Caregivers as Managers of Subjective Wellbeing: A Homeostatic Perspective

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Background This paper proposes that the adequacy of service delivery and caregiving to people who are disabled should be assessed using two criteria. One is the objective circumstance of living, which should be at a standard acceptable to the community at large. The other is a level of subjective wellbeing (SWB) within the normal range.

Method This latter criterion is a novel conception based on an understanding that SWB is homeostatically managed to lie normally within a narrow range of values.

Results People who have a disability are more likely than usual to have a fragile homeostatic system because of the additional life challenges imposed by their disability. Conclusions The role of a caregiver is to provide resources and protection against strong threats to homeostasis, thereby ensuring that the person in their care has a normal-range level of SWB.

Keywords: caregivers, disability, homeostasis, quality of life, subjective wellbeing

Introduction

This paper provides an integration of subjective wellbeing (SWB) theory with the responsibility of caregiving. The broad framework for this thesis is well understood. Caregivers have a responsibility to facilitate the wellbeing of the people in their care (hereafter 'people'). But what does this really mean? How are caregivers supposed to 'facilitate' wellbeing and how do they know if they are succeeding? This paper will argue that such responsibilities can be understood through SWB homeostasis theory and the measurement of people's SWB as an outcome. This framework also provides guidance as to the nature of the caregiving environment that is likely to facilitate people's SWB. So, in order to place this account into context, it is first necessary to describe SWB as a measurable phenomenon.

Subjective Wellbeing

The systematic study of SWB is now over 30 years old. Two extraordinary publications (see Andrews & Withey 1976; Campbell *et al.* 1976) launched the idea that 'happiness', 'subjective quality of life', 'life satisfaction' and SWB could be reliably measured and that such meas-

ures exhibit trait-like properties. While the terms above may legitimately be used to indicate somewhat different aspects of the wellbeing construct, I will not pursue these differences here. These terms are operationalized by measures that produce far more shared than unique variance, and SWB is now widely accepted as the generic descriptor. The research base interrogating and describing this construct is now vast and the dismal science of psychology has finally discovered its positive side. However, any new endeavour that threatens the status quo will meet resistance.

Prior to 1976, and indeed for several decades following, there was general skepticism concerning the measurement of 'happiness', most particularly through the process of asking people how happy they felt. Economists, in particular, were scathing in their condemnation of such measurement as scientifically trivial (see McCloskey 1983). Surely, they argued, people's reported happiness will vary hugely from one moment to the next such that, even if they are prepared to report accurately their own perceived wellbeing, which is also unlikely, then momentary fluctuations will make such measures unreliable.

The two seminal publications in 1976 cited above provided substantial and compelling evidence that such

judgments were unfounded. That, in fact, measures of SWB could be reliable, valid and sensitive to expected population differences, such as rich people being happier than those who are poor. Despite the nay-sayers the research floodgates had been opened. There was an exponential rise of interest, most particularly within the social sciences, and much understanding has subsequently been achieved.

Perhaps the most important idea to gain acceptance was that these new measures were different from the traditional 'wellbeing' measures. Prior to 1970, wellbeing was assessed in purely objective terms, most commonly in terms of wealth or health. Money, according to the economists, was a proxy for happiness (e.g. Wilson 1972), and more is better. But the new measures of SWB were producing data inconsistent with this view. Physically able people were found not necessarily more satisfied with their lives than people with a disability. So, the subjective measures were accessing something different from the objective indicators. Quality of life (QOL), as a global construct, clearly had two components that were somewhat related to one another, yet different.

This objective–subjective distinction has survived and remains as the most fundamental idea underpinning understanding the QOL construct. In order to gain a complete view of life quality, both objective and subjective measures must be made. Moreover, it is invalid to combine such different types of measures into single scales, given the variable nature of their relationship to one another.

Subjective Wellbeing Homeostasis

In order to understand how the objective world of tangible quantities influences the private world of perceived life quality, a theory of 'subjective wellbeing homeostasis' has been proposed. This posits that, in a manner analogous to the homeostatic maintenance of blood pressure or temperature, SWB is actively controlled and maintained by a set of psychological devices (see Cummins & Nistico 2002 for an extended description) that function under the control of core affect (Davern, 2005). The operation of these devices is most evident at the level of general, personal wellbeing. That is, homeostasis operates at a non-specific, abstract level, as exemplified by the classic question 'How satisfied are you with your life as a whole?' Given the extraordinary generality of this question, the response that people give reflects their general state of SWB which it is proposed, is approximately the level at which the homeostatic system operates. As one consequence, the level of satisfaction people record to this question has the following characteristics:

- 1 It is remarkably stable. While unusually good or bad events will cause it to change in the short term, over a period of time homeostasis will normally return global satisfaction with life to its previous level (see Headey & Wearing 1989; Hanestad & Albrektsen 1992; Suh & Diener 1996).
- **2** The 'set-point', around which an individual's SWB varies, lies in the 'satisfied' sector of the dissatisfied-satisfied continuum. That is, on a scale where zero represents complete dissatisfaction with life and 100 represents complete satisfaction, people's set-point normally lies within the positive-scale range of 50–100 (see Cummins *et al.* 2002).
- **3** At a population level within Western nations, the average is 75. In other words, on average, people feel that their general satisfaction with life is about three-quarters of its maximum extent (Cummins 1995, 1998).

While this generalized sense of wellbeing is held positive with such remarkable tenacity, it is not immutable. A sufficiently adverse environment can defeat the homeostatic system and, when this occurs, the level of SWB falls below its homeostatic range. For example, people who experience the chronic pain of arthritis or the stress of caring for a severely disabled family member at home have low levels of SWB (e.g. Cummins 2001). However, for people who are maintaining a normally functioning homeostatic system, their levels of SWB will show little relationship to normal variations in their chronic circumstances of living.

Set points

Central to the idea of homeostasis is the 'set-point' for SWB, and recent studies by Davern (2005) point to its origin in a construct called 'core affect' (Russell 2003). Core affect is not linked with any object but, like body temperature, can be brought to consciousness. It is 'free floating' in that, in the absence of challenge by experience, it will attain its genetically endowed level of positivity. Also like body temperature, it is most evident to consciousness when the level of experienced affect lies outside the normal set-point range.

As measured by Davern (2005) it can be represented as the combined affects of satisfaction, happiness, contentment and excitement. These represent the activated and deactivated positive quadrants of the affective circumplex (for a review of affect see Cropanzano

et al. 2003). Core affect is envisaged as the tonic state of affect that provides the activation energy, or motivation, for behaviour. It also produces cognitive awareness in interaction with both genetic and experiential memory.

Core affect perfuses all cognitive processes to some degree, but the ones that are most strongly influenced are those rather abstract notions of the self (e.g. I am a good person). These self-perceptions are held at strength of positivity that approximates core affect.

Homeostatic Buffers

The set-point range of wellbeing is under constant threat. Environmental experience is seldom neutral. Thus, interaction with the environment constantly threatens to move wellbeing up or down in sympathy with such experience. And to some extent this does occur. Strong and unexpected positive or negative experience will shift the sense of personal wellbeing to abnormally higher or lower values, at least for a brief period of time. However, there are two kinds of defences against this happening. The first is to avoid, or at least attenuate, negative environmental interactions. This is the role of the external buffers. The second is to ensure that the negative experience, when it does occur, does not diminish the positive sense of self, and this is the role of the internal buffers. The external buffers will be discussed first.

External buffers

Anything that protects people from the potentially negative experiences in their environment can be considered an external buffer. For example, the distinctive nuns' habit affords some protection within the population at large. Other people have personal characteristics that make people react to them more positively than usual. These attributes may be either physical (e.g. being physically attractive) or behavioural (e.g. friendliness). But the two most important buffers for people in general are money and relationships.

Money is the most desirable commodity on earth. But there are misconceptions as to what it can and cannot do in relation to personal wellbeing. What it cannot do is shift the set point. So, in this sense money cannot buy happiness because, no matter how rich someone is, their set point will determine their average level of SWB. Moreover, people adapt readily to luxurious living standards, so genetics trumps wealth at the high-end of wellbeing. However, what wealth can do is to maximize people's genetic potential for happiness by increasing the probability that they will maintain their set-point range in conditions of potential adversity.

In these terms, money is the most flexible resource in terms of its capacity as an external buffer (see Cummins 2000a). Wealth allows people to minimize the negative potential inherent within their environment. Wealthy people pay others to perform the maintenance tasks they do not wish to do themselves. If they are bored they buy entertainment, if they are medically ill they buy the best medical care. Companionship, also, can be readily purchased. on the contrary, poor people lack such resources and are consequentially at the mercy of their environment to a far greater extent.

As an example of the power of money to change the experience of life, the following data are drawn from the Australian Unity Wellbeing Index: Report 12.0 (Cummins et al. 2004). These data are cumulative over 12 general population surveys, each of about 2000 respondents, and derive from the question 'has anything happened to you recently that has caused you to feel happier or sadder than normal?'. On average, about half of the sample responds in the affirmative and these, in turn, are split almost evenly into those who have experienced a positive or a negative event. As can be observed, people on very low incomes are more likely to have recently experienced a sad than a happy event in their lives. This differential probability disappears at higher levels of income (see Figure 1).

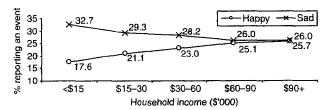


Figure 1 Income versus life event frequency.

The other major type of external buffer is a relationship that involves mutual sharing of intimacies and support. Almost universally, the research literature attests to the power of such relationships as moderators of the relationship between potential stressors and SWB (for reviews see Henderson 1977; Sarason et al. 1990).

Internal buffers

The nature of the internal buffering system in humans is complex. In lower order animals such as slugs it is presumed that core affect is the essential motivator for volitional activity. The relative lack of cognitive activity within such animals means that, aside from habituation and learned avoidance/approach behaviours, there is little in the way of internal buffering. Their set-point for core affect is so dominating that there is little variation.

However, this lack of variation changes as cognitive systems become more complex. Such systems confer the benefit of advanced information processing, but the downside is elevated levels of conscious awareness and imagination. Such systems have the potential to control the set point through the imposition of pathological thoughts concerning either the dark side or the bright side of life. As the set point is, presumably, the average optimum setting for the SWB system, the potential for such pathology must be controlled. Hence the homeostatic system needed to be developed. Its function is to protect the set-point setting for SWB against the conscious reality of life. A detailed discussion of these systems is provided in Cummins & Nistico (2002) and Cummins et al. (2002).

Robustness and Fragility

Homeostatic systems can be inherently robust or they can be fragile. To some extent this dimension is a product of the person's constitution and to some extent it is dependent on resources.

In terms of constitution, this attribute has been studied for many years, commonly under the rubric of 'resilience'. A resilient person is someone who functions normally even in the face of considerable environmental hardship and challenge. The term applied to children denotes that they have developed normally despite adverse living conditions. What allows such people to function in such a robust manner has been much debated, but it may be simply a function of the set point.

Someone with a high set point has the advantage that their normal level of SWB is far away from the 'danger zone' of 50 points which signals an increased probability of depression. Moreover, their high set point will drive extraversion more than neuroticism, ensuring a socially oriented personality that is likely to garner the involvement of other people in the person's life. Thus, their social capital is likely to be high. In addition, the high set point will deliver a robust sense of self-esteem, control and optimism, all of which will ensure a strong buffering system.

What, then, is the nature of the relationship between the circumstances of people's lives and their SWB? Almost universally, researchers assume the relationship to be linear. However, necessarily, if homeostasis theory is correct, the linearity assumption is wrong. All homeostatic systems operate around a threshold. The purpose of homeostatic systems is to create relative stability in whatever system is being defended. In the current context, the positive sense of self is being defended against challenge by sources beyond core affect. Thus, it is predicted, the strength of any source of environmental challenge will show no relationship with SWB provided that homeostasis can be maintained. But at some critical strength, the environmental challenge will become too severe for the homeostatic system to buffer.

When this degree of challenge occurs, the threshold for homeostatic maintenance is breached, and control of personal wellbeing shifts from the homeostatic system to the challenging agent. This causes a change in the correlation between SWB and the challenging agent, from a very weak relationship to strong interdependence as the threshold gives way. A description of this change is provided in Cummins (2000b).

As the challenging agent causes wellbeing to fall, this creates a progressive increase in the condition called depression. The pathological state of depression is hypothesized to be the loss of SWB and the relationship between SWB and the extent of environmental challenge is shown below in Figure 2.

Disability and SWB

The special relevance of SWB within the context of disability lies within the need for services. What should guide the nature of the services that are provided? Should they reflect societal philosophical ideals such as normalization and integration (for reviews see Allen 1989; Emerson & Hatton 1996; Anderson et al. 1998; Felce 1998; Young et al. 1998; Ager 2002), or the dustedoff, recycled form of these constructs as 'social inclusion' (Bates & Davis 2004). Should medical health and norma-

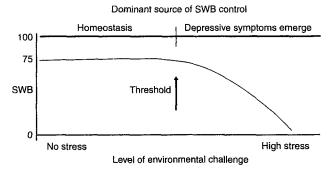


Figure 2 The Relationship between stress and subjective wellbeing.

tive biological functioning be given precedence? Should people be encouraged to be independent?

While all of these issues are relevant to the provision of appropriate service delivery, none define the essence of a life worth living. Almost 30 years ago Throne (1979) pointed out that there was no theoretical reason to predict that the application of normalizing principles would enhance the sense of personal wellbeing, selfconfidence, self-respect or happiness. A later review supported this conjecture (Felce 1998) and highlighted the important insight that normalization is a necessary but not sufficient condition for this purpose. Subsequent research has confirmed this view. For example, physical integration into the general community is certainly not the simple path to happiness (see Cummins & Lau 2003 for a review). Moreover, medical health and biological functioning are mainly independent of SWB (see Cummins et al. 2004), as predicted by homeostatic theory, while living independently has the downside of enhancing the probability of loneliness (see e.g. McDevitt et al. 1978).

All such considerations are too limited in their scope to give unitary guidance to service providers. Clearly they are relevant to the total picture of excellent service provision, but what is the optimum balance between them? Given the reality of limited resources, what emphasis should be chosen in order to deliver the best service to people who require assistance in their daily lives? One way of approaching this vexed issue is to concentrate on a global measure of outcome.

In agreement with many previous authors (Dennis et al. 1993; Renwick et al. 1994; Brown 1996, 1999; Schalock 2004), I suggest that the primary consideration underpinning service delivery should be QOL. In this context Schalock (2004) has elegantly described the QOL concept as a 'sensitizing notion' in that it provides a sense of reference and guidance from the individual's perspective. He also accords it the property of a 'unifying theme', or an inclusive framework for service delivery, and as a 'social construct', in that it provides an over-riding principle upon which service delivery should be based.

Within such a conceptualization, QOL incorporates the essence of normalization (Wolfensberger 1972) in that objective QOL should reflect a standard that is acceptable to the person's society at large. Subjective QOL should reflect the adequacy of the person's environment that permits them to experience normal-range SWB. Thus, in these terms, the primary role of service delivery is to counteract the potentially harmful consequences of disability on the whole person.

Within this framework, two statements of outcome suffice to provide a minimal standard for service delivery. These are:

- 1 To provide an objective life quality that is acceptable to society at large.
- 2 To ensure normal-range SWB.

The former could be measured by an independent panel familiar with the ordinary living circumstances of people in their society. The latter could be operationalized as a level of SWB within the normative range for the general population. Using the Personal Wellbeing Index within the Australian population, this level would be 50 points or higher as a criterion for individuals, and 70 points or higher as a group mean (Cummins et al. 2004).

Therefore, it is of considerable interest to enquire whether people who have an intellectual disability have a normal-range SWB. The answer to this is a qualified 'yes' (see e.g. Wacker et al. 1983; Sands & Kozleski 1994; Cummins et al. 1997; Verri et al. 1999) but there are two caveats. The first is that such measurement can only be validly made by instruments that measure SWB alone. It is not valid, within this context, to employ QOL scales that confound measures of normalization and levels of physical or intellectual ability, adaptive behaviour or challenging behaviour. Thus, excluded from this is the QOL Questionnaire (Schalock & Keith 1993), which is strongly contaminated by adaptive behaviour and challenging behaviour (Schalock et al. 1994).

The second caveat is that, even when people with a disability report normal range SWB, their homeostatic system is likely to be more fragile than normal. This is a consequence of the additional stresses they experience because of the challenges provided by their disability. As a consequence, their ability to regulate their SWB will be somewhat compromized.

Disability and Homeostatic Fragility

The fact of having a disability of any kind is a potential source of challenge to the homeostatic system additional to those faced by the general population. Whether the disability constitutes a source of stress depends on the individual's external and internal resources. If these resources are sufficient to neutralize the additional demands caused by the disability, the homeostatic system will manage SWB and the person will experience normal levels of wellbeing. If the demands exceed the resources, homeostasis will fail, and SWB will lie below the normative range.

While it can be assumed that the genetically determined level of core affect is unaffected by disability, the external resources available to such people may well be lower than is average for the population in general. Many people with a disability have a lower income than is age-normative and many have little control of the income they do receive. Additionally, many will experience more difficulty than is normal in developing friendships or intimate relationships. This problem has been well documented in relation to children (Baldwin 1958; Williams & Asher 1992; Heiman & Margalit 1998), adolescents (Brown & Timmons 1994; Hughes et al. 1999; Hornby & Kidd 2001) and adults (Richardson 1978; Ashman et al. 1990; Edgerton 1990; Azmi et al. 1997). As a natural consequence of this, many of these people feel lonely much of the time (Halpern 1989).

These factors, together with the negative challenge imposed by their disability in negotiating the routines of life, represent a double jeopardy. They have a higher probability of low external resources and a higher probability of encountering difficulties with daily living. As a result, their management of SWB will be more tenuous because their homeostatic systems will be under constant pressure. While this does not imply widespread homeostatic failure it does imply that people with a disability will have a reduced capacity to deal with unexpected negative experiences. They are, thus, predicted to be more susceptible to depression than the general population.

Caregivers and SWB

The increased homeostatic fragility of people with a disability means that interaction with their environment is very important. And when they become dependent on a caregiver, such interaction becomes part of the caregiver's responsibility. This understanding has the potential to allow caregivers to view their role in a new light.

It makes little sense to characterize caregiving responsibilities in such vague terms as 'maximizing the client's potential or 'maximizing their wellbeing' because the meaning of these terms is uncertain. Moreover, characterizing responsibilities in functional terms such as cleanliness or community integration misses the essential target of person happiness. One unfortunate outcome of misunderstanding the role of services provision is exemplified by studies finding that support services provided within the context of a family situation are not always judged as being helpful (e.g. Pixa-Kettner 1998).

In order to develop guidelines for caregivers it is useful to reiterate some of the key ideas that have been discussed. These are:

- 1 If the person who is disabled is provided with a sufficient level of resources, their homeostatic system will take control and manage wellbeing within the person's set-point range.
- 2 These resources may be either external or internal. So how may such resources be facilitated?

It is an unfortunate fact that the provision of adequate external resources in terms of money and relationships is likely to be difficult. Many people with a caregiver are on a pension and have no reasonable prospect of acquiring additional funds. As pensions allow little discretionary expenditure, money is a weak external resource for these people.

Relationships offer another challenge. The presence of a disability severe enough to require a caregiver makes it less likely that the person will have an intimate relationship with some other person. This is particularly true of a severe psychiatric or an intellectual disability. So providing such resources through the caregiving process is often very difficult to achieve. Indeed, many people with an intellectual disability who are asked to list their closest friends will include their paid caregiver (see e.g. Ager et al. 2001) and this has led several authors to recommend strengthening this connection as part of the professional role (e.g. Tonkens & Weijers 1999).

An extended form of relationship is the sense of 'belonging'. This is very different from 'community integration' and a recent article (Cummins & Lau 2003) has argued that the service concentration on objectively defined integration has been largely misguided and without benefit (for discussion see Cummins & Lau 2004; Emerson 2004). Far more relevant to life quality is the subjective sense that one is part of a dependable, supportive social group. Whether the people who comprise this group are themselves disabled or not is entirely irrelevant. In an essay before its time, (Rautman 1943) recognized the importance of this life dimension 'without which no individual can achieve peace or happiness' (p. 449) and he argues, within his context of institutional living that this should be a major staff responsibility. Some 60 years later the living circumstances may have changed but the determination of this responsibility remains largely unfulfilled. Numerous researchers report that people with an intellectual disability, living in community settings, have lower social belonging and lower empowerment than their nondisabled peers (e.g. Bramston et al. 2002).

Internal Resources and Client **Empowerment**

Empowerment and independence are practically synonymous, and independence in our Western society is highly valued. Disability Services Victoria (2000) report on the outcome from 14 focus groups and 444 face-toface interviews involving people with a wide range of disability types. This research sought to determine the life areas that people considered most central to their QOL, and the most essential domain they identified was personal independence. Independence is essentially freedom - the freedoms that are seen to be employed by people who do not have disabilities' (p. 16).

So what is it that allows people to be independent? The answer to this question will generally reflect the most restrictive influence on people's lives, and for people with severe disabilities this is likely to be their level of adaptive behaviour (see e.g. Heal et al. 1998). So, facilitating functional independence is one potential avenue to empowerment. But note judicious use of the use of the term 'potential'. There are two concerns. The first is the recognition of substantial objective barriers to improved adaptive behaviour. These may be biological or behavioural, where the emotional and practical cost of improvement greatly exceeds the potential benefit to life quality. The second barrier may be subjective. There is little point in adaptive behaviour training if the person does not view the end result as desirable. But there is far more to empowerment than adaptive behaviour.

An entirely different level of empowerment is personal confidence and self-esteem. These are crucial concerns as they normally have only the most tenuous contact with objective reality. People who are very physically disabled may have great confidence in themselves and feel highly empowered. Or they may not, and this is clearly an area where caregivers can facilitate perceived independence through positive feedback and by encouraging activities that are regarded as meaningful by the person. But do caregivers commonly act in such facilitating ways?

There is a romantic view of caregiving, quite common within the minds of bureaucrats and academics, which imagine caregivers engaged in judicious training in adaptive behaviour, positive feedback and encouraging desired activities. However, a rather deeper and darker reality is that caregiving can deliver a very different experience. With the best will, caregiving is a burden to the caregiver. Moreover, the more dependent is the person requiring care, the deeper the burden becomes. So, quite naturally and appropriately in order to protect their own wellbeing, caregivers generally seek the easiest way to perform their role. And that does not necessarily involve client empowerment. Teaching is a laborious and time-consuming activity, difficult to sustain in the hurley-burley of ordinary life. Here, efficiency is the key to effective management, and the most efficient way of getting things carried out is to perform them by yourself.

Data in support of this harsh reality are readily available. When hospital staff are caring for profoundly, multiple disabled children, do they choose to spend time interacting and empowering the children, or do they choose to spend time on other, maybe easier, maybe more self-rewarding, tasks? In a UK hospital, Beail (1985) found that staff spent 16% of their time interacting with the children. Similarly, Felce et al. (2002) found in UK group homes that staff spend about one-third of their time directly concerned with the residents. Moreover, increasing the staff/client ratio resulted in a greater increase in staff/staff interaction than staff/client interaction. Supportive findings have been reported in Australia, with Jenkinson et al. (1992) finding a very low level of decision making among the residents of group homes.

This general situation is little different within families. For example, adolescents with an intellectual disability experience less autonomy than their non-disabled counterparts (e.g. Brown & Timmons 1994). And the appointment of guardians may well actually reduce the level of personal control exercised by individuals as their guardians assumed control of their lives (Stancliffe et al. 2000).

However, in this as in most areas of life, more is not necessarily better. A relentless commitment to independence training is not the way to enhance life quality. An important perspective, as noted by Romney (1995), is the considerable individual variation in the extent to which people desire autonomy. Complete control is never a virtue for anyone, yet frequently within the literature researchers assume more is better. It is not. Each individual person has an optimal level of control that will maximally reinforce their SWB. This level will depend on personal preference and limitations imposed by their circumstances of living. Caregivers need to be sensitive to this and provide accordingly.

A different form of empowerment is control of the self, such that those aspects of the environment that the individual finds uncontrollable are ignored or accommodated. This is called 'secondary control' (Rothbaum et al. 1982) and the techniques of such control can be taught. However, in the current context, there is an ethical issue to be addressed.

If a caregiver makes the decision to train the person for whom they are responsible in such techniques, the choice is being made to concentrate not on the acquisition of external resources but on the protection of self against the inadequacy of such resources. It is clear that such strategies have the potential for abuse. Thus, informed consent and independent monitoring of extrinsic resource allocation becomes very important. Provided that such ethical matters were attended to, such training could, in theory, be of great personal benefit. With this in mind a model for effective caregiving is provided below Figure 3 summarizes the hypothesized elements of SWB control and their moderation by caregivers as follows:

- 1 Under normal operating conditions, core affect defines the set-point at which all other systems are held. Thus, the buffering systems and the conscious appraisal of the entire subjective state (SWB) are held at an average strength of 75-points positive.
- 2 Potential stressors are appraised within the buffering systems. It is the role of the caregiver to ensure that these sources of threat remain below the threshold strength that causes homeostatic defeat.
- 3 Caregivers may facilitate the provision of either external or internal resources. External resources may be in the form of money, relationships or active caregiver intervention to reduce the strength of the threat.
- 4 Caregivers may also facilitate internal resources, such that the person is provided with the skills to exert greater control, connectedness, sense of belonging and purpose in life.

In summary, this proposition defines the role of caregivers in terms of maintaining normative levels of SWB. This provides a clear focus for the evaluation of caregiver adequacy that can be empirically evaluated. Notably, it does not comment on the other aspects of life that are normally used as essential benchmarks for successful caregiving such as normalization (Wolfensberger 1972), rights (Ames & Samowitz 1995), integration within mainstream society (Gow et al. 1988; McGaughey et al.

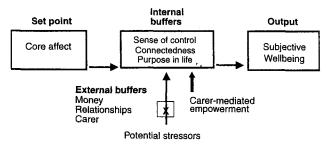


Figure 3 Role of caregivers.

1995; Emerson et al. 2000), or independence (James & Brown 1993). In my view these are all subsidiary to normal-range SWB. All are driven by imposed values, not necessarily shared by the person with the disability. If these imposed values conflict with the needs of the person, the SWB of the individual should be the paramount concern and this, in turn, is the responsibility of the caregiver.

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