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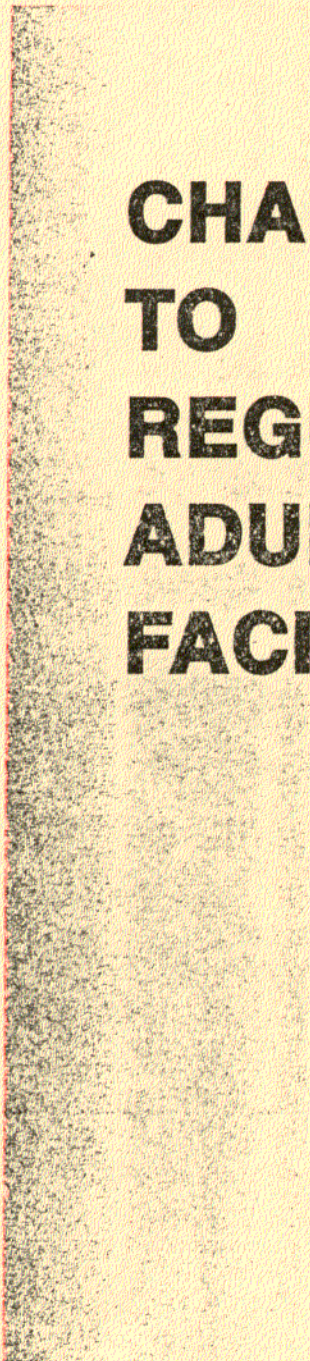

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Challenges to regulating adult care  
facilities

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# **CHALLENGES TO REGULATING ADULT CARE FACILITIES**

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**OHIO LONG-TERM CARE RESEARCH**

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**Ohio Long-Term Care Research Project**

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**Challenges to  
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**Robert Applebaum**

**February 1992**

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## INTRODUCTION

As the size of the long-term care population continues to increase, so too does the search for care alternatives. One of the policy and practice options in use is the adult care facility or board and care home. Operating under a variety of other labels such as domiciliary care, personal care, residential hotels, geriatric foster care, and adult foster care, adult care facilities have become a major component of long-term care in the United States. Despite some differences in definitions, most of these providers share a common objective: to furnish room, board, and personal assistance to residents on a 24-hour basis in return for payment.

Information describing the adult care industry is limited. In fact, there is considerable variation even in the estimates of the number of residents receiving such care. Published reports have estimated the number of adult care residents nationally as ranging from 300,000 to 1.5 million (McCoy and Conley 1990; Mor, Gutkin, and Sherwood 1985; Newcomer and Stone 1985; U.S. Congress 1989). Given the lack of accurate data about even the number of residents, we are not surprised that our ability to assess the quality of care in these homes is limited.

## REGULATORY EFFORTS

Board and care homes have a long history; at least as early as the fourteenth century in Belgium, people with emotional problems received care in such places. Even so, little information is available about the characteristics of good board and care homes (Eckert and Lyon 1991). The growth of these homes throughout the 1970s and 1980s, coupled with concerns about quality, have caught the interest of the regulatory world. The Keys Amendment to the Social Security Act, passed in 1976, represented an attempt by the federal government to take some regulatory responsibility for adult care homes. That legislation required states to establish and enforce standards for homes serving residents who received Supplemental Security Income (SSI). A second federal initiative, included in the reauthorization of the Older Americans Act in 1981, expanded the authority of the nursing home ombudsman programs to include board and care homes. The 1980s also were marked by increased local and state regulations: in a study of state agencies with regulatory responsibility for adult care facilities, 82 of the 98 agencies responding had adopted or revised regulations within five years of the study period (Reichstein and Bergofsky 1983). Numerous county and local governmental units also have implemented regulations in this area.

In an era when we have made substantial gains in health and long-term care technology, it is paradoxical that assuring the quality of adult care homes, with their focus on the delivery of basic care, would remain a major challenge. Why is it so difficult to regulate such homes? On the basis of data from a survey of Ohio board and care homes and a review of previous research, this paper examines the challenges faced in regulating adult care homes. To provide a framework for analyzing the regulatory challenges, we have identified a series of factors that influence the ability of the regulatory system to monitor the quality of care. These elements include locating the providers, determining the characteristics of residents and operators, financing adult care homes, fragmentation of regulatory responsibility, and agreement on the concept of quality.

#### **Where Are The Board and Care Providers?**

A fundamental step in monitoring the quality of any service is knowing whether, when, and where the service is being delivered. The national and state estimates about the number of board and care providers vary dramatically. National estimates range from 25,000 to 75,000 adult care homes; estimates in Ohio range between 750 and 3,500 such homes.

Our recent survey experience in Ohio highlights the challenges faced in determining the number and location of adult care homes in the state (Ritchey and Applebaum 1992). Because

the great majority of homes in Ohio were not licensed, we used health and social service experts to identify board and care homes. This strategy relied on the long-term care ombudsman programs in the 12 area agency regions of the state. The list compiled from these programs contained 1,028 adult care homes located throughout the state. We conducted telephone interviews with 570 homes selected at random.

Of the homes identified on the original list, 45% were no longer in existence at the time of our survey call; an additional 7% reported no active residents. Thus, more than half of the board and care homes identified as current operators by the long-term care ombudsman programs, the government financed group responsible for consumer advocacy, were not operating.

We expect that licensure requirements will increase the pool of known board and care homes. Yet, even if all states require licensing, our survey experience suggests that the industry will continue to include a high number of short-term providers, who are the least likely to go through the licensing process and the most difficult group to track.

### **Residents' and Owners' Characteristics**

Results from survey work in Ohio (Eckert and Lyon 1991; Ritchey and Applebaum 1992) show that board and care residents are a vulnerable population. Many of these residents are older, suffer physical disabilities, mental illness, retardation, or cognitive



disabilities, have limited financial resources, have limited formal education, and receive less family support than the general older population. In a detailed study of homes in northeastern Ohio, Eckert and Lyon (1991) reported that two-thirds of the residents had limitations in activities of daily living, 56% were reported to be at least mildly confused, 21% reported having been in a hospital or institution for people with mental problems, and 20% were classified as mentally retarded. Information on education revealed that 40% of the residents had less than an eighth grade education and 86% had not gone beyond high school. The residents' annual median income was less than \$3,000. Survey data from our Ohio statewide survey of adult care operators reinforced this portrait. For example, residents in 57% of the homes suffered continuing problems with confusion or disorientation, and two-thirds of the homes reported providing personal care assistance such as bathing.

Although these findings suggest that adult care residents are a vulnerable group, they may underrepresent the frailty of this group because of sampling bias in the resident survey. Researchers in the northeastern Ohio study reported a 50% completion rate for their survey and stated that the survey resulted "in a sample biased in favor of the more alert and less frail residents" (Eckert and Lyon 1991, p. 156). This experience suggests that a number of adult care residents may have difficulty in advocating for their own care needs.

A description of the adult care operators also can provide insight into the issues surrounding home regulation. The statewide and the northeastern Ohio surveys yielded similar profiles. The typical Ohio operator was female (90%), with a median age in the early fifties, a high school education or less (70%), and a median annual income between \$15,000 and \$20,000. Eighty percent of the respondents reported having received some form of specialized training; about two-thirds had been employed in a variety of health care settings. Data from the statewide survey disclosed that a majority of homes (83%) reported hiring additional staff. In about half of these homes, staff members are required to receive specialized training. Respondents in both studies reported a range of operational experience from short-term (one month) to long-term (more than 30 years), with an average of five years in the northeastern Ohio study and more than eight years in the statewide survey. Twelve percent of the homes in the statewide survey had been in operation one year or less. As noted earlier, we suspect that a number of short-term providers are missing from the statewide sample; thus the sample is biased toward the providers who have been in operation longer.

The portrait of adult care operators is mixed. Some have had limited formalized work experience in health care, limited access to educational opportunities, and no specialized training or supervision; others have worked in health care settings, have

received specialized training, and have worked in the industry for a long time. About one-third of the respondents to the statewide survey reported belonging to a state organization of adult care home owners. These results suggest a range of experiences and orientations among the operators. The next challenge in this area is understanding whether or how these variations affect the quality of care.

In the statewide study, operators also were surveyed about their attitudes toward the delivery of board and care. Operators showed relatively high agreement (about 95%) on several attitudinal items, such as whether residents should have access to a private area to receive visitors, be allowed to bring personal property into the home, and be allowed to remain restraint-free. Other areas showed more variation such as whether residents should participate in community services (79% yes), be allowed to refuse nonemergency medical care (62% yes), be allowed to manage their own finances if competent (55% yes), have access to the kitchen (44% yes), and have a choice of meal time (33% yes).

Recent research has examined the relationship between increasing autonomy among residents and higher perceptions of quality (Applebaum, Regan, and Woodruff, 1991; Kane et al. 1990). These studies suggest that positive attitudes among operators toward residents' activities could enhance residents'

perceptions of quality. It is very difficult, however, to incorporate such concepts into regulations.

### **Financing Adult Care Homes**

One of the concerns voiced commonly by adult care operators and long-term care policy analysts involves the financing available for board and care homes. Although the current financing system for long-term care continues to be dominated by allocations for nursing home care, in the last 10 years the public funds for in-home long-term care services have expanded significantly (Applebaum and Austin 1990). Yet, there is no major source of funds for aged and disabled people who do not or cannot reside in nursing homes but who no longer can live independently. Individuals who need assisted living typically must rely on their own economic resources. Adult care homes and assisted living centers find themselves attempting to deliver care for individuals who fall between the in-home and the institutional service delivery systems. Some of these potential residents have adequate financial resources; many, however, rely solely on Social Security or on the Supplemental Security Income program for funds. Thus the board and care industry developed at least in part to provide assisted living to low-income individuals who typically do not have other living alternatives.

A review of residents' rental fees provides more detail on this issue. In the northeastern Ohio study the monthly fee charged

to residents ranged from \$150 to \$1,100 per month. More than half of the homes reported costs of \$450 or less (Eckert and Lyon 1991). In the statewide survey, owners reported charges ranging from \$100 to \$2,100. About one-third of the homes charged less than \$500 per month; almost two-thirds charged \$700 or less. About one-quarter of the homes charged \$900 or more. Data on source of payment suggest that almost half of the residents rely primarily or exclusively on SSI to fund their care. It is a challenge to provide room, board, personal assistance, transportation, and social activities for disabled individuals for about \$400 per month (1990 Ohio SSI benefit: \$386). Such a system of financing has implications for the success of any regulatory process.

Resource constraints also have contributed to some direct challenges to regulators. Current restrictions on state budgets for personnel have caused regulatory agencies to be short of the staff needed to conduct inspections or reviews of homes. Because the population with long-term care needs is continuing to increase and because the funding for personnel at the state level is under careful scrutiny, it is likely that shortages of staff will continue to be a regulatory issue. Although the optimum strategy for external review of adult care is not clear, some regulatory personnel will be required in this area.

## **Fragmentation of Regulatory Responsibility**

One of the ironies of the regulatory strategy for adult care homes is that regulation is limited in scope but fragmented in responsibility. At the state level in Ohio, for example, numerous agencies have responsibility for some regulatory aspect of care, including the Departments of Health, Mental Health, Aging, Human Services, and Mental Retardation. This situation is multiplied at the county level, where a number of local communities have established licensing or certification programs. Inadequate communication between state and local agencies has been a concern to both providers and regulatory staff. Although such fragmentation is not unique to this component of long-term care, it creates a barrier to developing an effective regulatory strategy.

## **Agreement on the Concept of Quality**

A final barrier to developing an effective regulatory strategy is the lack of agreement on the concept of quality. As in other areas of long-term care delivery, quality care has many dimensions. To some, the main determinant of quality is the physical environment. To others, it is the technical method by which care is provided. To others, it is the level of kindness and dignity with which care is delivered. To some residents, quality is determined by their interactions with fellow residents. Complicating our understanding is the fact that family members,

providers, and regulators also have their own ideas about quality care. In some cases these assessments are consistent with those of the recipients; in others they may be in conflict. It is a considerable challenge to understand how these factors are blended to form the concept called "quality care."

Historically, the uncertainty about defining quality has resulted in a regulatory process emphasizing structural quality factors. Until recently, for example, nursing home regulations focused heavily on structural aspects such as staffing ratios, chart completion, fire safety, and sanitation rules (Zimmerman 1989). Adult care facility regulations also have adopted this structural emphasis through regulations for items such as fire sprinkler systems, wheelchair accessibility, and emergency call buttons or intercoms. Although such structural elements indeed can be important, there is considerable agreement that a one-dimensional approach to assuring quality is not adequate (Kane and Kane 1989; Lohr 1990). Since the mid-1960s, when Donabedian (1966) first introduced the quality components of structure, process, and outcomes, observers have called for quality assurance efforts to be multidimensional. Yet despite this interest, long-term care regulations remain focused on structure. The major cause of our inability to broaden the concept of quality is the difficulty in defining and measuring quality care. Thus, as we attempt to enter the realm of board and care regulation, we are left with the

continual challenge of designing regulations in the face of disagreement about the definition of quality care. Where uncertainty exists, the strategy has been to revert to structural mechanisms.

### **THE ROLE OF THE REGULATORY SYSTEM**

Regulatory actions in the United States can be traced back to the Constitution, which initially included regulations of foreign trade. More aggressive regulations were implemented in the 1880s and 1890s through a series of trade and antitrust laws (Green 1973). The 1930s, 1960s, and 1970s have been identified as the periods of greatest increase in regulation (Gatti 1981). Over the years, legislation has developed in an array of areas such as the environment, communications, occupational safety, aeronautics, energy, pensions, health care, and foreign and interstate trade, and is implemented through a series of regulatory units operating as part of the federal government. Many of these agencies (such as the EPA, OSHA, FTC, FCC, and FDA) have become household names (or at least initials) in American society. At the state and local levels as well, regulatory agencies have become well-known to consumers and service providers.

The expanded role of regulations in American society has not been free of controversy, however. Some observers, such as noted economist Milton Friedman, argue that the marketplace is a much better means of protecting the consumers against



exploitation. He suggests that major regulatory activities actually have a negative effect on consumers.

Few people argue that no regulatory actions are necessary; an intermediate position appears to be most common in the literature. Supporters of this position recognize the need for regulation, but acknowledge at the same time that regulatory activity does not ensure success. Lawschool professor Clark Havighurst articulates this argument in the arena of health policy:

As a remedy for public policy, regulation is over prescribed. Indeed, regulatory programs are to many legislators what prescription drugs are to doctors: a useful tool which is tempting to overuse in an effort to demonstrate to the "consumer" that the decision maker cares and is trying to do something about the problem. One hopes in both cases that professional integrity supplies a check on the oversupplying tendencies. Not the least of the problem is the accumulating evidence that regulation is habit forming and, once prescribed, is practically impossible to discontinue... [Even so], policy options in health care probably no longer include (if they ever did) the possibility of not regulating the health care sector at all or of placing primary reliance on market forces (Havighurst 1975, pp 577, 578).

Thus, although some people believe that government should have little or no regulatory involvement, and others lobby for an expanded governmental role, the major focus appears to be on improving the regulatory process. Critics of the regulatory system have identified two main areas of concern: 1) Has the correct regulatory policy been implemented, thus improving the situation in the area under regulation? 2) Has a cost-benefit analysis of the regulatory activity been conducted? We apply these questions in

an effort to understand the regulatory struggles of the board and care industry.

### **Does Regulation Improve the Situation?**

Evaluation of efforts to assure the quality of both health care and long-term care is relatively rare. For example, despite several decades of efforts to assure the quality of nursing homes, evaluation-based information on the effects of regulation is almost nonexistent (Potter-Sommer et al. 1991). Nursing homes have been studied extensively and are reported to be heavily regulated, but little of the existing information examines the effects of these activities on the quality of care received by residents. In view of this scenario, it is not surprising that the relatively recent efforts to regulate board and care homes have not been evaluated formally. As a result, we have very little evidence to suggest that the licensing and certification requirements which are implemented actually affect the quality of care. This issue is highlighted by a former Senate Special Committee on Aging staff member in a recent article on legislating quality:

The passage of quality reforms for Congress has been in large measure an act of blind faith that definitions and measures of quality can in fact be developed (Smith 1989, p 42).

### **Have the Benefits and Costs of the Regulations Been Assessed?**

The underlying assumption of a benefit/cost analysis is that the costs of a regulation can be examined in the context of the

achieved benefits, and in this way the value of the regulatory effects can be assessed. In this area, however, both essential ingredients are missing. First, as discussed above, evaluation-based information on the effects of regulation in adult care facilities has not been collected. We simply do not know what improvements in quality, if any, can be attributed to regulation. In addition, financial information on the costs of regulatory efforts typically has not been examined. This information should include the direct costs to the regulatory agency at both the local and state level, as well as the costs to those who comply with specific regulations. Data on costs in these areas have not been available, however. Thus the individuals who are asked to create regulatory legislation must do so with neither cost nor benefit data.

### **How Do We Regulate Adult Care Homes?**

This paper began with the question "Why are adult care homes so hard to regulate?" Certainly there is no shortage of answers, but we seem to lack answers to the question "How do we regulate adult care homes?" On the basis of our research in adult care homes and in other long-term care environments, we recommend that efforts to develop an effective regulatory approach must involve four critical areas: joint development of care standards, increased involvement of consumers, cost/benefit research, and an adequate allocation of resources.

## **Joint Development of Reasonable Care Standards**

Identifying the aspects of care that affect quality is a major challenge in all areas of long-term care. Because regulations are based on care standards, the development of successful standards is a critical part of the regulatory equation. The process for developing such standards in adult care homes has rarely involved either consumers and their families or adult care operators, the two groups most familiar with the delivery of this care. If successful regulations are to be developed, these two groups must be involved in the design. This is not to minimize the importance of state and local regulatory staff members, external experts or professionals, professional associations, or even researchers, but rather to highlight the importance of a jointly designed process. A broad-based development process requires resources, however; most importantly, it is time-consuming. Often timeliness is one of the essential factors when a state or federal legislative body is ready to focus its attention on a specific area. Thus, the legislation and the subsequent rule development typically are narrowly based. As a result, legislation often reverts to indicators of structural quality because it is easier to reach agreement on such standards than on qualitative criteria such as residents' dignity or autonomy.

## **Increased Involvement of Consumers**

One of the major criticisms of regulations in health care has been that they did not involve consumers sufficiently. Adult care

homes and other long-term care providers have received similar criticism. Recent changes in the federal and state process for surveying long-term care, as well as recent work by private health regulatory organizations such as the Joint Commission on Accreditation of Health Care Organizations (JCAHO) and the National League of Nursing (NLN), have highlighted the importance of consumers' input in assessing the quality of care. Although adult care residents are a vulnerable group, increased efforts must be made to involve them as consumers in the regulatory process. This involvement would include both the development of standards, as identified above, and ongoing participation in feedback and assessment about the quality of care. The regulatory system needs input from various perspectives, and the consumers' perspective must be a key element.

#### **Cost/Benefit Research**

Regulations are implemented with one major purpose: to assure the quality of the service or product relative to the cost to the society. Although regulatory legislation will always belong to the political domain, additional information is required to aid the decision-making process. As discussed above, information on regulation in adult care homes is almost totally devoid of data on either costs or benefits. Research that attempts to assess the effects of alternative regulatory strategies is essential. Thus it is incumbent on the regulatory process to ensure that the regulation

does not do more harm than good. This goal is achieved by assessing the costs and benefits of any proposed regulation.

### **Adequate Allocation of Resources**

The board and care industry is a safety net for some low-income and chronically impaired individuals. Because of rising nursing home costs, many states have attempted to restrict the development of additional nursing home beds. At the same time, efforts to minimize federal expenditures have resulted in an SSI program in which minimum benefits are set at a rate 25% below government poverty levels.

In view of limited resources and limited options, it is likely that adult care homes will continue to expand. Although the optimum charge for an adult care home is not clear, it is very difficult to provide a caring and stimulating environment for this vulnerable group of citizens for \$400 or \$500 per month. Until the issue of adequate resources is addressed, we are unlikely to be satisfied with the quality of these homes.

### **CONCLUSION**

The demographic challenges faced by Ohio mirror the changes facing the nation. The growth in the population of aged and disabled people in need of long-term care is undeniable. How will the long-term care system respond to these challenges? What will be the role of regulations in assuring that quality care is delivered? Although the answers to these questions remain cloudy,

it is clear that the regulatory challenges to adult care homes and to long-term care in general will continue to increase in an "aging Ohio."

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