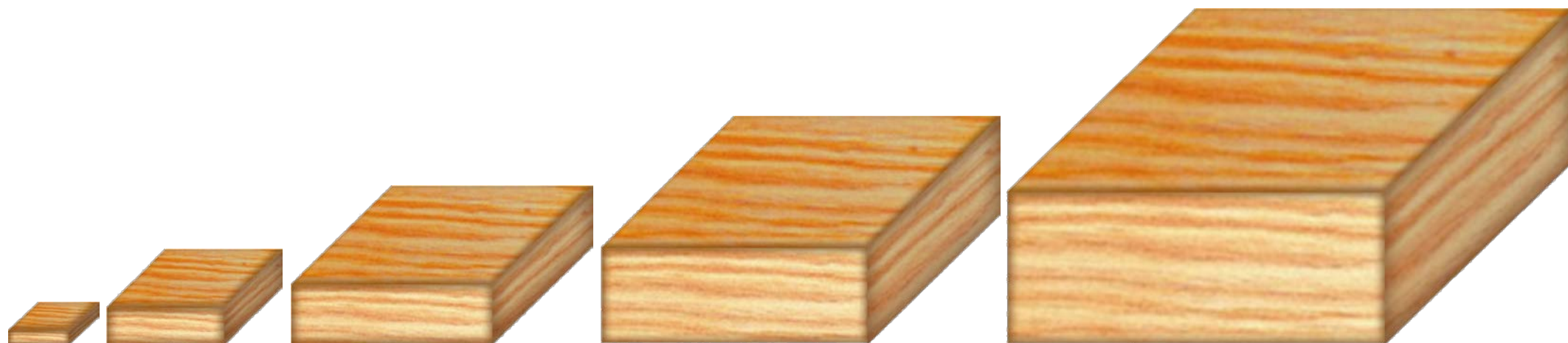
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TWO STEPS



THREE STEPS



FIVE STEPS



