Review Article

THE PRESENT AND FUTURE OF LONG-TERM CARE

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Lee Bowker, *Humanizing Institutions for the Aged*, Lexington Books, D. C. Heath and Co. (Gower, Hampshire), 1982, £11.50, 115 pp., ISBN 0 669 05209 4.
Robert L. Kane/Rosalie A. Kane, *Values and Long-Term Care*, Lexington Books, D. C. Heath and Co. (Gower, Hampshire), 1982, £23.50, 290 pp., ISBN 0 669 04685 x.
Martin Wolins and Yochanan Wozner, *Revitalizing Residential Settings: Problems and Potential in Education, Health, Rehabilitation, and Social Service*, Jossey-Bass Social and Behavioral Science Series, Jossey-Bass (San Franciso, Washington, London), 1982, $18.95, 314 pp., ISBN 0 87589 517 4.
Paul Lerman, *Deinstitutionalization and the Welfare State*, Rutgers University Press, New Brunswick, New Jersey, 1982, $26.00, 246 pp., ISBN 0 8135 0934 3.
Judith Meltzer, Frank Farrow and Harold Richman (eds.), *Policy Options in Long-Term Care*, University of Chicago Press, Chicago and London, 1981, 244 pp., ISBN 0 226 51973 2 (cloth), ISBN 0 226 51974 0 (paper).

There are no new issues in long-term care. The underlying question is the same as that faced by the Elizabethan Poor Laws: indoor vs. outdoor relief. Several centuries later it continues to be a 'wicked problem', a 'perplexing and ill-defined area... truly a catastrophe... a field where value dilemmas abound'. These are the words of those who have studied it most, including the authors of the five books under review. Developed societies are still seeking answers for such basic questions as: *Who shall be served? What kind of care works best?* But there is a growing number of researchers and policy analysts able and willing to take a fresh look at the problems and to formulate possible approaches.

A particularly appealing approach is the title of the Bowker book: *Humanizing Institutions for the Aged*. Observers of present-day closed care

institutions, who find many as dehumanising as the almshouses of Dickens' time, will welcome the author's proposal for humanisation audits, and agree with many of his recommendations for improvement. Generations of sociology students reared on Goffman's *Asylums* will have no difficulty in conceptualising homes for the aged as total institutions, strongly resembling maximum security prisons. The book is useful in several ways. Bowker's excellent and comprehensive literature review pinpoints a number of possible models, as well as indicators of the quality of care. His analysis of the six major groups of social roles involved, and of the dominant attitudes expressed by staff and by residents offers a tool for categorising myriad impressionistic observations. Contrasting with this brilliant sociological performance, however, is the sparse and uninformative description of the four Wisconsin institutions where research data were collected. Possibly this is related to his manifest desire to accentuate the positive, and in this way to undercut the muckraking literature on the burgeoning nursing home industry which has captured the attention of the American public.[1]

A second study by Wolins and Wozner is broader in scope. *Revitalizing Residential Settings* covers the whole range of what the authors term 'internat' settings, including monasteries, military academies, and boarding schools, as well as homes for the aged, mental health and other closed care institutions. Their point of view is essentially the same as Bowker's: residential settings where people go, or are sent to live for an express purpose, can and must be imroved. If all kinds of settings share basic features, it is argued, then ineffective institutions (such as nursing homes for the aged) may benefit from practices proven effective in very different environments (such as boarding schools). This kind of brief summary fails to do justice to the authors' original and far-ranging approach to human behaviour in closed or semi-closed systems. Using a highly developed form of systems analysis, they suggest that human and institutional identities are formed by the flow of events in time as society's inmates and internats' time frames interact. A better grasp of the ways in which resources and sanctions can be manipulated permits some internats to engage in 'reclaiming missions', altering the decisional structure and redistributing power, in spite of opposition from countervailing groups of Opponents and Fanatics. Their final chapter, appropriately entitled 'Concepts for Action' concludes that an internat, like any social creation, mirrors its creator – the society to which it belongs.

Can the Universal Reclaimers then create integrated reclaiming internats from present old-age institutions? The answer of Wolins and Wozner would be 'possibly', if their insights are utilised. On the other

hand, if old-age institutions are, in fact, a failed system, then deinstitutionalisation (DE) represents a way out, although not necessarily an improvement. Both professional and popular thinking in the United States view DE as a dumping syndrome, depositing frail individuals in service-poor communities, without adequate help and support.[2] In a more sophisticated analysis, utilising historical sources, Lerman sees DE as a product of the welfare state, reflecting accompanying shifts in public welfare policies, practices, and beliefs. In the United States, post-1930 welfare programmes provided funds for a reduction in the number of people cared for in traditional state institutions (such as mental hospitals and reformatories) in favour of non-traditional alternatives (such as community-based intermediate care facilities and halfway houses).

Bowker, Wolins and Wozner would all argue that these newer settings are actually closed systems, total institutions, or internats. Lerman would agree. His research provides empirical evidence that the total number of institutionalised persons has not decreased, but has shifted. A prime example would be the shift of American old people out of state mental hospitals into nursing homes, which are actually more, rather than less restrictive. Lerman also finds that the new modalities exercise increased social controls over residents in the form of locks, rules about routines and outside visiting, access to and use of clothing, withholding funds and, finally, threats to return people to traditional institutions. In the case of old people, there has been since 1965 a pronounced tilt towards the profit-making sector, dominated by a proprietary nursing home industry, presently being augmented by proprietary home care and hospice industries.

Thus the American attempt to assume a degree of responsibility for the health and social care of old people has introduced further dysfunctionalities into long-term care, which continues to rely mainly on families and the unorganised sector to do the bulk of the job. The entire world is now impacted by two major social factors: demographic projections for significant increase in the numbers of old people, in particular the old-old, and the increased participation of adult women in the paid labour force. There is an increased supply of dependent persons in need of care at a time when available female caregivers are already experiencing severe pressure and role conflict.[3] It was this perceived dilemma, at a time of world economic recession and fiscal stringency, which precipitated the first World Assembly on Aging, held in Vienna, from 26 July to 7 August 1982. The discussions and debates of delegates from 123 countries, and the expert advice of non-governmental representatives, produced an international draft plan of

action, including a set of recommendations for governments to consider, but failed to contribute anything new to the long-term care problem.

The policy option thus chosen, either consciously or unconsciously, is one of muddling through, hoping that families will continue and even increase informal care as formal programmes are cut back. An emerging theme shifts the emphasis from caring for frail old people to 'caring for the carers'.[4] The carers are, in addition to family members, home helpers, social workers, nurses, paraprofessionals and others working with old people, who may themselves become 'burned-out cases' if they continue to be overburdened and undersupported. This represents a beginning recognition of the 'women in the middle', but is not where the decision-makers are 'at' in coming to grips with the policy puzzles of long-term care.

The research insights of Bowker, Wolins, Wozner and Lerman remain largely within the realm of academia. Americans who participated in the White House Conference on Aging or late 1981 have temporarily retreated to gird their loins for upcoming battles on reducing social security (old age pensions). The Federal Council on the Aging has also retreated from its proposed public policy on the frail elderly to issuing a chartbook on long-term care. Meanwhile, a Congressional subcommittee, headed by Congressman Biaggi of New York, has come up with a proposed Human Services Model for eldercare. Persons aged 60–75 are to be treated as 'senior adults', entitled to assessment, case management, and referral to available adult services. Only the 'elders', aged 75 and over, are to receive a 'guaranteed floor' of more comprehensive programmes and services. This notable attempt to confine the target population for public programmes to the old-old has so far received little attention or serious discussion.

This does not mean that the policy options are not receiving more intensive consideration behind closed doors in Washington, D.C. and elsewhere. In an effort to identify and clearly set forth what these policy options are, a research group at the University of Chicago, including Meltzer, Farrow and Richman, investigated the long-term care problem. Part of the project, which was funded by the Federal Administration on Aging, was to convene a symposium of experts in Williamsburg, Virginia in June 1980 to review their work. In the book issued in 1981, the authors identify four major issues which have received inadequate attention.

1 Developing an awareness and beginning consensus on the goals and objectives of long-term care.

2 Determining the nature and extent of public responsibility for meeting long-term care needs.

3 The practical and political choices governing the alloction of scare public resources.

4 Designing a system or systems to deliver the necessary services to people.

The research group also identifies four alternative directions, representing significantly different choices.

1 Modest improvements in current programmes.

2 A separate Federal long-term care benefit programme, to be coordinated with existing programmes.

3 An income strategy for developing adequate long-term care resources.

4 Private sector-based long-term care initiatives.

Whichever alternative is chosen, they feel that the situation is urgent, and that improvements should begin at once. Their own preferred direction for change is a broadened Federal income strategy, supported by expanded service and resource development. This would be accomplished mainly by additional benefits and payments under Supplemental Security Income and social security, and then turning to tax credits and private pensions for further assistance.

Those concerned with long-term care options would find all the papers included in this volume of considerable interest and value. An outstanding contribution is that by Robert L. Kane and Rosalie A. Kane. This unique husband–wife team (he is a physician, she a social worker with doctorate) have been specializing on long-term care and the health and social problems involved. Their first notable publication was a study of long-term care in six countries (England, Scotland, Sweden, Norway, the Netherlands, Israel), under the sponsorship of the John E. Fogarty International Center for Advanced Study in the Health Sciences.[5] After presenting their joint observations on each of the countries visited, the Kanes in a concluding chapter traced some common themes and dilemmas.

When eldercare is perceived as both a social and a health problem, there are dangers of divided responsibility. Comparisons of other countries with the United States need to be viewed against the background of important differences in public involvement and national control over old-age homes, as well as in community and hospital care patterns. From this study the Kane team emerged with questions about how to measure the quality of care and provide incentives for excellence. In the final analysis, they concluded, the standard of care given to the elderly seems to be determined by society's values, and the image such provision have in the eyes of both young people and older potential recipients. Thus they came out at essentially the same point as Wolins and Wozner did in their study of internats.

However, they have not been content to stop there. As an outcome of their comparative study they advanced their first proposal that a patient's own progress, compared to pre-estimated prognostic guidelines, be used as the basis for calculating nursing home payments. This was later elaborated in a May 1978 article in *Science* magazine, and in a 1980 article in *The Gerontologist*, seeking to go 'beyond the dichotomy' of institutional vs. community care.[6]

How do we advance from the dichotomy? One route is to delineate the nature and extent of public responsibility, the subject of the Rands' contribution to the University of Chicago policy options book. This immediately leads them to the question of values or preference positions. Because human service programmes represent uneasy compromises among diverse interests and values, they move to define them more precisely in terms of outcomes that are publicly valued. Thus, public responsibility can be defined in part as filling in the voids not met by other systems.

This leads to an alliterative typology of multiple public roles: pensioning, purchasing, providing, policing, protecting, preventing, peopling, promoting policymaking, priority setting and planning. This laundry list of roles is applicable to death and dying, as well as to long-term care. For each of the public roles decisions about implementing a long-term care policy become a matter of collective value judgement. Without widely shared initial value commitments the necessary rationing of scare resources will be highly imperfect, and possible good outcomes will be sacrificed to less desirable or no outcomes.

This chapter indicates one of the major directions in which the thinking of the Kanes is proceeding. It leads directly to the final volume under review here, their book on values.[7] This presents work done at the Rand Corporation (where both the Kanes are employed) in conjunction with the Center for Health Services Research at the University of California at Los Angeles, to develop measures of long-term care outcomes. Overall, the effort is to bring together two diverse streams of endeavour: research in health status assessment and value preference measurement with long-term care practitioners and policy analysts. Nine of the chapters consist of revised conference papers originally presented at a California conference in December 1980 organised by the Kanes. They are also the editors.

What emerges in this book represents primarily the first stream of endeavour, health status and value preference measurement. This is unfamiliar to most practioners and long-term care analysts. Similarly, the problems of long-term care are not known to other researchers, and hence are summarized in the first chapter. Chapter 3, by Keeler and

Robert Kane, also attempts to answer the question 'What is special about long-term care?' as a lead-in to measurement problems.

Although long-term care is admittedly a field in search of values, the research findings presented are only the first step in a long journey. Those who are less mathematically knowledgeable will find many of the chapters heavy going indeed. Mathematics aside, the new work attempting to measure health preferences, and to test willingness to pay and multi-attribute theory is not immediately relevant to long-term care issues and options, although there is a potential relevance. The state of the art of measuring value preferences appears to be in its early stages, an exciting intellectual adventure now, with possible future payoffs, in optimising patient and societal decision-making.

Meanwhile, it does not speak to the condition referred to in the Kanes' introduction as 'the drift of long-term care into patterns preferred by no one'. The constituencies they identify – legislators, the general public, the children of the elderly, the elderly themselves – will find little solace until care in fact becomes more humane and more responsive to human preferences. The present situation for the identified population at risk is a choice/no choice position in which pseudo-decisions by others lead to nursing home placement, regardless of what they prefer.

The Kanes know this, and hopefully will continue in their leadership role in developing a method to make individualised prognoses of expected nursing home outcomes. The Rand Corporation kind of think-tank, previously known for its attempts to introduce precision into military defence and foreign policy problems, now has an opportunity to make a contribution to the long-term care of the frail elderly. But there is an accompanying danger that the Kanes will experience the fate of other researchers in being co-opted by Rand, rather than vice versa.

The Chicago policy options book opens with a letter from an 84-year-old woman who, because she is chronically ill and familyless, is placed in a convalescent hospital which is a total institution, leaving her in 'an unbelievable lonely nightmare', with no freedom of choice. This is an image which we need to keep in centre stage as we struggle to improve long-term care.

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NOTES

1 For example Vladeck, B. C., *Unloving Care: The nursing home tragedy*, Basic Books, New York, 1980.

2 See Donahue, Wilma, 'What about our responsibility towards the abandoned elderly?', The Donald P. Kent Award Lecture, *The Gerontologist* 18(2), 102–111.

3 Brody, Elaine M. *et al.*, 'Women in the middle and family help to older people', *The Gerontologist* **21** (5), 471–481.
4 *Care in the Community: Recent research and current projects*, edited by Frank Glendenning, Age Concern, England, 1982.
5 Kane, R. L. and Kane, R. A., *Long-term Care in Six Countries: Implications for the United States*. Fogarty International Center Proceedings no. 3, Washington D.C.: G.P.O., DHEW publ. no. (Nih) 76–1207, 1976.
6 'Care of the aged: old problems in search of new solutions', *Science*, **200** (26 May 1978), 913–919; 'Alternatives to institutional care of the elderly: beyond the dichotomy', *The Gerontologist* **20**, 3 (1980), 249–260.
7 See also: *Assessing the Elderly: a Practical Guide to Measurement*, Lexington Books, 1981. *Geriatrics in the United States: Manpower Projections and Training Considerations*, Lexington Books, 1981; two other works on which the Kanes collaborated.