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LONG TERM CARE ADVOCACY DELIVERY SYSTEMS:
STATE AND LOCAL RESPONSIBILITIES

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ABSTRACT

This paper reports the results of a national comparative study of nursing home ombudsman programs for the institutionalized elderly. Of recent origin, patient representative programs have received little critical assessment as to their success in improving the quality of life of America's most vulnerable aged. At the same time, anticipated increases in the number of institutionalized aged coupled with current austerity measures in the health and human services underscores the present and future need to design effective and efficient monitoring/advocacy mechanisms to prevent abuses in long stay institutions. The paper focuses on a de-

scription of the current configuration of state and local sector roles and responsibilities in carrying out long term care monitoring services. Based on study findings, proposals are presented for suggested program changes and innovative strategies for coordinating state and area level advocacy initiatives.

Introduction

The nursing home industry is faced with an impending crisis. Federal budget cuts coupled with the current administration's philosophy of reducing the scope of regulatory policies in the long term care sector portends potentially negative consequences for the institutionalized elderly. The federal government contends that relaxing or eliminating many of its own regulations on the nursing home industry will reduce costs and paper work and give long term care facilities greater operating flexibility. It is claimed that this can be achieved without jeopardizing the rights and safety of patients (New York Times, March 4, 1982). Others, however, are less convinced. Opposition to current deregulation initiatives transcends professional disciplines and traditional biases of particular aging interest groups. Such diverse associations and organizations as the American Medical Association, the American Nurses Association, the National Association of Social Workers, the National Citizens' Coalition for Nursing Home Reform, the American Association of Retired Persons, Americans for Better Care and the American Association of Homes for the Aging have all voiced serious concern with the current anti-monitoring climate in Washington. More recently, even Richard S. Schweiker, Secretary of Health and Human Services, has also expressed disapproval of

current initiatives by the Reagan Administration (New York Times, March 20, 1982). These groups and others have suggested that nursing home self-regulation may eventually lead to decrements in the level of care provided the long-stay facility resident.

In light of what seems to be inevitable reductions in Federal long term care oversight responsibilities, alternative mechanisms for patient redress in institutions gain significance. Of particular relevance may be the set roles and responsibilities that state and local advocacy bodies will have to assume in the field of institutional brokerage.

Study Methodology

A two phased study of local and state level long term care ombudsman programs throughout the United States provides data as to the feasibility of non-regulatory community empowerment strategies in nursing homes (Monk and Kaye, 1981; Monk, Kaye and Litwin, 1982). Of particular research interest was the issue of the form institutional mediation has taken in the recent past, and the form it should take in the future. Potential variation in state wide versus local programming efforts was anticipated. The relative dearth of data available on the preferred course of development and the actual effectiveness of the ombudsman function in long term care at various levels within the individual states spurred this aspect of the study.

The research was conducted during the period January 1980 to December 1981. It followed an ex post facto survey design. No appropriate base line data or prior measures existed at the inception of the research to allow for panel or other long-

itudinal study designs. Data collection during the second phase (on which this paper is based) stemmed principally from structured questionnaires mailed to targeted respondents. Semi-structured interviews conducted during observational on-site visits to nine selected state programs supplemented the questionnaire data. Additional non-obtrusive data in the form of reports and other printed material solicited from the state ombudsmen further illuminated the primary data derived from the questionnaire.

Two foci of inquiry were encompassed in the study design: measurement of perspectives on the current state of the nursing home ombudsman program in each state, and consideration of varying views concerning the future design of such programs. Two major groups of respondents were addressed: the state nursing home ombudsmen and representatives of the long term care delivery network.

The long term care network was composed of state level representatives from the following:

1. Older Americans Advocacy Assistance Programs (Legal Service);
2. State Units on Aging;
3. State Departments of Health;
4. State Departments of Welfare;
5. State Associations of Not-For-Profit Long Term Care Facilities;
6. State Associations of Proprietary Long Term Care Facilities; &
7. State Community Action Interest Groups for the Elderly.

The total study N was 265 or 74.0 percent of all respondent group categories. Findings presented in this paper are based on responses received from state ombudsmen only.

Ombudsmen and Ombudsman Programs

The ombudsman, which originated in Scandinavia, was first conceived as an independent, impartial officer of the legislature who responded to complaints by citizens about public maladministration. The function of the ombudsman was to investigate such complaints and to recommend appropriate avenues for redress. The power of the position, however, was informal, rooted in the prestige of the officeholder, and effected by means of persuasion. The ombudsman was not empowered to reverse or revise administrative action (Rowat, 1965; Gellhorn, 1967).

The nursing home ombudsman program has evolved over the last decade from at least three separate mandates. President Nixon's 1971 eight point plan for improving nursing home care resulted in the first model ombudsman projects. They remained operational until 1975. Subsequent program development funds were provided through Administration on Aging discretionary grants issued between 1975 and 1978 to any state desiring to implement a nursing home ombudsman program. Finally, the 1978 amendments to the Older Americans Act required all states to establish a long term care ombudsman program.

Findings

Findings presented below will serve to summarize differences in experience between state level and local level long term care mediation programs in the areas of: 1) nursing home problems and complaints; 2) issue effectiveness; and 3) program impact.

1) Nursing Home Problems and Complaints

Two scales measuring long term care issues and long term care facility complaints were constructed and found internally reliable. Their application serves to measure state ombudsmen's perception of the nursing home mediation program's current problem focus, and to identify issues and complaints which are of foremost concern.

Table 1 summarizes the means, standard deviations and relative internal rankings for each of twelve long term care issues. The table summarizes the state ombudsmen's perceptions of the frequency of addressing each issue and of the relative difficulty in addressing them. As can be seen, a general trend emerges from the data.

The five most frequently addressed issues at the state level--1) residents' rights; 2) consumer education for long term care; 3) nursing home regulation/enforcement; 4) resident abuse; and 5) alternatives to institutionalization--were all among the issues perceived as less difficult to address, with the exception of nursing home regulation/enforcement. On the other hand, the six least frequently addressed issues--12) relocation trauma; 11) resident participation in facility governance; 10) Medicaid discrimination; 9) boarding home standards; 8) mental health needs of long term care residents; and 7) the upgrading of nursing home staff--were all among the issues perceived as more difficult to address, with the exception of mental health needs of long term care residents.

The data thus suggest two possible explanations concerning the ombudsmen's perceived problem focus. It may be interpreted that ombudsmen came to perceive those areas of most frequent contact as

less difficult to handle, or, conversely, they indeed tend to concentrate more activity in areas that are objectively less difficult to address. It should be noted in addition that the issues identified as those most frequently addressed are the very areas with which state ombudsman activity is associated: rights, regulation and public education. Those issues perceived as less frequently addressed (and more difficult to address) involve areas peculiar to long term care. Hence perhaps the the greater difficulty of an ombudsman mechanism in its initial development to address and resolve specific long term care problems.

An analysis of the frequency and perceived difficulty of addressing complaints at the facility or local level reveals the opposite trend: with the exception of one item, there seems to be a general positive correlation between the frequency and difficulty of addressing long term care facility complaints. Table 2 summarizes these data.

The problem or complaint found to be most often addressed by the ombudsman program is the quality of food and nutrition in the long term care facility. This complaint is seen by ombudsmen to be one of the least difficult to address and resolve. The remaining complaint items reveal the opposite trend. The more often a complaint is addressed, the more difficult it is generally seen to be. The following complaints, addressed in descending order of frequency, were found to constitute the four most difficult complaints to resolve--health care, protection of personal property, administration and personal care. Personal allowances and facility sanitation complaints are addressed less often and

perceived to be less than moderately difficult. Environmental safety as a problem is perceived to be the least difficult and the least frequently addressed of all the complaint areas listed.

The findings, therefore, suggest opposing trends at the state and local levels in the relationship between perceived frequency and difficulty of addressing issues and complaints. Consideration of state level issues reveal a negative correlation between perceived frequency and difficulty while attending to local level complaints reveals on the whole a positive correlation between perceived frequency and difficulty. While the data did not allow for examination of causality, support is nevertheless presented for differing trends in perceptions of local and state level ombudsman activity. The next two sections of findings examine the state and local differences hinted at in the findings to this point. Comparative perceptions are presented by state ombudsmen of ombudsman program effectiveness and impact at the state and local program levels.

2) Issue Effectiveness

Table 3 summarizes the comparative analysis of a selected number of advocacy issues measured across state and local levels. The analysis clarifies in which issue areas the respective program levels have achieved significantly greater effectiveness.

In terms of the relative ranking of responses, the state level ombudsman program was perceived to achieve the greatest effectiveness in the area of provision of information for legislators and long term care program planners, closely followed by

their capacity to assist in the protection of resident rights. Moderate success rates were reported for the establishment of a complaint resolution mechanism, the alerting of nursing home staff to patient needs and the establishment of better relationships between the nursing home and the community. Less than moderate effectiveness was indicated for the state level ombudsman program in proposing changes in nursing home policies and regulations.

The same issues considered for effectiveness at the local ombudsman program level reveal both differences and similarities. Greatest effectiveness was realized in the alerting of nursing home staff to patient needs. Assisting in the protection of resident rights, on the other hand, retained its second place position as noted for state level ombudsman programs. Efforts at establishing better community/nursing home relations and complaint resolution mechanisms were seen to have been moderately successful. The provision of information and making policy proposals, on the other hand, were viewed as activities less effectively carried out at the local level.

Comparative T-tests showed significant differences in the perceived effectiveness rates when viewing selected issue areas at both state and local levels. The nursing home ombudsman program was found to be significantly more effective at the state level in proposing changes in nursing home policies and regulations, and in providing information for legislators and long term care program planners, than at the local level. Conversely, the local level ombudsman program was viewed as significantly more effective than its state level counterpart in alerting nursing home staff and administration to patient needs. The

remaining issue areas were perceived by the respondents to be equally well addressed at both state and local levels of the nursing home ombudsman program.

3) Program Impact

A similar analysis conducted for areas appearing in a larger scale of program impact further clarifies which dimensions of monitoring are better addressed at the local level. Table 4 summarizes the means, relative ranks, standard deviation and comparative T-tests for four areas of possible impact. As the table indicates, state ombudsman respondents assigned identical patterns for the ordering of impact items at both the state and local levels of the ombudsman program. Increasing the accountability of staff in nursing homes was seen to be the area most positively impacted upon at both program levels, followed by upgrading the quality of nursing home/community relations, staff/resident relations and relation among staff in nursing homes.

Comparative T-tests point, however, to significant differences in the relative magnitude of impact at the respective program levels. Specifically, the local nursing home ombudsman program was seen to achieve significantly greater impact in improving the quality of nursing home/community relations and staff/resident relations than the state level program. The accountability of staff actions in nursing homes on the other hand, was seen to be positively impacted on at equivalent levels at both state and local levels of the nursing home ombudsman program.

The findings from the two tables suggest, therefore, that areas related to the establishment and enforcement of

patient rights, including legislative influence, are most effectively addressed and impacted on at the state level. The more immediate, interpersonal issues emerging out of the day-to-day operations of the long term care facility, on the other hand, are seen to be most successfully addressed by the mediational interventions of a local ombudsman program.

Conclusions

In looking toward a future scenario for nursing home monitoring programs, and based on study data, two divergent models can be sketched here. They have direct implications for program planning at the state and local levels, extending well beyond long term care ombudsman projects specifically.

Figure 1 presents in summary fashion the range of relevant patient representation program dimensions and their respective characteristic features in each of the two potential program models (state-based and locality-based). It should be noted that the dimensions and characteristics are dichotomized as exclusive "ideal types" for the sake of analytic comparison. In all likelihood, however, each dimension constitutes a continuum of choice for which the respective program pathway components serve as end points. Thus a given state-level or community-level institutional mediation program may be situated at variant points on the continuum for each program dimension. The reasons as to why a given program is placed at one rather than another point along the continuum are considered subsequent to presentation of the pathway models. Implications for the collective selection of characteristic program dimension choices will also be addressed.

As can be seen from Figure 1. state level nursing home advocacy programs may best develop along the path of a "patients' rights" program model, whereas local level initiatives would do well to reflect a "quality of life" oriented mode. Each has its concomitant cluster of programmatic characteristics. Sets of such components may be grouped within three dimensions: 1) program philosophy; 2) external organizational factors; and 3) internal management factors.

A summary statement of the state level "patients' rights" model reflects an advocacy program which is statutorily empowered government based, statewide in scope, formalistic in its organizational relations and established and funded through state legislation. The basic approach of the "patients' rights" model entails a watchdogging focus, partisan on behalf of long term care consumers and geared toward systemic changes. Such programs are more likely to be staffed by professionals -- specialists in legalistic and long term care regulatory matters -- who engage in joint efforts with public interest law representatives and citizens' organizations. The "patients' rights" advocate utilizes complaint statistics compiled through formal record keeping to advocate impact upon those areas of recurring complaints.

The "quality of life" program model, on the other hand, is more often than not operationalized by a smaller scale, community embedded, voluntary organization which works through its own fundraising efforts and gains informal bases of co-operation at the long term care facility level. The basic approach of this model may be said to be a collaborative one in which volunteers work with facility personnel to support individual nursing home patients

who have expressed some difficulty. Such volunteers are recruited through their own strong desire to aid others, and are sustained by peer support and intensive supervision from local ombudsman program staff. The focus of the "quality of life" ombudsman is the improvement of the day-to-day life of nursing home patients by ameliorating interpersonal conflict and individual, concrete conflicts with facility staff, or with other resident/patients.

What determines whether a given nursing home advocacy program will: a) develop in the predominant direction of one pathway or the other; b) select a varied mix of components from each path model; or c) attempt the simultaneous operationalization of both models for patient representation services? Clearly there is no single formula to predict a specific outcome for a developing long term care advocacy program. Variations can be seen to occur due to the degree of financial and legislative resources made available to the evolving service, the scope of necessary coverage and other factors that may or may not be influential in a particular state. A selected list of such factors that shape decision rules and which in turn determine program choices immediately follow. Additional factors invariably can and should be identified for each state and locality engaged in ombudsman and other patient representation-type services. The factors identified here include:

- 1) the funding level and/or presence of alternative sources of financial support;
- 2) the size of the institutionalized aged population;
- 3) the scope and configuration of the long term care system;
- 4) the influence of special interest

- groups;
- 5) the status of enabling legislation;
 - 6) the status of alternative state regulatory and monitoring systems;
 - 7) community norms/public attitudes;
 - 8) predilections of the state's chief executive;
 - 9) the history and severity of past abuse in long term care; and
 - 10) the state population -- size -- ethnicity and rural/urban composition.

In sum, two major programmatic types have been identified and described. They respond to the presumed capacities of state level and community level advocacy initiatives. Factors which may guide the selection of program development emphasis have been suggested. The two program pathways outlined above are equally legitimate courses for long term care advocacy programs to follow. Even so, conditions may dictate the appropriateness of one strategy of the other regardless of geographic scope.

It is also conceivable that state and community programs may follow both orientations to programming at certain points, depending on the types of long term care grievances elicited. Indeed, long term care advocacy remains a highly variable art. It will be useful for patient representatives to maintain ongoing lines of communication with their counterparts operating along both pathways to facilitate the sharing of effective interventive strategies.

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