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Author: Cummins, Robert

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**Abstract**

The central argument of this paper is that more attention must be paid to providing accommodation options with a concern for each individual's quality of life. It takes the closure of St. Nicholas Hospital in Melbourne as an example. While very disabled people demonstrated a remarkable enhancement in like skills development when out of institutional living, social integration remained low and no subjective measuring of self-esteem, happiness or self fulfilment occurred. The author argues we must change the ways in which we measure success or failure and provides examples of how this can be done. **Keywords: Accommodation**

# **On Being Returned to the Community: Imposed Ideology versus Quality of Life**

**Robert A Cummins**

The closure of institutions for people with intellectual disabilities, and the consequential return of the people to the community, is an ideological imperative among service providers. However, this process of deinstitutionalization is generally undertaken with little or no client choice; an action which relies for its empirical justification on studies which have demonstrated an objective improvement in life quality following such relocations. It is argued here that increased attention should be given to the provision of alternative accommodation options and the measurement of subjective life quality for these people who are returned to the community.

## **Introduction**

While the North American literature has contained systematic studies of deinstitutionalization for more than two decades (e.g. Aninger and Bolinsky, 1977; Conroy and Bradley, 1985; Lord and Pedlar, 1991), the Australian documentation is more recent. The First of these studies, and still the most extensive, documented the closure of St Nicholas Hospital. Located within the inner Melbourne suburb of Carlton, St Nicholas represented the epitome of a Dickensian institution. High ceilings and bare walls caused sounds to reverberate within the wards, small windows restricted natural light and required the day-time use of fluorescent lighting, meals were cooked in a central kitchen, wheelchair mobility was difficult, and there was no privacy. Quite clearly the building was unsuitable for human habitation and, due largely to a series of events which focussed increasing public attention on the place (Eisen, 1979; Cummins and Bancroft, 1980; Crossley and McDonald, 1980) the Government decided to close it down and commission a study into the consequences of relocating the 100 or so residents out of the institution and back into the community.

The study had more interest than simply a local version of previous North American studies. The reason was that the residents were among the most disabled young people in the state. Most had been classified as having severe/profound intellectual disability and many were multiply disabled as well. How would such very disabled people manage the transition to community living?

Previous literature provided no unequivocal answers to this question. Professional opinion was divided on such central issues as whether residents would die from the shock of re-location, and whether people with such severe disabilities would really gain in the development of life skills. The St Nicholas Project was designed to address these issues.

## **The St Nicholas Project**

The study was established in the year prior to hospital closure. Its aim was to evaluate the effects of re-location into Community Residential Units (CRUs) on residents, their families and staff. The CRUs were regular homes in the community, scattered throughout metropolitan Melbourne with a couple located in regional centres. Following necessary modification, such as for wheelchair access, they each housed 4-6 residents and had 24-hour attendant care.

### **Resident Characteristics**

At the beginning of the study period in August 1983 the residents were aged from 5-26 years (mean: 16 years of age). Their duration of residence in St Nicholas ranged from 3-20 years (mean: 9 years). Over 90% had been classified as profoundly/severely intellectually disabled and most had multiple disabilities.

### **Study Design**

Baseline measures were made on two occasions prior to the residents moving into the CRUs; at 6 months prior to and just before they moved. Follow-up measurements were made at 6 months, 12 months and 4 years following the move.

### **Results**

A considerable volume of data emanated from the study and some of the main results have been published as a series of four articles in the Australian and New Zealand Journal of Developmental Disabilities (Cummins and Dunt, 1990; Cummins, Polzin and Theobald, 1990a, 1990b; Dunt and Cummins, 1990).

There were three major findings:

1. There was no increase in the death rate.
2. Life Skill Development: The previous literature suggested that a predictable outcome of being returned to community would be a burst of skill development in the first few months following the move. However, the likely long-term consequences for further development were unclear. On this matter the literature was generally gloomy, suggesting that development could either be expected to stabilise at a low level or the long-term rate of development to be no more than occurred in the institution (Aninger and Bolinsky, 1977). There was, therefore, considerable interest in the long-term outcome for skill development in this particular population.

Skill development was measured using the Progress Assessment Chart (Gunzburg, 1974) and, after four years, calculations could be performed which allowed a comparison of the number of skills that the residents actually had with the number of skills they would have had if they had remained at St Nicholas.

What these calculations revealed was that over the four-year period these people had gained the equivalent of 2.3 developmental years over what they would have experienced by remaining at St Nicholas. This translates into a 46% advantage in skill development over this period.

3. Normalised routines: Other results demonstrated a normalisation in daily routines and activities, an increased level of parental/family contact, and an increased level of engagement in community-activity.

Very positive conclusions were drawn from the above results. They demonstrated a remarkable enhancement in the life-skill development of these very disabled people and this, together with other findings, were highly supportive of the deinstitutionalization philosophy.

## **Objective vs. Subjective Life Quality**

While the data, which emerged from the St Nicholas study, were undoubtedly positive, they also need to be seen in perspective. For example, in absolute terms the level of social integration remained very low. The average rate of contact with relatives rose only to about six times per year and then usually for a brief visit. Similarly, the average rate of contact with friends outside the CRU rose only to a frequency of less than once a week.

So, there is a need to be cautious about the conclusions that can be drawn from this study, and also from the many other similar studies which have now been conducted around the world. While not disputing that the closure of institutions is obviously a good thing, for all sorts of ideological and practical reasons, it is also salutary to examine the kinds of measures people have used in order to judge the effectiveness of the deinstitutionalization process.

Typically researchers measure variables such as the type of accommodation, the number of accessed community resources, the number of life skills, etc. It is notable that these are all objective measures of life quality, and while they are undoubtedly important, they do not reflect how people feel about themselves and their lives. People's feelings lie in the subjective domain which involves a quite different set of variables such as self-esteem, having close friends and intimate relationships, feeling secure in understanding and controlling their immediate environment, and being happy.

It is therefore quite instructive to note this almost exclusive concern with objective measures because, on reflection, is it not the subjective measures, which should concern us more? When we move people back to the community why do we not measure whether they are more happy, more self-fulfilled, more satisfied with their lives?

To the knowledge of this author such studies have not been done, and there are great dangers in assuming that we know the answers. For example, we know from the literature that objective and subjective life quality are very poorly correlated with one another (Andrews and Withey, 1976, Edgerton, 1990). Furthermore, while it seems eminently reasonable to expect an enhanced subjective life quality for these people, what is our point of reference? If we choose the institution then subjective life quality has probably been enhanced for most people, although the data remain to be gathered. But if we choose a quite different reference point, such as "The optimum subjective quality of life that our resources can provide" then we are presented with a quite different picture.

This suggests that we should start to change our focus away from a preoccupation with objective measures and towards an understanding of subjective life quality. In order to bring about such a change in focus our thinking needs to change in at least two ways. We must change the ways in which we measure the success or failure of our interventions: Not just in relation to deinstitutionalization either, but more broadly across the field of human service delivery. We must stop judging success simply on the basis of objective criteria and start asking the recipients of the service how they feel, how their lives have been improved, what they would like to happen, and so on. In this way we can monitor the influence of our interactions on their subjective life quality. The second way in which our thinking should change is to reassess our ideological stance. The fact of the matter is, subjective well being is peripheral to the ideological driving force behind many of our interventions in the area of intellectual disability.

## **Subjective well-being and Ideology**

As we all know, deinstitutionalization has been driven by an ideology with two major tenets based on human rights as:

- The principle of normalisation: The right to live a life-style which is similar to that enjoyed by the population at large.
- The principle of the least restrictive alternative: In which people should be allowed to live as freely as possible from imposed constraints.

While these ideologies have been powerful and positive determinants of change, they also have their limitations because:

- They are justified through the use of objective criteria.
- They do not easily incorporate individual choice.
- People who espouse such ideologies frequently act as though they have discovered the Holy Grail, or some fundamental system of truth, which cannot be challenged.

Well, all ideologies can and should be challenged; no one has access to the absolute truth, especially in terms of what constitutes a high quality life. Moreover, strong ideological commitments have an unfortunate consequence of requiring thinking to conform with the ideology. This inevitably stifles the rational consideration of alternatives. And so, perhaps, it is time to think anew. The achievement of optimum life quality for people returned to the community is still some way off, and optimal life quality cannot be achieved through the continuation of an ideology, which focuses on objective indices, and the imposition of lifestyle. Our next step must be to concentrate on the subjective needs of individuals.

### **Measuring Subjective Well-being**

One of the problems with this line of thinking is gaining agreement on a definition of subjective life quality, and then upon how to measure it. Despite the continuation of uncertainties in this area, a large amount of research has been conducted into quality of life over the past two decades and some general principles have emerged. Indeed, this knowledge has recently been utilised to create a new scale to measure the QOL construct; a scale which is quite different from any previous instrument and which is intended to be state-of-the-art incorporating current understanding of what constitutes quality of life. This scale has been called the Comprehensive Quality of Life Scale, or ComQoL (Cummins, 1992a). It has the following features:

It is multidimensional: There is general agreement in the literature on this point: Any QOL scale should represent several aspects of life quality.

It measures both objective and subjective life quality. Both make an important contribution and yet tend to be poorly correlated with one another.

It contains only relevant variables: In ComQoL this has been achieved through the use of a thorough literature review and two pilot studies. A full description of this process has been published (Cummins, McCabe, Gullone and Romeo, 1992).

It caters for individual differences. Indeed, this is one of the special features of subjective ComQoL. Most scales simply ask questions in relation to 'satisfaction', for example, "How satisfied are you with the money you have?" But if someone does not regard money highly, they could answer very positively yet this could have very little relevance for their subjective QOL. Therefore ComQoL asks

two questions in relation to each QOL domain: First it asks "How important to you is...", and then it asks, "How satisfied are you with...?" The 'importance' is then used as a personalised weighting factor for the measure of satisfaction. These two responses also, thereby, provide insights into the processes of subjective QOL.

Finally, any good scale must use simple language and must be quick to administer. ComQol takes about 20 minutes to complete.

### **Comprehensive Quality of Life Scale - Intellectual Disability**

ComQol-ID (Cummins, 1992b) is a parallel version of ComQol. It measures both objective and subjective life quality across seven life 'domains' of material things, health, productivity, intimacy, place in community, safety, and emotional well-being. For adults without disabilities the scale is self-administered. However, for people with an intellectual disability it is more difficult to administer since the subjective scales require quite a high level of cognitive functioning in order to be validly completed. They require the conceptualisation of the abstract terms 'importance' and 'satisfaction' and the ability to rate these on a Likert Scale.

In order to allow for the valid administration of the instrument, the intellectual disability version (ComQol-ID) incorporates a pre-testing protocol to determine whether the person being tested can validly use the scales. This involves a three-step process as:

- arranging wooden blocks in order of large to small,
- matching the blocks to a 'ladder' scale of size on paper,
- using an importance scale with objects known to be important to the person being tested.

If the person is able to succeed with this pre-testing, then they can use a version of ComQol-ID that adjusts the complexity of the Likert Scale to match their own level of competence. At a minimal level of usage this involves a binary choice for each item.

The level of intellectual functioning required to use the scale is currently the subject of a research project, but preliminary data suggest that it requires an upper-moderate level of functioning. Which brings into question the means by which we might measure QOL in people with a severe/profound level of disability.

An approach we are currently investigating assumes that direct measurement is not possible and third party responses are necessary. Here we are undertaking a two-stage research effort:

1. Can primary carers accurately respond to questions on subjective life quality on behalf of the people for whom they are caring?

This is the traditional way of measuring QOL in people with intellectual disabilities; to ask someone else to give a third-party report. The literature on this topic is skimpy but discouraging, indicating that, in general, people are not able to make valid third-party responses (e.g. Burnett, 1989; Rigby et al, 1990).

For this reason the current edition of ComQol-ID involves a separate section for caregivers where the parent/primary caregiver is asked to respond AS THOUGH THEY WERE THE PERSON. Our

preliminary data are indeed discouraging. The data indicate not only differences in the perceived magnitude of domain importance and satisfaction between carers and clients, but also significant differences in the rank ordering of domains on both of these characteristics.

While these results are as yet tentative due to the relatively small number of cases so far investigated, if they are confirmed such data will reinforce the problems in using third-party responding instead of asking the people themselves.

However, of course, some carers can perform such judgements better than others can and this leads to the second phase of this research as:

2. What kinds of characteristics allow carers to accurately make such determinations on behalf of their clients?

In order to answer this question we plan to measure the personal characteristics of carers which determine how accurately they can predict the subjective QOL of the people in their care. If we were able to make predictions about such characteristics then at least we will be able to make informed decisions when selecting carers for third-party responses on behalf of people who cannot complete the scale themselves.

A copy of the ComQol scale (Third edition) is available on request.

### **Imposed Ideology vs. Quality of Life**

Subjective life-quality, by its very nature, is an individual thing. What comprises a subjectively high QOL will differ between people, and so any system of intervention that seeks to enhance life quality must be sensitive to this. With this in mind let me return to the specific issues of deinstitutionalization and social integration to see what has been achieved and what might be achieved through a new approach.

The problem being posed can be set within the context of Nirje's (1980) six levels of integration as:

- **Physical: Moving physically into community**
- **Functional: Living in community**
- **Organisational: Using community organisations**
- **Social: Mixing socially with members of community**
- **Personal: Developing friendships with members of community**
- **Societal: Full integration into society**

In terms of these six levels it is instructive to note which levels have been achieved through the use of our current approaches to deinstitutionalization. In fact the literature indicates that only the first three levels have been achieved to any significant degree. So, how do we progress further?

One way is to think outside the current ideology in two dimensions. The first is to devise more effective ways of facilitating community integration than placing people in group homes which are isolated from one another in the community. It is probably not surprising that full integration under

such circumstances is difficult to achieve. Such homes can easily form an enclave, which exists within society but is not properly interactive with it. People living in the home can find social companionship within their living environment and venture out only in groups. This is not conducive to personal integration. What is needed are some alternatives. For example:

- Smaller homes than the current 5-6 residents.
- Greater use of the private sector by paying families to provide support to people as a 'boarder' or family member.
- Loose groups of residences: determinedly - spaced housing in a suburban area that allows easy access between say, half-a-dozen homes.

Undoubtedly there are many other types of living arrangements that could be used to facilitate people's interaction with society at large; arrangements which act as an effective bridge to main-stream society and personal integration. Moreover it is interesting to note that, in Victoria at least, the required infrastructure support for such innovations is already in place. The Community Living Support Service provides an excellent vehicle for the delivery of support to whatever accommodation option is most appropriate (Cummins, Baxter, Hudson, Polak and Romeo, 1992).

The second new dimension would be to respect people's choice to be integrated into their society at a level chosen by them. That is, alternative forms of accommodation should not be forced on people. Instead, our duty should be to provide people with an informed choice; to provide them with the opportunity to experience different living arrangements if they choose to do so, and for them to make the final choice.

In the implementation of such a process we would need to be tolerant of the choices people make. Some people may even choose not to be integrated, and this is consistent with the new form of service ideology, which is being proposed. Such service should be driven not through the imposition of values derived from middle-class Australia but rather through a concern for each individual's quality of life.

Finally, we need to monitor not only social integration (or the lack of it) but the whole construct of subjective life-quality in these people. The reason for such studies would be to understand the dynamics of how each living arrangement interacts with other aspects of people's lives. This understanding can then be fed back into the service model to make it more effective.

The end result, or the goal of our interventions, then becomes the optimal enhancement of people's lives, not so that their lives conform to some pre-determined standard, but so they can obtain the greatest degree of happiness and life-fulfilment that our resources can bestow.

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### **References**

Andrews, F.M. and Withey, S.B. (1976) *Social indicators of well being: Americans' perceptions of life quality*. New York: Plenum Press.

Aninger, M. and Bolinsky. K. (1977) 'Levels of independent functioning of retarded adults in apartments', *Mental Retardation*, Vol.1 5, pp.12-13.

- Burnett, P.C. (1989) 'Assessing satisfaction in people with an intellectual disability: Living in community - based residential facilities', *Australian Disability Review*, Vol.1, pp.14-19.
- Conroy, J.W. and Bradley, V.J. (1985) *The Pennhurst Longitudinal Study*. Washington: US Department of Health and Human Services.
- Crossley, R. and McDonald, A. (1980) *Annie's coming out*. Ringwood, Victoria: Penguin Books.
- Cummins, R.A. and Bancroft, H.A. (1981) *The St. Nicholas Hospital inquiry.. A supplementary report*. Melbourne: Authors
- Cummins, R.A., Baxter, C., Hudson, A., Polak, S. and Romeo, Y. (1992)'The Community Living Support Service: An operational overview', *Australian Disability Review*, Vol.3, pp.51-59.
- Cummins, R.A. and Dunt, D. (1990) 'The deinstitutionalization of St. Nicholas Hospital: H. Lifestyle, Community contact and family attitudes', *Australia and New Zealand Journal of Developmental Disabilities*, Vol. 16. pp. 19-32.
- Cummins, R.A., McCabe, M.P., Gullone, E. and Romeo, Y. (1992) "Re Comprehensive Quality of Life Scale: Instrument development and psychometric evaluation on tertiary students and staff", *Psychological Test Bulletin* (in press).
- Cummins, R.A., Polzin, U. and Theobald, T. (1990) The deinstitutionalization of St. Nicholas Hospital: III. Four-year follow-up of life-skill development', *Australia and New Zealand Journal of Developmental Disabilities*, Vol. 16, pp.209-232.
- Cummins, R.A., Polzin, U. and Theobald, T. (1990) 'The deinstitutionalization of St. Nicholas Hospital: IV. A four-year follow-up of resident routines and activities'. *Australia and New Zealand Journal of Developmental Disabilities*. Vol.1 6, pp.305-321.
- Cummins, R.A. (1992a) *The Comprehensive Quality of Life Scale: Third edition*. Melbourne: Psychology Research Centre. Deakin University.
- Cummins, R.A. (1992b) *The Comprehensive Quality of Life Scale: Intellectual Disability*. Third edition. Melbourne: Psychology Research Centre. Deakin University.
- Dunt, D. and Cummins. R.A. (1990) 'The deinstitutionalization of St. Nicholas Hospital: I. Adaptive Behaviour and Physical Health', *Australia and New Zealand Journal of Developmental Disabilities*, Vol. 16, pp. 5 - 18.
- Edgerton. R.B. (1990) 'Quality of life from a longitudinal research perspective', in Schalock, R.L. (ed.) *Quality of Life*. Washington: American Association on Mental Retardation, pp. 149-160.
- Eisen. P. (1980) *Report of the Committee of inquiry to investigate claims about children at St. Nicholas' Hospital*.
- Gunzburg, H.C. (1974) *Progress Assessment Chart of Social and Personal Development Manual* (41h Edition). Warwickshire, England: Sefa Ltd.

Lord, J. and Pedlar, A. (1991) 'Life in the Community: Four years after the closure of an institution', *Menial Retardation*, Vol.29, pp.213-221.

Nirje, B. (1980) 'The normalization principle', in Flynn, R.J. And Nitsch, K.E. (eds.) *Normalization, social integration and community services*. Baltimore: University Park Press, pp.31-49.

Rigby, K. McCarror-4 L. and Rigby, J. (1990) *Quality of life in a nursing home: a report on the perceptions of residents and staff at Julia Farr Centre*. Adelaide: South Australian Institute of Technology.

Address correspondence to:

Robert A Cummins  
School of Psychology  
Deakin University  
336 Glenferrie Road  
MALVERN VIC 3144