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The measurement of subjective wellbeing in people with intellectual disability in Australia.

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Abstract

The importance of measuring quality of life, and most particularly the personal wellbeing of people with intellectual disabilities (ID), is now recognized. The measurement of wellbeing is an important component of program evaluation and can assist in the identification and planning of individualized support needs. There remains, however, a need for further research in this area. This paper describes a new scale, the Personal Wellbeing Index Intellectual Disability Scales (PWI-ID), which has been shown to be valid and reliable. Data is presented regarding its use in the measurement of wellbeing in people with ID and the focus of discussion is on its advantages and limitations.

The measurement of quality of life has been the focus of increased research attention with respect to people with ID. The importance of this work lies in the fact that the right to receive services and the conditions of life that promote wellbeing in this population is now enshrined in legislation & policy. Local examples are the Disability Services Act (Commonwealth of Australia) (1986); Disability Act (Victoria) (2006); Victorian State Disability Plan 2002-2012. The principals & rights inherent in these and similar Acts have fuelled efforts to develop valid & reliable measures of quality of life in people with ID. Quality of life is increasingly being employed as an outcome measure in service delivery and to evaluate specific interventions. Such measures have the potential to assist in the identification and planning of individualized support needs and also to enhance the consumer’s role in these processes.

There is now general consensus, that quality of life should be conceptualized as a multi-dimensional construct (Cummins, 2005; Petry, Maes, & Vlaskamp, 2007; Verdugo, Schalock, Keith, & Stancliffe, 2005), with various components of an individual’s life contributing to their overall quality of life. It is also widely accepted that a combination of both objective and subjective dimensions of wellbeing are critical in determining overall quality of life (Cummins, 2000; Verdugo et al., 2005). However, there is generally poor correspondence between these
dimensions (i.e., objective measures do not equate with happiness) and thus each requires separate consideration (Cummins, 2003). Importantly, it seems that where basic needs are met, life quality can be most meaningfully assessed by subjective variables. It is thus important that life satisfaction be measured from the perspective of the person with ID.

The capacity to respond on their own behalf, of course, is dependent on the intellectual and communicative ability of the individual concerned. ‘Proxy responding’, which involves the provision of responses by another person on behalf of the person with the disability, is occasionally adopted to overcome the respondent’s difficulty in coping with the cognitive demands of self-report scales. This method, however, has been found to be unreliable and invalid for assessing subjective wellbeing in individuals with ID (Cummins, 2002; Perkins, 2007; Rapley, Ridgeway & Beyer, 1998; Schalock et al., 2002; Stancliffe, 1999). The review by Cummins (2002) further concludes that validity is not improved by the use of multiple proxies, nor is it likely that acceptable validity could be achieved through proxy training. Reliable assessment of subjective aspects of wellbeing is thus likely to be restricted to individuals with milder levels of disability.

A further issue in assessment of wellbeing relates to the desirability of being able to norm-reference findings regarding particular groups against the general population and to be able to apply common theoretical principles. Whilst a number of potentially relevant scales for the assessment of wellbeing in individuals with ID have been developed, for example the Quality of Life Scale (Schalock & Keith, 1993), the Lifestyle Satisfaction Scale (Heal & Chadsey-Rusch, 1985), and the eight-domain Model of Quality of Life (Verdugo, Gomez & Martinez, 2007) these scales do not allow ready comparison with normative samples. Furthermore, most wellbeing scales designed for the general population are not suitable for individuals with ID due to a lack of sensitivity to their learning characteristics, in terms of their scale construction or procedural aspects involved in their administration. For example, individuals with ID often have difficulty in sequencing information or events and with processing abstract concepts. They also commonly acquiesce or perseverate in their responses and the likelihood of response bias increases with level of disability (Schalock & Felce, 2004).

The need for a valid and reliable measure of subjective wellbeing that is appropriate for self-report by individuals with mild to moderate levels of ID and enables comparison with general population norms has led to the development of a parallel version of the Personal Wellbeing Index (PWI) (The International Wellbeing Group, 2006) suitable for people with intellectual disability or other forms of cognitive impairment (PWI-ID) (Cummins & Lau, 2005).

The PWI has been widely used for assessing subjective wellbeing in the general population. In recognition that the construct of quality of life can be represented across several life domains, the PWI scale asks respondents how satisfied they are with each of seven domains. These domains include standard of living, personal health, life achievement, personal relationships, personal safety, community connectedness, & future security. More recently, an additional domain of religion/spirituality has been included. The scale has shown strong stability over time and has been demonstrated to be valid and reliable (Cummins, Woerner, Tomyn, Gibson & Knapp, 2007). Its Cronbach (alpha) lies between 0.7 and 0.8 and a single stable factor derived from the seven domains predicts over 50% of the variance in “satisfaction with life as a whole”. The PWI is imbedded in the Australian Unity Wellbeing Index in which the Australian general population is surveyed on a quarterly basis regarding how satisfied they are with their lives. This data provides a norm reference for specific sub-groups, including people with ID.
In addition to the availability of a normal comparison sample, the PWI-ID has several other advantages. It commences with a comprehensive pre-testing protocol that includes a screen for acquiescent responding; a test for Likert scale competence; and a determination of whether the individual is able to reliably respond, as well as the level of complexity at which they are able to do so. In this way, individuals who are not able to respond reliably are excluded from testing at the outset. The PWI-ID has the option of a reduced choice format (2-3-5-pt) involving a series of illustrations of happy to sad faces for those unable to use the standard 11 point rating scale. These are systematically presented during the pretest to assess the individual's ability to manage a scale with an abstract reference and are used as an alternative reduced choice format during testing.

In contrast to the general population version of the PWI, the PWI-ID includes simplified and concretely worded questions. Questions referring to 'satisfaction' are substituted by the term 'happiness'. Although it is recognized that these two terms are not equivalent, with some research suggesting that 'happiness' is an affective component which is closely related to, but conceptually different from 'satisfaction', which is cognitive dominant (e.g., McDowell & Newell, 1996; Okun & Stock, 1987), previous research has indicated that they yield very similar data (Cummins, Eckersley, Pallant, Misajon & Davern, 2001; Lau, Cummins & McPherson, 2005).

The PWI-ID has been demonstrated to be a reliable and valid tool for the measurement of subjective wellbeing in a recent study of 114 Australians with ID, ranging in age from 18-60 years (mean age of 33 years) (McGillivray, Lau, Cummins & Davey, in press). This sample was comprised of 82 individuals with mild ID and 32 individuals with moderate ID. The selection criteria of being able to follow simple verbal instructions and offer verbal responses meant that these participants were at the upper end of the moderate range. The majority lived with parents and or siblings in the family home and most were engaged in sheltered employment or vocational training. Regarding psychometric properties, the scale demonstrated sound reliability and validity. It had a minimum Cronbach alpha value of 0.76 and good test-retest reliability (intra-class correlations coefficient of 0.572, and test-retest coefficient of 0.58). All of the scale items demonstrated an item-total correlation higher than the recommended minimum of 0.30, and one-factor emerged to explain 58% of the variance. Collectively the domains demonstrated satisfactory predictive power to explain satisfaction with "life as a whole" (refer to McGillivray et al. for more detail regarding this study).

Domain ratings range from 70.5 to 82.1, with a mean PWI-ID score of 77.08. The personal relationships and feeling part of the community domains had the highest mean scores, with scores for health and future security being below the PWI-ID mean score. These results are similar to those obtained in a 2005 Victorian general population sample in which domain scores ranged from 75.3 to 83.7, with a mean PWI score of 78.8 (Lau et al., 2005). They are also similar to those from a larger Australian sample (Cummins et al., 2007) where domain ratings ranged from 72.4 to 80.1, with a mean PWI of 77.6 (refer Table 1 for comparisons).
Table 1: PWI range of Australian ID sample and Australian general population samples.

<table>
<thead>
<tr>
<th>DOMAINS</th>
<th>AUST ID</th>
<th>AUSRTALIAN GENERAL POPULATION</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>PWI-ID</td>
<td>PWI</td>
</tr>
<tr>
<td></td>
<td>McGillivray et al. (in press) n=114</td>
<td>Lau et al. 2005 n=180</td>
</tr>
<tr>
<td>Standard of living</td>
<td>75.2</td>
<td>83.7</td>
</tr>
<tr>
<td>Health</td>
<td>70.5</td>
<td>76.2</td>
</tr>
<tr>
<td>Life achievement</td>
<td>79.3</td>
<td>75.3</td>
</tr>
<tr>
<td>Personal r/ships</td>
<td>82.1</td>
<td>81.1</td>
</tr>
<tr>
<td>Personal safety</td>
<td>79.3</td>
<td>82.9</td>
</tr>
<tr>
<td>Feeling part comm.</td>
<td>81.8</td>
<td>74.0</td>
</tr>
<tr>
<td>Future security</td>
<td>72.4</td>
<td>75.5</td>
</tr>
<tr>
<td>PWI</td>
<td>77.1</td>
<td>78.8</td>
</tr>
<tr>
<td>Life as a whole</td>
<td>75.3</td>
<td>79.4</td>
</tr>
</tbody>
</table>

It is often assumed that people with ID have a reduced quality of life (Cummins, 1997). The external resources available to them may be lower than that of their non-disabled counterparts (Cummins, 2005). Also, negotiating life with a disability can present a considerable challenge, possibly leading to a fragile personal quality of life system. However, the McGillivray et al. results support previous findings that people with ID do not report quality of life lower than individuals without disability (Cummins, McCabe, Romeo, Reid, & Waters, 1997; Pretty, Rapley, & Bramston, 2002). On the basis of the theory of homeostasis (Cummins, 2005) people with ID, like other people, may actively maintain their wellbeing within a narrow positive range (Cummins & Nistico, 2002). Even in situations where adverse factors cause defeat, adaptation returns satisfaction to previous levels over time and subjective wellbeing is maintained above a minimum threshold. Furthermore, McGillivray et al.‘s finding of no significant difference between the PWI-ID scores of participants with mild versus moderate ID and between those who could use the full 11-point version of the scale versus those restricted to the reduced choice format, could also indicate homeostasis at work to maintain satisfaction against the challenge of greater disability.

The value of the pre-test of the PWI-ID for teasing out people unable to reliably report subjective wellbeing is demonstrated clearly in a recent total agency study of 60 residents with ID (15 mild, 39 moderate, 4 severe) (McGillivray & Woerner, 2007). Of these individuals, 37 were unable to complete the pre-test and a further 6 were excluded during testing due to response bias. Thus only 28% (n=17) of the sample were able to successfully complete the PWI-ID.

Of those 37 unable to complete the PWI-ID, the majority 43.2% demonstrated acquiescent
responding); 9 (24.3%) could not successfully complete Step 4-Phase 1 (Order of magnitude test); and a further 5 (13.5%) discontinued at Step 4-Phase 2 (Matching to concrete reference) (see table 2). Of the 17 who were successful, the majority (82.4%, n=14) were able to use the standard 11-point scale, with one each using 2-, 3-, and 5-point scales.

Table 2: Number or participants x Level of discontinuation of PWI-ID testing.

<table>
<thead>
<tr>
<th>Point where testing ceased</th>
<th>Number of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Failed step 1 (Initial selection criteria)</td>
<td>3 n=8.1</td>
</tr>
<tr>
<td>Failed step 2 (Test for Acquiescent responding)</td>
<td>16 n=43.2</td>
</tr>
<tr>
<td>Failed step 3 (Test for Likert scale competence, counting from 1-10)</td>
<td>1 n=2.7</td>
</tr>
<tr>
<td>Step 4 (Test for Likert competence reduced choice format)</td>
<td></td>
</tr>
<tr>
<td>Failed step 4 – Phase 1 (order of magnitude-discrimination between blocks)</td>
<td>9 n=24.3</td>
</tr>
<tr>
<td>Failed step 4 – Phase 2 (matching to concrete reference – size discrimination and matching blocks to steps)</td>
<td>5 n=13.5</td>
</tr>
<tr>
<td>Failed step 4 – Phase 3 (using abstract reference – discrimination between facial expression)</td>
<td>2 n=5.4</td>
</tr>
<tr>
<td>Withdrawn from participation</td>
<td>1 n=2.7</td>
</tr>
<tr>
<td>Total</td>
<td>37 n=100.0</td>
</tr>
</tbody>
</table>

The measurement of subjective wellbeing with the PWI-ID is limited to individuals in the mild and moderate ranges of ID. Examination of the relationship between level of ID and success on the PWI-ID indicates the importance of conducting the pre-test. Those able to complete the PWI-ID were comprised of 11 individuals with mild ID (64.7%) and 6 individuals with moderate ID (35.3%). Those unable to complete the test were comprised of 4 individuals with mild ID (11.4%), 27 with moderate ID (77.1%) and 4 in the severe range (11.4%). Thus it cannot be assumed that all individuals in the mild range of ID are able to complete the PWI-ID. Although time consuming, the pre-test is required whenever cognitive impairment is suspected and this is not always clearly evident, especially in borderline individuals.

Although more research is required, there appears to be good support for the PWI-ID as a measure of subjective wellbeing in most individuals with ID in the mild range and some individuals with moderate levels of ID. Given that more disabled individuals are not able to self-report and that proxy responding is not reliable, the measurement of quality of life in these individuals presents a challenge. Some indication may be obtained through a focus on more tangible, objective circumstances of living. These variables tend to involve counts of frequency or quantity that are amenable to observation by others. For example, the number of social outings undertaken by the individual, the number of times they are administered PRN medication, or the degree of impairment they experience on the basis of concomitant physical or sensory disabilities. Alternatively, the focus may be on individualized measures of goal attainment or may involve systematic recording of positive versus negative response, tracking of non-verbal communication, etc. Although these variables inevitably involve some degree of subjective judgement, if they are tightly defined, they can yield a high degree of inter-rater
agreement. Although these measures may provide some indication of some aspects of quality of life, of course, it would not be valid to infer SWB from them.

Several researchers have undertaken work on the measurement of quality of life in severely disabled individuals. Lyons (2005), for example, has developed the Life Satisfaction Matrix, a procedure and instrument for assessing the subjective quality of life of individuals with profound multiple disabilities (PMD). This work is based on the assumptions that life satisfaction is improved when more time is spent on preferred activities; inner states are expressed through consistent behavioural repertoires; these can be discerned by familiar others and validated by independent others; and that routine daily activity preferences can be determined from their affective behavioural repertoires. Perhaps in some individuals it really comes down to careful monitoring of their reactions and then promoting activities that result in an absence of distress.

Petry et al. (2007) have recently attempted to operationalize quality of life for people with profound multiple disabilities. On the basis that subjective experience is difficult and perhaps impossible to assess in people with profound disability, Petry et al.’s instrument is limited to a proxy approach. An item pool was developed and then assessed by an expert panel for structure and content. The final instrument is comprised of 176 wellbeing items, including measures of outcomes and support roles. Items relate to the areas of physical wellbeing (mobility, health, hygiene, nourishment, rest); material wellbeing (living environment, technical aids); social-emotional wellbeing (communication, treatment, basic security, family bonds, social relationships, social participation); development and activities (engagement, influence and choices, development). Petry et al. acknowledge that these objective variables do not directly measure subjective wellbeing. However, they may provide a measure of some of the key components of a quality life.

In conclusion, the PWI-ID is a reliable and valid instrument for measuring subjective wellbeing in people with intellectual disability in the mild – moderate range. The availability of normative data for comparison is an important feature of this instrument. The pre-test is an essential component of the testing protocol, enabling the identification of individuals who are not able to successfully complete the PWI-ID. We now have data from individuals with ID to use for comparison and as a basis by which to detect and address any anomalies in particular individuals or sub-groups, and to inform service delivery. The measurement of wellbeing in people with profound & multiple disabilities continues to present a challenge.

References


**Victorian State Disability Plan 2002-2012.** Melbourne, Victoria: Disability Services Division, Department of Human Services, Government of Victoria.