



# Quality of Life of Adults with an Intellectual Disability

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## Abstract

**Purpose of Review** Quality of life can be measured both objectively, by frequencies and quantities, and subjectively through feelings. The subjective dimension is the most difficult to measure and the topic of this review.

**Recent Findings** Subjective wellbeing is commonly measured by asking how “happy” or “satisfied” people feel on a standardized set of questions. One crucial requirement is that these questions are the same for everyone, whether they have a disability or not. This ensures equivalent standards for judging high and low life quality. The Personal Wellbeing Index meets these requirements. It contains seven items, three of which form the “Golden Domain Triangle” as satisfaction with money, relationships, and achieving in life.

**Summary** These three “Golden Domains” represent the key resources supporting life quality for both disabled and non-disabled people. For service provision to be maximally effective in facilitating life quality, it should target sufficiency in these areas.

**Keywords** Quality of life measurement · Life domains · Subjective wellbeing · Homeostasis theory

## Introduction

There are two very different ways of measuring the life quality of individual people. The traditional form of measurement concerns the objective circumstances of their life, such as the standard of their accommodation and the number of their friends. Such measures are valued by governments and service providers because the collected data can be verified by other people. However, an equally important form of measurement cannot be experienced by anyone other than the individual person. Subjective Wellbeing (SWB) is more challenging to measure, yet it is crucial in defining the overall experience of life quality. As Schalock [1] points out, if people feel their lives are not worth living, then what is the use of life?

SWB is measured at the level of individuals by each person rating their satisfaction with a standard list of life areas. So is it worth the bother to make this additional measure? An intuitive expectation is that the objective and subjective dimensions are so closely related to one another that such measurement is

redundant. Surely people who are extremely wealthy and healthy will also have an extremely high level of SWB? Curiously, and importantly, this is not so. An authoritative review within the disability literature [2] describes the strength of the relationship as being only “modest” (p. 458), which opinion has liberal support within the empirical literature. Therefore, finding an explanation for this counter-intuitive finding requires an understanding of the underlying science.

## Understanding Subjective Wellbeing

The standardized measurement of SWB has yielded data with several strange features. One of these is that the level of SWB is both positive and remarkably stable over time. This was first demonstrated at a population level by Cummins [3] who used the sample mean scores from multiple surveys as data. When such data from Western population samples were standardized into a standard 0–100 percentage-point (pp) format, the grand mean was 75 pp, with a standard deviation of just 2.5 pp. Thus, within the range 70–80 pp, there is a 95% probability of including any Western population mean score.

Since that time, the normative range for SWB has been refined in two main ways. First, the inclusion of non-Western population mean scores has expanded the normal range downward to 60–80 pp [4]. The second refinement is to make the normative range relevant to individual people.

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This range has been calculated for Australia [5•] using the Australian Unity Wellbeing Index surveys, which measure SWB using the Personal Wellbeing Index [6]. Table A2.1 of this publication shows that based on the responses from 60,000 people, the population mean is 75 pp and a standard deviation of 12.5. This provides a normative range for individuals between 50 and 100 pp. In other words, not only is the level of SWB remarkably stable but it is also normally positive.

The usefulness of this normative range is immense. It allows a determination of whether the mean scores of population groups, or the scores of individuals, are normal (within range) or pathological. Such determination has usefulness for policy, in allowing the identification of population sub-groups with high levels of pathological functioning [7]. It also has great importance for researchers studying the properties of SWB because samples high in pathology (scores of < 50 pp) exhibit abnormal psychometric characteristics [8].

While these normative standards have been calculated using general population data, a crucial understanding is that they apply to everyone, including people with a disability [9]. The reason for this universality is that the level of SWB for each person is being genetically managed around a set point. Thus, each person's natural level of SWB is set genetically and does not change due to disability [10].

### Set Points and Homeostasis

Within physiology, it has been understood for over 80 years [11] that biological parameters which must be kept at constant levels are managed by homeostatic systems. Consistent with the description by McEwen and Wingfield [12], homeostasis can be defined as the “management of an essential variable to a set-point, representing an optimal level for the operation for each individual.”

Each homeostatic system manages its own dependent variable to a level dictated by a genetic “set point.” A familiar example is the core body temperature. When forces external to the homeostatic system cause movement of the variable away from its set point, the system generates counteractive measures designed to return the variable back to its optimal level. For example, the sensation of feeling cold causes changes in blood distribution and behavior, both directed to retain more body heat [10].

There has been much controversy over the existence of set points for SWB. While it has long been suggested that SWB has a strong genetic basis [13], the evidence that such set points exist has been elusive. However, this has recently changed, with the first demonstration of SWB set points showing that they have a normal distribution within the range of about 70 to 90 pp on the 0–100 pp scale [14]. Moreover, this finding has been confirmed using two different data sets

[15]. Thus, this essential component for the demonstration of SWB homeostasis is now in place (for a review see [16••]).

The second component of homeostasis is the system that maintains SWB around its set point for each person. That is, a system that recognizes the optimum level of the managed variable, as determined by the set point, and seeks to return the variable to that level if it is displaced [17••]. In order to understand this system, a deeper understanding of SWB is required.

### The Character of SWB

SWB can be described as normally positive, stable, and mainly comprising mood. The positivity and stability characteristics have already been described. Understanding mood requires further explanation.

When most authors define SWB, they cite classic publications such as [18] and [19]. These support the statement that SWB comprises a mix of high positive affect, low negative affect, and cognition in the form of a global, personal life assessment. This view requires revision. As first demonstrated by Davern et al. [20] and confirmed using factor analysis and structural equation modeling [21–23], the composition of SWB is dominated by mood. It is this mood, named homeostatically protected mood (HPMood) [24], which homeostasis is maintaining at a steady level around its set point.

HPMood provides each person with a constant, stable, gentle, background level of affective positivity, and alertness. This constant mood can be described as a general feeling of low-level contentment but also comprises happy and alert [10]. Homeostasis is responsible for maintaining HPMood at a level that approximates set point for each individual person. This does not mean, however, that SWB is stable.

While it is postulated that HPMood is indeed stable, as dictated by each set point, measured SWB also includes emotion. This is the affective response to cognitive processing, informing conscious experience of changes in the perceptual environment and internal processes. Thus, due to the mood + emotion combination, conscious evaluations of SWB show considerable variation. In a recent review of longitudinal state-trait model analyses, Yap et al. [25] estimate that about a third of the measured variance in life satisfaction is stable even over very long time periods, another third changes slowly over time, and the remaining third is occasion specific. While these proportions require substantiation, the general model is a good initial estimate. Certainly, there is substantial variation in the levels of measured SWB on a moment-to-moment basis, due to strong experiences challenging homeostatic control. Thus, the overall level of stability in SWB is consistent within a homeostatic system which has a limited capacity to prevent acute change, but with a substantial capacity to bring SWB back to set point on a chronic basis.

As evidence of this homeostatic capacity, within normal population samples, only a very small proportion of Australian people lie below the scale mid-point. Using data from over 60,000 people gathered over 13 years by the Australian Unity Wellbeing Index surveys [26], only around 4% of scores lie below 50pp. It is, thus, normal for people to feel good about themselves, whether they have a disability or not [27].

## Measuring Subjective Wellbeing

SWB is referred to by a number of different positive terms, such as mood happiness or life satisfaction. This is not very important for understanding because such terms are highly correlated with one another and generally refer to the same construct (see, e.g., [28, 29]). While measurement scales for SWB come in many shapes and sizes, the simplest measure involves a single question: “How satisfied are you with your life as a whole?” This is by far the most commonly used measure, much beloved by researchers running surveys because it takes up minimal space in their questionnaire. However, this single question is not as reliable as scales with multiple items. Over the years, a great number of such multi-item scales have been devised, as can be seen by the “Instrument” list available from the Australian Centre on Quality of Life. So, one of the key issues facing scale developers and scale users is the method by which the items for such scales are chosen in order to be efficiently and validly representative of the SWB construct.

A determined effort to address this issue took place in 2002 when members of the Special Interest Research Group of the International Association for the Scientific Study of Intellectual Disabilities (IASSID) considered how best to define life quality. The result of their deliberations was published in Schalock et al. [2] and includes the opinion that “Most conceptions of quality of life share these common features: general feelings of well-being, feelings of positive social involvement, and opportunities to achieve personal potential” (p. 458). While few people would disagree with this view, the statement is so general that it does not greatly assist decisions as to what aspects of life should be measured and which should not. This understanding can best come from dividing QOL into sectors, called life domains, and then empirically testing these domains for relevance.

Within the generic literature, the idea that QOL measurement could be achieved through life domains was first operationalized by Andrews and Withey [18]. Since that time, many authors have followed within the context of both the general population (e.g., [30, 31]) and people with a disability (e.g., [32–34]). While a very substantial literature has developed progressing these ideas, the IASSID group proposed two overriding principles for domain-scale development, both of

which hold sway today. One is that any set of domains proposed as forming a scale must encompass the complete QOL construct. The second principle is that the same set of domains must be used for both people with and people without a disability.

Developing a scale that meets these two principles has proved to be challenging. There is concern that any collection of domains (a) may not reliably represent the SWB construct for all population sub-groups and (b) that each domain will have different levels of relevance for each individual. A solution to this problem was provided by Evans [30], through his “personal integrative model.” This requires that all domains must relate to the global construct of “satisfaction with life as a whole” (Global Life Satisfaction: GLS).

One scale that meets these requirements is the Personal Wellbeing Index (PWI: 6) and its parallel version, the Personal Wellbeing Index – Intellectual Disability. The seven items ask about satisfaction (or happiness) with the standard of living, health, achieving in life, relationships, safety, connection to the community, and future security. It is proposed that these domains are sufficiently universally relevant, in sharing unique variance with GLS, to form a valid comparative scale [31].

This requirement can be tested statistically by multiple regression. Here, data from the seven domains are together regressed against data from GLS. If the domains really do represent the global construct, then each domain will contribute unique variance to GLS. However, when tested empirically, the extent of their unique contribution is found to be quite variable [6, 35]. For example, in general population Australian samples, the domain of “safety” rarely makes a unique contribution to GLS, while in general samples from other countries, it does [6]. However, the seven domains do represent an approximation of Evans’ [30] “personal integrative model,” accounting for some 45 to 50% of the variance in GLS.

A further examination of the pattern of domain contributions reveals that three of the domains are more universally reliable than the other four. These three key domains are money, achieving, and relationships.

## The Golden Triangle Domains

The three Golden Domains of money, relationships, and achieving in life represent the major resources which facilitate homeostasis. While their primary function is to defend against homeostatic failure, they can also assist homeostatic recovery. Each of these three will now be separately considered.

### Money

There are serious misconceptions as to what money can and cannot do in relation to SWB. People who are rich experience

rapid adaptation to high living standards, so living in a mansion with servants may feel luxurious in the short term, but over time, it will just feel “normal.” Moreover, high wealth cannot shift the set point to create a perpetually happier person. So, in this sense, money cannot buy happiness. No matter how rich someone becomes, once their level of income saturates the wealth-dependent buffering capacity of the homeostatic system, additional wealth will not raise SWB further [10].

The real power of wealth is to protect wellbeing through its capacity as a flexible resource to assist homeostasis [36]. It does this by allowing people to minimize the unwanted challenges they experience in their daily life. Wealthy people pay others to perform tasks they do not wish to do themselves. Thus, SWB rises, from low income to high income, as an asymptotic curve.

The power of money is particularly evident for people who are disabled. Such people are more likely to encounter discrimination, to be unemployed, and to have ill health and dependence on care staff. So, for these people, the importance of money to support homeostasis is often magnified. This has been confirmed in a major study by Emerson and Hatton [37]. Their cross-sectional investigation, of 1273 people with a mild or moderate level of intellectual disability in England, revealed that health status was dominantly predicted by the level of socioeconomic disadvantage. Of particular note was their finding that the predictive power of their model was not increased by the addition of commonly measured variables describing personal characteristics and living circumstances.

## Relationships

The second golden domain is an interpersonal relationship involving the mutual sharing of intimacies and support. Almost universally, the research literature attests to the power of such relationships to moderate the influence of stressors on SWB [38]. Because of this positive influence, the quality of social relationships for the residents of share homes is strongly associated with happiness [39], self-esteem, and confidence [40].

Many different aspects of the living environment can be engineered to facilitate friendship formation and maintenance. These include architectural design and the organization of shared activities [41]. But, the most important facilitating agent is a positive staff attitude to relationship formation among the people in their care. This is especially crucial for those people with a disability who have limited mobility and difficulty interacting with other people. While it might be expected that social media use would also assist friendship formation, results from the general adolescent population are cautionary. A recent large-scale panel study [42] found that social media use was not, in and of itself, a strong predictor of life satisfaction. Rather, some people benefited under some conditions, which seems to make good sense.

What is more certain is the power of emotionally intimate relationships is painfully evident in their absence. When relationships are insufficient for people’s needs, they feel lonely and excluded. The dreadful consequence is a highly susceptible to depression.

## Achieving in Life

The process of active engagement, providing purpose in life, is the third golden domain [43]. In their review, McKnight and Kashdan [44] conceive purpose in life as “a cognitive process that defines life goals and provides personal meaning.” A voluminous literature attests to the fact that when people lose this homeostatic buffer through; for example, unemployment, their SWB is severely threatened [45].

There are two main ways people engage in an activity that provides them with a purpose in life. One is taking an active role in a family group and the other is through outside employment [46]. People with a disability are at risk of having neither avenue open to them.

When people live in an institution or group home, the simplest and most cost-efficient method of care is to create predictable routines and for the staff to conduct the necessary operational procedures. This, then, deprives the residents of the most available source of activity through which they could gain a sense of purpose and responsibility, by contributing to the collective. Organized activities are a weak substitute because they lack self-direction. The result of these institutional processes is to deny the residents access to an important golden domain.

## Conclusions

It is concluded that the seven domains of the Personal Wellbeing Index (PWI) meet the theoretical and practical requirements of a domain-based scale to measure subjective life quality. In theoretical terms, the PWI measurement is a valid representation of subjective wellbeing (SWB) due to its item content, representing the first-level deconstruction of Global Life Satisfaction. In practical terms, the scale is parsimonious by virtue of its construction. The PWI also meets the requirement of being applicable for all people, thereby ensuring that the same standard of SWB, used to judge life quality, is universal.

Of the seven domains forming the PWI, three domains represent key resources supporting homeostasis for both disabled and non-disabled people. These “Golden Domains” are money, relationships, and achieving something of personal value to give life purpose. It is notable that providing for each of these domains represents a severe challenge for service providers. Nevertheless, targeting these three resource areas

is usually the most effective means of facilitating normal levels of subjective life quality [10].

## Compliance with Ethical Standards

**Conflict of Interest** Robert Cummins declares no conflicts of interest relevant to this manuscript.

**Human and Animal Rights and Informed Consent** This article does not contain any studies with human or animal subjects performed by any of the authors.

## References

Papers of particular interest, published recently, have been highlighted as:

- Of importance
- Of major importance

1. Schalock RL. The conceptualization and measurement of quality of life: current status and future considerations. *Journal on Developmental Disabilities*. 1997;5(2):1–21.
2. Schalock RL, Brown I, Brown R, Cummins RA, Felce D, Matikka L, et al. The conceptualisation, measurement, and application of quality of life: report of an international panel of experts. *Ment Retard*. 2002a;40:457–70.
3. Cummins RA. On the trail of the gold standard for life satisfaction. *Soc Indic Res*. 1995;35(2):179–200.
4. Cummins RA. The second approximation to an international standard of life satisfaction. *Soc Indic Res*. 1998;43(3):307–34.
5. Capic T, Hutchinson D, Fuller-Tyszkiewicz M, Richardson B, Khor S, Olsson C, et al. Australian Unity Wellbeing Index: - Report 34.0 - The Wellbeing of Australians: Financial Wellbeing. Melbourne: Australian Centre on Quality of Life, School of Psychology, Deakin University. <http://www.acqol.com.au/projects#reports>; 2017b. **This paper contains normative ranges for subjective wellbeing**
6. International Wellbeing Group. *Personal Wellbeing Index Manual: 5th Edition*. Melbourne: Australian Centre on Quality of Life, School of Psychology, Deakin University; 2013. Available from: <http://www.acqol.com.au/instruments#measures>.
7. Tomy AJ, Weinberg MK, Cummins RA. Intervention efficacy among 'at risk' adolescents: a test of subjective wellbeing homeostasis theory. *Soc Indic Res*. 2015;120(3):883–95.
8. Richardson B, Fuller-Tyszkiewicz MD, Tomy AJ, Cummins RA. The psychometric equivalence of the personal wellbeing index for normally functioning and homeostatically defeated Australian adults. *J Happiness Stud*. 2014;15(1):43–56.
9. Cummins RA, Lau ALD, Davey G, McGillivray J. Measuring subjective wellbeing: the personal wellbeing index - intellectual disability. In: Kober R, editor. *Enhancing the quality of life of people with intellectual disability: from theory to practice*. New York: Springer; 2010. p. 33–46.
10. Cummins RA. Using subjective wellbeing homeostasis to understand the personal impact of neurodevelopmental disorders. *Advances in Neurodevelopmental Disorders*. 2018d;2(2):151–9. <https://doi.org/10.1007/s41252-017-0039-z>.
11. Cannon WB. *The wisdom of the body*. New York NY: Norton; 1932.
12. McEwen BS, Wingfield JC. The concept of allostasis in biology and biomedicine. *Horm Behav*. 2003;43(1):2–15.
13. Tellegen A, Lykken DT, Bouchard TJJ, Wilcox K, Segal N, Rich S. Personality similarity in twins reared apart and together. *J Pers Soc Psychol*. 1988;54:1031–9.
14. Cummins RA, Li L, Wooden M, Stokes M. A demonstration of set-points for subjective wellbeing. *J Happiness Stud*. 2014b;15:183–206.
15. Capic T, Li N, Cummins RA. Set-points for subjective wellbeing: A replication and extension. *Social Indicators Research*, doi: 101007/s11205-017-1585-5. 2017.
16. Cummins RA. *Subjective Wellbeing Homeostasis - Second edition*. New York Oxford University Press; 2017a. Available from: <http://www.oxfordbibliographies.com/view/document/obo-9780199828340/obo-9780199828340-0167.xml>. **This is a review of subjective wellbeing homeostasis.**
17. Capic T, Li N, Cummins RA. Confirmation of subjective wellbeing set-points: foundational for subjective social indicators. *Social Indicators Research*. 2018;137(1):1–28 **This is the confirmation of setpoints for subjective wellbeing.**
18. Andrews FM, Withey SB. *Social indicators of well-being: American's perceptions of life quality*. New York: Plenum Press; 1976.
19. Diener E. Subjective well-being. *Psychol Bull*. 1984;95:542–75.
20. Davern M, Cummins RA, Stokes M. Subjective wellbeing as an affective/cognitive construct. *J Happiness Stud*. 2007;8(4):429–49.
21. Blore JD, Stokes MA, Mellor D, Firth L, Cummins RA. Comparing multiple discrepancies theory to affective models of subjective wellbeing. *Soc Indic Res*. 2011;100(1):1–16.
22. Longo Y. The simple structure of positive affect. *Soc Indic Res*. 2015;124(1):183–98.
23. Tomy AJ, Cummins RA. Subjective wellbeing and homeostatically protected mood: theory validation with adolescents. *J Happiness Stud*. 2011a;12(5):897–914.
24. Cummins RA. Subjective wellbeing, homeostatically protected mood and depression: a synthesis. *J Happiness Stud*. 2010a;11:1–17.
25. Yap SCY, Anusic I, Lucas RE. Does happiness change? Evidence from longitudinal studies. In: Sheldon KM, Lucas RE, editors. *Stability of happiness: theories and evidence on whether happiness can change*. USA: Elsevier; 2014. p. 127–45.
26. Cummins RA, Woerner J, Weinberg M, Collard J, Hartley-Clark L, Horfiniak K. Australian Unity Wellbeing Index: -Report 30.0 - The Wellbeing of Australians: Social media, personal achievement, and work. Melbourne: Australian Centre on Quality of Life, School of Psychology, Deakin University. <http://www.acqol.com.au/projects#reports>; 2013b.
27. Cummins RA, McCabe MP, Romeo Y, Reid S, Waters L. An initial evaluation of the comprehensive quality of life scale - intellectual disability. *Int J Disabil Dev Educ*. 1997;44:7–19.
28. Kozma A, Stone S, Stones MJ. Stability in components and predictors of subjective well-being (SWB): implications for SWB structure. In: Diener E, Rahtz DR, editors. *Advances in quality of life: theory and research*. Great Britain: Kluwer Academic Publishers; 2000. p. 13–30.
29. Anglim J, Weinberg MK, Cummins RA. Bayesian hierarchical modeling of the temporal dynamics of subjective well-being: a 10 year longitudinal analysis. *J Res Pers*. 2015;59(3):1–14.
30. Evans DR. Enhancing quality of life in the population at large. *Soc Indic Res*. 1994a;33:47–88.
31. Cummins RA. The domains of life satisfaction: an attempt to order chaos. *Soc Indic Res*. 1996;38:303–32.
32. Felce D, Perry J. *Quality of life: the scope of the term and its breadth of measurement*. Cheltenham, UK: Stanley Thornes; 1997. p. 56–71.
33. Perry J, Felce D, Lowe K. Subjective and objective quality of life assessment: their interrelationship and determinants. *Welsh Centre*

- for Learning Disabilities. Wales, UK: : University of Wales College of Medicine.; 2000.
34. Schalock RL, Keith KD. Quality of life questionnaire. Worthington, OH: IDS Publishing; 1993.
  35. Cummins RA. Cultural Response Bias. In: Keith KD, editor. Encyclopedia of cross-cultural psychology. New York: Wiley-Blackwell; 2013b. p. 1–4. <https://doi.org/10.1002/9781118339893.wbeccp604/pdf>.
  36. Cummins RA. Personal income and subjective well-being: a review. *J Happiness Stud.* 2000b;1(2):133–58.
  37. Emerson EB, Hatton C. Socioeconomic disadvantage, social participation and networks and the self-rated health of English men and women with mild and moderate intellectual disabilities: cross sectional survey. *Eur J Pub Health.* 2008;18(1):31–7.
  38. Sarason IG, Sarason BR, Pierce GR. Social support: the search for theory. *J Soc Clin Psychol.* 1990a;9(1):133–47.
  39. Chadsey J, Beyer S. Social relationships in the workplace. *Ment Retard Dev Disabil Res Rev.* 2001;7:128–33.
  40. Srivastava AK. Developing friendships and social integration through leisure for people with moderate, severe and profound ID transferred from hospital to community care. *Tizard Learning Disability Review.* 2001;6:19–27.
  41. Forrester-Jones R. Friendships and social integration through leisure. *Tizard Learning Disability Review.* 2001;6:28–32.
  42. Orben A, Dienlin T, Przybylski AK. Social media's enduring effect on adolescent life satisfaction. *Proc Natl Acad Sci.* 2019;116(21):10226–8.
  43. Trope Y. Self-enhancement and self-assessment in achievement behavior. In: Sorrentino RM, Higgins ET, editors. Handbook of motivation and cognition: foundations of social behavior. New York: Guilford; 1986. p. 350–78.
  44. McKnight PE, Kashdan TB. Purpose in life as a system that creates and sustains health and well-being: an integrative, testable theory. *Rev Gen Psychol.* 2009;13(3):242–51.
  45. Clark AE, Diener E, Georgellis Y, Lucas RE. Lags and leads in life satisfaction: a test of the baseline hypothesis. *Economic Journal.* 2008a;118:F222–F43.
  46. Schaffer RH. Job satisfaction as related to need satisfaction in work. *Psychological Monographs.* 1953;67:14.

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