NORMALIZATION: THE NEW ORTHODOXY IN HUMAN SERVICES?

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Provision of services and accommodation for elderly people is a controversial and value-laden activity - something which has caused providers, researchers, policy makers, and elderly people themselves considerable anguish. As yet, there are no clear and unambiguous solutions to the problems identified, nor in fact, is there much agreement on what are the real problems.

Our residential care system which provides sheltered and supported accommodation for disabled people both young and old, is on the verge of significant and monumental change. The new Commonwealth Department of Community Services has made admirable moves in identifying the strengths and weaknesses in the present system, gathering vast amounts of data, and considering sympathetically and humanely how people requiring residential care can live with dignity and services appropriate to their needs.

The changes mooted in the system are based on the principles of reducing the ratio of institutional beds, providing better community support so that people are not unnecessarily institutionalised, providing appropriate assessment to ensure

that the services received by people match their needs and, if institutionalised, ensuring that their rights are maintained, that the services they receive are appropriate, and are geared towards enhancing and maximising their life chances.

Maximisation of opportunities and well being is a major objective of the principle of normalization . This principle as formulated in the literature is embedded in controversy, and in its application runs the risk of being greatly misunderstood. Commitment to the terminology and methods of normalization has become quite widespread in the aged care field. Moreover, there is an increasing tendency for both providers and consumers in this area to polarise according to their own particular views.

The purpose of this article is to open a necessary, balanced debate - a debate which has so far eluded policy makers in their search for appropriate and equitable models of care that can enhance the quality of life of older people in Australia. In particular, we focus on issues pertinent to the residential care sector.

If as is likely the number of nursing home beds is reduced to 40 per 1000 persons aged 70 or more, and if, as is also likely the other changes mentioned above are instituted, then it follows that the reduced number of nursing home beds will, of necessity, be filled by people who are considerably more

dependent than many of the people in nursing homes today. There will be no place in Australia's nursing homes for people who are not highly dependent and who have not been assessed as such. While no more than 4% to 5% of Australia's elderly population (those aged 65 years and over) is resident in nursing homes at any particular point in time, changes in Commonwealth policy will ensure that those who are will have some medical condition requiring such accommodation. Furthermore, their disabilities and dependencies will require good professional and other support to ensure that their needs are met and to maintain them at a quality of life that is deemed appropriate. With the high prevalence of organic disorders such as stroke, cancer, and Alzheimers disease, among nursing home residents, strict attention will need to be paid to issues of adequacy of medical and nursing care as well as social justice.

Many of these people are unable to organise and lobby on their own behalf. Most people in nursing homes will be there because they have chronic multiple diseases, resulting in progressive disability and impairment, and these realities must be recognised in policy and planning.

Normalization as currently promulgated in Australia seems to us to ignore these realities and thus may well do considerable harm to our nursing home population.

"Normalization" has been defined by its chief proponent, Wolf Wolfensberger, as "the utilization of culturally valued means in order to establish and/or maintain personal behaviours, experiences, and characteristics that are culturally normative

or valued". The principle was first developed and applied in the field of childhood intellectual disability but is seen by Wolfensberger to have universal application across the human services, including aged care.

In the various publications dedicated to normalization we have been unable to identify any reference to research nor evidence that the principle and its "corollaries" can be validly transported in unmodified form from the field of mental retardation to aged care.

The developmental dynamics applying to young intellectually disabled people are quite different to those applying to chronically ill older people. In the former case the functional deficits are relatively static, whereas in the latter many of the disabling conditions are of a progressive nature.

While we agree with the general thrust of normalization as proposed by Wolfensberger, and agree that normalization objectives appear desirable, we question the approaches being used to implement them in Australian aged care services. Our major criticisms relate to the manner of inflexible and uncritical implementation of normalization principles in our nursing homes. In these settings the current approach probably leads to a biased, "self-selection" of only those individuals who conform to socially acceptable norms, or who are more easily cared for, thereby excluding those who do not fit easily into the culturally normative or valued mould.

With major funding and planning decisions on the horizon we are concerned that should the Commonwealth embrace normalization and use it as a camouflage for cost cutting it will harm many elderly and disabled people, it will alienate and isolate many staff in the caring field, and it will discredit the Commonwealth Department of Community Services thereby undoing the excellent and perceptive work it has commenced in the human services.

PASSING (Program Analysis of Service Systems' Implementation of Normalization Goals), a technique also based on the work of Wolf Wolfensberger, is being heavily promoted and funded by the Commonwealth Department of Community Services. The telephone directory sized PASSING manual contains within it the set of normalization principles and means for evaluating those principles. On its opening page the manual states that PASSING has two major goals: to assess the normalization quality of any human service; and to teach the principle of normalization.

PASSING is shrouded in difficult jargon, is inflexible and rigidly conformist. These characteristics will appeal to those not used to critical evaluation of complex issues and to those who find comfort in simple black and white solutions. When applied in aged care the conservatism of the technique denies the diversity and individuality of older peoples' needs and interests, for example it ignores or diminishes the values and needs of ethnic minorities and those of low socio-economic status. These intristic problems are exacerbated when there are mixtures, within a residential complex, of ethnicity, class and status.

Recently, two of us spent a week at a PASSING workshop hoping to learn about client outcomes, and about how organizations could better serve and support their older client group. We came away disappointed. Our expectations were not fulfilled.

A PASSING workshop typically involves a day of lectures followed by four days of application of the PASSING rating scales. The simple messages of normalization, namely that one should not harm or devalue people, were couched in convoluted and elusive jargon designed to convey a mystique that was out of proportion to its meaning and content. One visits a facility, and after many hours of observation works in a small group situation to score the program on 42 different rating scales. Each rating seems to have an arbitrary numerical value or weight applied it.

There is no way of understanding how the weights on these ratings were derived, and without adequate discussion of their theoretical or empirical basis in the PASSING manual we seriously question whether they are socially meaningful or scientifically defensible.

For instance, "External Setting Appearance Congruity with Culturally Valued Analogue" (sic) ranges from -14 to +14, while "Competency-Related Other Integrative Client Contacts and Personal Relationships" (sic) ranges from -42 to +42. (We could hardly hope to improve on Peter Medawar's observations in Pluto's Republic by saying that "... no one who has something original or important to say will willingly run the risk of

being misunderstood; people who write obscurely are either unskilled in writing or up to mischief"). Once the exercise is completed the facility may achieve a score somewhere between -1000 and +1000.

In our workshops mention of formal health services, or of professional health care was dismissed as "medical model" and denigrated without due regard for the benefits to sick or disabled clients of appropriate medical and nursing intervention. If this narrow orientation were to be applied to other sick people in our community, there would be an outcry. In residential care settings this false dichotomy of "normalization" versus "medical model" is incomprehensible.

Apart from the substantial cost to government of each PASSING Workshop, a critique of PASSING as it is being applied in Australian aged care program development and services should also encompass at least two other factors. First, these PASSING workshops focus almost exclusively on some highly subjective measures, in particular on clients' quality of life as perceived by external observers. Second, they deliberately avoid consideration of the limits or constraints by which service agencies are bound. Such a flagrant disregard of "real world" problems can scarcely provide information useful for answering all questions of interest to funding agencies and other key decision-makers. Human services operate within a complex political and economic environment; one could question whether a standards-based evaluation tool, such as PASSING, is sufficiently broad in scope to address important issues over and above quality of life concerns for individual program

recipients. For example, the broader issues of access, equity and resource distribution are not addressed, and neither is the quality of professional support received. These are crucial issues in residential care of elderly people.

It would be unfortunate if PASSING scores were to be used as a basis for funding decisions, or if PASSING criteria rather than need criteria were to be used in service development. The manner in which PASSING is currently being promoted by the Commonwealth suggests it may become a convenient and "easy" tool for implementing departmental policy. At first we were bemused by PASSING but this quickly turned to concern at the political ramifications of the whole exercise. The message of PASSING is spreading quickly through the human services system, through the Commonwealth Department of Community Services and through some of the more progressive social service agencies.

At a time of shrinking budgets and other resource constraints in the human services those responsible for allocating scarce resources must consider carefully the economic and human implications of decisions made on the basis of inadequate and inappropriate information. If normalization of services and PASSING scores are pursued as funding criteria, we may lose sight of other important objectives in the provision of services for older people. The external and opportunity costs inherent in acceptance of an evaluation method that ignores cost issues are likely to be significant.

We must therefore examine who are the beneficiaries and who are the losers in any rigid interpretation of normalization or

PASSING principles in this country. Old people accommodated in nursing homes and hostels have diverse physical and emotional needs. This self-evident fact, long recognized by the Australian Geriatrics Society, must also be accepted within Commonwealth policy and practice.

We have been distressed to hear of agency staff being forbidden by their directors, to make any critical comment about PASSING or normalization - presumably motivated by fears of Commonwealth retribution. While this may be an over-reaction it illustrates a perceived inability to discuss the matter openly and in a rational fashion.

Our purpose then is to open up such debate. This technique, specious to us, but highly regarded by others should be scrutinised carefully and discussed. We went to PASSING hoping to develop understanding, but got faith presented as science, we hoped for analysis but were presented with jargon and simple solutions, we thought there might be evidence and theory but were overwhelmed by the lack of it.

There is, in our opinion, a very great danger that under the guise of a caring, progessive philosophy the Commonwealth Government may in fact be being conned.

If this is so, it is on the basis of ignorance rather than malice. The issue is too important to move so rapidly towards a new and doubtful orthodoxy in aged care. It is too important for our evolving service system for our workers in that system, and most importantly of all, for our dependent and disabled population, for this debate to be stifled any longer.

* Although the authors are all employed by the South Australian Government, Adam Graycar in policy, Margaret Dorsch in research and Lu Mykyta as a geriatrician, the views expressed here are those of the authors and not those of the Government of South Australia.