REPORT OF THE
DEPARTMENT OF MENTAL HEALTH, MENTAL
RETARDATION AND SUBSTANCE ABUSE SERVICES ON

Special Care Units In Long Term Care Facilities

TO THE GOVERNOR AND
THE GENERAL ASSEMBLY OF VIRGINIA

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PREFACE

The 1992 General Assembly passed House Joint Resolution 51 (HJR51) which requested the Department of Mental Health, Mental Retardation and Substance Abuse Services to study special care units in long-term care facilities that provide programs and services to persons with dementia to determine the need for operational guidelines for such facilities. The study resolution directed the Department to consider i) whether specialized units are providing appropriate interventions specific to the needs and characteristics of people with dementia and how these differ from the standard care provided elsewhere in long-term care facilities; ii) whether there are identifiable components of the quality care provided by some special care units which should be provided by all; iii) how special care units address the issues of safety, security, and appropriate activities; and iv) what the basis should be for a price differential for special care units compared to standard care units in long-term care facilities.

The Department convened a committee pursuant to HJR51, which studied special care units, special programs, and specialized services. The Committee was Chaired by Delegate Julia Connally and included representatives from the Virginia Health Care Association, the Virginia Association of Homes for Adults, and the Virginia Association of Nonprofit Homes for the Aging. Also represented on the Committee were family members of clients receiving special care, health care professionals specializing in the care of individuals with dementia, representatives of local chapters of the Alzheimer's Association of Virginia, owners and managers of long-term care facilities, representatives of public and private health insurers, and staff of designated state health and human resource agencies.

We would like to give special thanks and recognition to the following individuals who served on the Committee convened to assist the Department in the completion of the study:

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EXECUTIVE SUMMARY AND RECOMMENDATIONS

Over the past decade there has been a dramatic increase in the number of special care units for individuals with Alzheimer's disease and related disorders. These units have proliferated throughout the United States, despite a lack of consensus regarding their characteristics and possible effectiveness.

Ideally, special care is defined as the maximization of the functioning and quality of life of the individual with dementia by utilizing specially trained staff, specially adapted activities, and a supportive environment. Special care may be provided in special care units, special programs, and specialized services. Such programs and services can benefit families/caregivers who want the most appropriate care for the individual with dementia.

Many complex issues are involved in developing public policy regarding special care units. The lack of standards for these units means consumers have no assurances as to what, if any, special care a facility provides. Yet, premature governmental regulation could preclude creative innovations to special care, escalate cost, and would not guarantee improvements in care.

This report describes the current status of special care units, special programs, and specialized services in Virginia and other states. Prior to this study, there were no data to identify which facilities in Virginia provided special care to individuals with Alzheimer's disease or a related disorder. It was determined a survey questionnaire would be used to learn which facilities were providing special care, and what their characteristics were.

The survey questionnaire was developed by the Department of Mental Health, Mental Retardation and Substance Abuse Services (DMHMRSAS) and distributed to all nursing facilities (NFs), homes for adults (HFAs), adult day care centers (ADCCs) and hospitals, in the state for a total of 908 facilities. Approximately two thirds of the facilities responded to the questionnaire. Of those responding, 34 (15%) of the NFs, 20 (3.8%) of the HFAs, 15 (37.5%) of the ADCCs and four (3.3%) of the hospitals, indicated they offer special care in some form to individuals with dementia.

The survey results indicated the state has at least 73 facilities offering special care: 31 special care units, 22 special programs, and 20 facilities which offer specialized services for individuals with dementia. The survey revealed almost half of the special care programs in the state have been established since 1990. Also noteworthy was the fact that in addition to the 73 facilities that currently provide special care, 44 facilities reported they planned to develop a special care unit, a special program, or specialized services in the future. These results

confirm the rapid growth of special care for persons with dementia in Virginia, a trend found throughout the United States.

It was also revealed there is great diversity among programs in costs, charges and staffing levels. The difference in costs for hospitals and NFs compared to HFAs is attributed to regulatory requirements for staffing, training, equipment and other health related items. Much of the variation can be attributed to differences between the types of services and the facilities providing the services. For example, there was more consistency among programs concerning admission and discharge criteria, types of patient activities, programs, the extent of family involvement, procedures to control "disruptive behavior", and physical design of the unit. The wide range of characteristics among facilities providing special care in Virginia is similar to what has occurred throughout the country, according to a recent report by the U. S. Office of Technology Assessment.

The statewide survey of special care units, special programs, and specialized services represents an important first step in assessing the current status of special care in Virginia and in guiding the future course of public policy on this complex issue.

RECOMMENDATIONS

In response to the issues raised and deliberations of the Special Care Units Study Committee and the Alzheimer's Disease and Related Disorders Commission, the following recommendations are offered:

STANDARDS/REGULATIONS: 1) State standards/regulations for special care units are not recommended at this time due to the lack of agreement among experts about what the particular features of a special care unit should be and the insufficiency of research-based data concerning the effectiveness of various program characteristics.

CONSUMER AWARENESS: 2) The Alzheimer's Disease and Related Disorders Commission and other interested individuals shall develop guidelines and other information such as a brochure regarding special care units, special programs and specialized services to assist and inform consumers in the evaluation and selection of a facility which provides special care. The brochure will include information regarding the state Ombudsman program under the auspices of the Department for the Aging.

In order to protect and inform consumers, facilities which advertise or market special

care units for individuals with dementia should disclose to consumers in writing specific information about how the unit is special. Information such as admission and discharge criteria, any additional staff training, environmental modifications, special programming, etc. should be described specifically. This disclosure would not in any way restrict what special care units could develop, it would, however, provide more complete information to consumers.

TRAINING/EDUCATION: 3) The Alzheimer's Disease and Related Disorders Commission in conjunction with the local chapters of the Alzheimer's Association and Long-Term Care provider organizations, pharmaceutical companies and other appropriate businesses, shall sponsor a statewide training conference, within the next 18 months, for professionals and paraprofessionals on the characteristics of Alzheimer's disease, current research, innovative approaches to specialized care, and interventions for maladaptive behavior and other relevant information.

4) The Alzheimer's Disease and Related Disorders Commission in conjunction with local chapters of the Alzheimer's Association shall develop a public/private partnership to provide training/ education regarding special care units, special programs and specialized services to professionals, paraprofessionals, family members, caregivers, and the general public.

The Education Committee of the Commission is currently developing a training module on the management of disruptive behavior for staff in nursing facilities and homes for adults. Additional topics for training will cover how to communicate with, and care for individuals with dementia.

DATABASE SYSTEM: 5) The DMHMRSAS shall maintain and expand a database for specialized dementia programs in Virginia using data from the recently completed survey on special care units, special programs, and specialized services.

6) The DMHMRSAS shall conduct a follow-up survey of special care in 1994 to obtain specific data on the characteristics of special care units, programs, services, activities and interventions used to manage maladaptive behavior and criteria for admission of individuals to special care units, special programs and specialized services. The survey should be enhanced by information obtained from site visits and interviews with staff of facilities and families.

7) The Alzheimer's Disease and Related Disorders Commission shall request the Virginia Department of Health and the Department of Social Services to develop a list of facilities with special care units, special programs, and specialized services, based on agreed upon definitions and, data that can be collected within their current reporting mechanisms which would be available to consumers and other interested persons.

AN OVERVIEW OF ALZHEIMER'S DISEASE AND SPECIAL CARE UNITS

There is currently much debate regarding the care of individuals with Alzheimer's disease and related disorders. Family members and long term care providers have struggled to find the most appropriate means of caring for these individuals. Alzheimer's disease affects people at different rates and with varying symptoms, which contributes to the challenge of defining appropriate care.

According to the National Alzheimer's Disease and Related Disorders Association, it is currently estimated that four million Americans have Alzheimer's disease, and by the year 2050 this number will rise to 14 million unless there is a breakthrough in medical research. The frequency of Alzheimer's disease increases with age, so that approximately 10% of the population 65 and over are effected, but by age 85 this percentage increases to 47.2%. These figures are particularly alarming because Americans 85 and over comprise the fastest growing segment of the population. Estimated annual costs for caring for individuals with Alzheimer's disease in the United States total $90 billion, with families and patients paying most of the cost.

In Virginia there are approximately 665,000 persons 65 years and older. Using the national formula, if 10% of these persons have probable Alzheimer's disease, 65,000 persons may need special care. Since the prevalence of the disease increases with age, 28,000 or 47.2% of Virginians 85 years of age and older may have probable Alzheimer's disease.

Throughout the United States there has recently been a proliferation of special care units for people with Alzheimer's disease and related disorders. The U.S. Office of Technology Assessment (O.T.A) in its 1992 report "Special Care Units for People with Alzheimer's and Other Dementias" found approximately 10 percent (1500) of all nursing homes in the United States have special care units, and most of these have been established since 1983. There appears to be growing demand for such units due to the increasing numbers of people with dementia, and because of concerns about the appropriateness of traditional nursing home care for these individuals.

Many of the problems caused by the rapid increase in the number of special care units are due to the fact there is little consensus as to what constitutes special care. Programs differ in their philosophy, staff composition and numbers, physical design, resident characteristics, activities programs, and staff interventions. In other words, there is currently no consensus on a formula or standard model for the development of an effective special care unit.

The lack of consensus regarding special care creates difficulties for both consumers and long term care providers. Individuals with dementia and their families currently do not have assurance that a special care unit will provide more specialized or appropriate care than any other unit. These consumers may be especially vulnerable to promises of special care as they seek to ameliorate the progression of a dementing illness.

Due to the lack of standardized models of care, long term care providers continue to struggle with the provision of the best possible care to individuals with dementia. Providers incur greater costs as they provide staff with additional training or modify their physical environment, yet these costs may not be adequately covered by existing reimbursement mechanisms. Of perhaps greater concern are those facilities which are marketing special care without substantial efforts to provide such differentiated care.

Special care units are an appropriate subject for public policy consideration for three main reasons, according to the O.T.A. The first reason is the large number of nursing facility residents who have some type of dementia. Estimates of the percentage of nursing facility residents with dementia range from 42% to 78%. The second reason is the high cost to governments to provide for their care. The O.T.A. estimated in 1990 government expenditures for the care of individuals with dementia in nursing homes totaled $11 billion. The third reason is government is already so extensively involved in the regulation of nursing facilities. The issue of dementia care must be considered to address concerns raised by families and to successfully resolve the complex issues involved.

In response to the rapid proliferation of special care units and the ambiguity surrounding them, the federal government has greatly increased research funding in this area through the National Institute on Aging. It is hoped this research will define special care, and resolve some of the regulatory and reimbursement issues government now faces. There are three main research questions that need to be answered, according to the O.T.A. First, whether special care units improve resident care and quality of life. Secondly, if special care units are shown to be effective, then the particular characteristics that make them effective must be determined. The third question is whether special care units are effective for all individuals with dementia or only for individuals with certain characteristics of the disease.

Many states are looking at the issue of special care for individuals with Alzheimer's disease and dementia. Six states (Iowa, Texas, Colorado, Washington, Tennessee and Kansas) have added requirements for special care units to their general nursing facility regulations, and five states (North Carolina, Nebraska,

New Jersey, Oklahoma, Oregon) are in the process of developing regulations.

Several states (New Hampshire, Missouri, Massachusetts, Maryland) have, or are in the process of developing guidelines for special care units, and six states (Georgia, Kentucky, Michigan, Mississippi, New Jersey, Ohio) have altered the process for obtaining a certificate of need to encourage the establishment of special care units. State regulations and guidelines have been intended to help inform and protect consumers, as well as to provide guidance to long term care providers and regulators. Six states (Massachusetts, California, Connecticut, Florida, Michigan, Rhode Island) have provided funding for individual special care units, for training of staff assigned to special care units, or for research on special care units.

While there are reasons to consider the regulation of special care units, there are compelling reasons not to regulate at the present time. The main concerns are the lack of agreement as to what a special care unit should be, and the scarcity of research at present concerning the effectiveness of various program characteristics. The O.T.A. suggests premature regulation may inadvertently hinder innovation and progress towards improving care for individuals with dementia. It may be possible, however, to address some of the public policy issues concerning special care by focusing on areas such as staffing, programs, admission and discharge criteria, family involvement, and training, without having a negative effect upon program innovation.

A variety of nongovernmental organizations are developing guidelines for specialized dementia care. Long term care provider and accrediting organizations have been developing guidelines, as have consumer advocacy groups. Guidelines by such organizations as the American Association of Homes for the Aging, Joint Commission on Accreditation of Healthcare Organizations, the Alzheimer's Association and others are intended to provide information as well as to stimulate further research and innovation. These organizations generally identify research areas of special interest.

The Alzheimer's Association's "Guidelines for Dignity", for example, identifies eight action goals for special care. These recommended goals include 1) a philosophy which reflects the needs of residents with dementia; 2) a pre-admission process which involves verifying the diagnosis and assessing the person's needs; 3) an admission process which is convenient and supportive; 4) a flexible care plan developed with the family, which is designed to maximize the person's dignity and functioning ability; 5) a plan for responding to changes in the resident's condition; 6) ongoing training for all staff and volunteers who work with the unit's residents (to include dietary, housekeeping, and administrative staff); 7) a physical environment which is safe, and encourages independence and maximum functioning; and 8) a process to evaluate

the unit's success, or lack thereof. These goals describe an interactive process between the family, the resident, and the facility, in order to best meet the specific needs of each individual.

The Joint Commission on Accreditation of Healthcare Organizations (JCAHO), a private not for profit standards and review organization, developed more extensive long term care standards and specific guidelines to assist surveyors who are reviewing special care units. Using these guidelines the JCAHO recently conducted a pilot study of facilities caring for patients with Alzheimer's disease and other dementias to determine the need for developing a survey process sensitive to patients' needs. The study determined that facilities are providing the services they promote for patients with Alzheimer's disease and new standards are not warranted at this time.

It should be noted, consumer protection may be increased without the development of regulations or guidelines for special care units. The O.T.A. suggests consumers need to be educated about special care units, informed of ways to evaluate these programs, and to realize units vary considerably in their costs and characteristics. Providing guidelines and other information regarding units in their local geographic area can assist families in making a more informed choice. In addition, the O.T.A. recommends nursing facilities disclose information such as how the special care unit is unique from the rest of the facility (i.e., what is special about it), how restraints and psychotropic medications are used on the unit, and specific admission and discharge criteria. Such information can be very helpful to family members who are considering placement for the individual with dementia.

SPECIAL CARE IN VIRGINIA

This study was initiated in response to concerns and discussions regarding the lack of information and standards in facilities that provide special care for persons with dementia. At the present time any facility in Virginia can promote a special care unit without providing any type of specialized care. In view of the rapid growth of these programs, it is important to determine the number of units, their costs and other characteristics, and how consumers and long term care providers can be protected from false claims of special care.

At the direction of the 1992 Virginia General Assembly, through HJR51, DMHMRSAS conducted a study of the characteristics of existing special care units within the state that provide care for persons with Alzheimer's Disease (AD) and other dementias. DMHMRSAS was directed to work in cooperation with the Virginia Health Care Association, the Virginia Association of Homes for Adults, and the Virginia Association of Nonprofit Homes for the Aging, and to utilize the information and experience of a variety of sources including legislators, family members of clients receiving care, health care professionals specializing in the care of persons with AD/dementia, Alzheimer's Association representatives, and owners and managers of long-term care facilities. DMHMRSAS convened a study committee composed of representatives of these groups and a resource committee of gerontologists and national experts in the field of Alzheimer's disease to provide consultation to the staff.

As part of the study process the Alzheimer's Disease and Related Disorders Commission visited nursing facilities and homes for adults which had special care units, and heard presentations from nursing facility staff regarding special care units. Family members and caregivers provided information and shared their experiences with the Study Committee regarding relatives residing in special care units. Joint meetings of the Commission and the Study Committee were held to share information and to provide additional suggestions for the study process. (Refer to Appendix B for a listing of the members of the Commission.)

Since no comprehensive listing of all facilities providing special care to individuals with AD/dementia, or detailed descriptions of the characteristics of special care provided in facilities in Virginia exists, a survey was conducted of all facilities in the state. The purposes of the survey were:

- To identify the facilities across the state that provide special care to persons with AD/dementia.

- To determine the current capacity of facilities which provide special care, and the extent to which other facilities are planning to provide special care in the future.

- To obtain information on the characteristics of the special care being provided; the physical features of separate units; staffing of special care; and charges and costs of special care.

- To use the information obtained from the survey in developing recommendations regarding operational guidelines for special care units in Virginia.

The study committee identified specific items to address through the survey. They included:

- Criteria for admission and discharge
- Description of treatment programs and services
- Types of ongoing assessment of individuals in special care
- Staffing patterns and staff training
- Extent of family involvement
- Characteristics of the physical environment
- Costs and charges for special care
- Methods of assuring safety and security
- Marketing strategies of facilities offering special care

The survey questionnaire was developed following a review of the relevant literature and consultation with national experts. In developing the questionnaire, it was recognized some facilities provide special care to persons with AD/dementia without establishing physically separate special care units. In order to maximize the usefulness of the survey, and to distinguish between facilities that had special care units and those that did not, it was decided to collect information on three distinct types of care: special care units (SCUs), special programs (SPs), and specialized services (SSs).

The definitions for the three types of special care were developed by DMHMRSAS staff in consultation with researchers and other national experts. The definition of each type of care is as follows:

- A special care unit (SCU) is a designated, physically separate unit in a residential facility serving individuals with AD or other dementias.

- A special program (SP) is a plan or schedule of services and care provided exclusively to individuals with AD or other

dementias on a regular basis, beyond the care provided for other individuals.

- Specialized services are specific services and care designed exclusively for individuals with AD or other dementias to meet their individual needs.

FINDINGS

This section presents the findings of the survey of special care units, special programs, specialized services and recommendations for future action by the state. Copies of the actual survey questionnaire and the tables of data are available through Geriatric Services, DMHMRSAS, P.O. Box 1797, Richmond, VA 23214, (804) 786-3054.

Provisions of and Plans For Establishment of Special Care

The survey questionnaire was distributed statewide to the administrators of 908 facilities. A total of 600 responses to the survey were received, for an overall response rate of 66.1%. Among the four types of facilities surveyed,

- 204 of the 227 (89.9%) nursing facilities (NFs) responded, 34 of which (15.0% of all NFs surveyed) were offering special care.
- 268 of the 521 (51.4%) home for adults (HFAs) responded, and only 20 of which (3.8% of all HFAs) were providing special care.
- 32 of the 40 (80.0%) adult day care centers (ADCCs) returned the surveys, and 15 of which (37.5% of all ADCCs) offered special care.
- 90 of the 120 (75.0%) hospitals responded, and only four of which (3.3% of all hospitals) were providing special care.

Among the 73 facilities that provided some type of special care to individuals with AD/dementia, almost half (46.6%) were NFs. HFAs accounted for approximately one-fourth (27.4%) of facilities offering special care, and ADCCs accounted for about 20%. Less than ten percent (5.5%) of the special care was provided in hospitals. It should be noted only four hospitals throughout the state that provide special care for AD/dementia responded to the survey; although the overall rate of response from hospitals was good (75%), the results described for hospitals represent a very small number of facilities. Also, it is important to note the rate of response for HFAs is substantially lower than the rate of response for other types of facilities; thus, the results for HFAs may not represent all HFAs that provide special care. (See Table 1)

TABLE 1
TYPE OF CARE PROVIDED BY TYPE OF FACILITY

	Nursing Facilities	Homes for Adults	Adult Day Care Centers	Hospitals	Total
Special Care Units	21 (67.7%)	8 (25.8%)	0 (0.0%)	2 (6.5%)	31 (42.5%)
Special Programs	7 (31.8%)	3 (13.6%)	11 (50.0%)	1 (4.5%)	22 (30.1%)
Specialized Services	6 (30.0%)	9 (45.0%)	4 (20.0%)	1 (5.0%)	20 (27.4%)
TOTAL	34 (46.6%)	20 (27.4%)	15 (20.5%)	4 (5.5%)	73 (100.0%)

NOTE: Numbers in parentheses indicate percent of total for each type of care.

In addition to the 73 facilities that had special care units (SCUs), special programs (SPs), or specialized services (SSs), a total of 44 additional respondents who did not provide special care indicated they planned to provide it at some point in the future. Fifteen facilities (34.1%) indicated they planned to establish SCUs, 27 (61.4%) planned to implement SPs, and 26 (59.1%) were developing SSs. The total number exceeds 44, since some respondents indicated they were developing more than one type of care.

Many respondents did not indicate the planned capacity of their special care, or indicated the capacity was not yet determined. Among those planning SCUs, the total anticipated capacity statewide was 383 beds. The majority of all respondents (26, or 59.1%) anticipated implementation of special care by the end of 1993, and two (4.5%) indicated they would begin their special care during 1994. A substantial number (16 respondents, or 36.4%) indicated they had no target date set for implementation.

Capacity of Care

For facilities providing special care in residential settings, capacity was defined as the number of beds. In non-residential settings, capacity was defined as the maximum number of persons the program or service could accommodate. The average capacity of SCUs was 34 beds. The average capacity of SPs was 33, while the average capacity of SSs was 27. The findings of the survey indicated the total statewide capacity of special care is 2143, with 1050 beds in

special care units, 660 slots in special programs and 433 slots in specialized services. Nursing facilities have the highest total capacity of special care with 1003, followed by HFAs with 670, ADCC's with 410 and hospitals with 60. (See Table 2)

TABLE 2

TOTAL CAPACITY BY TYPE OF FACILITY AND CARE

	Special Care Units		Special Programs		Specialized Services	
	Capacity	Range	Capacity	Range	Capacity	Range
Nursing Facilities	706	10-60	207	10-62	90	12-42
Homes For Adults	312	6-72	103	36-67	255	2-99
Adult Day Care Centers	0	0	342	9-50	68	18-30
Hospitals	32	8-24	8	8	20	20
TOTAL	**1050**		**660**		**433**	

Charges and Costs

A majority (58.1%) of facilities with SCUs indicated their charges for special care were higher than the charges in the rest of the facility. However, facilities providing SPs (82.4%) and SSs (75.0%) responded their charges were the same as other care. The proportion of ADCCs that said they charged the same or less for their special care than other care was higher than the other types of facilities; 90.9% of ADCCs (compared with 75.0% of hospitals, 54.8% of NFs, and 47.4% of HFAs) charged the same or less. (See Table 3)

TABLE 3
CHARGES FOR SPECIAL CARE COMPARED TO CHARGES FOR OTHER CARE, BY TYPE OF CARE/FACILITY

	More than other care	Same as other care	Less than other care	N/A *
Special Care Units	18 (58.1%)	11 (35.5%)	1 (3.2%)	1 (3.2%)
Special Programs	1 (5.9%)	15 (82.4%)	0 (0.0%)	2 (11.8%)
Specialized Services	2 (12.5%)	12 (75.0%)	1 (6.3%)	1 (6.3%)
Hospitals	1 (25.0%)	2 (50.0%)	1 (25.0%)	0 (0.0%)
Nursing Facilities	13 (41.9%)	17 (54.8%)	0 (0.0%)	1 (3.2%)
Homes For Adults	8 (42.1%)	9 (47.4%)	0 (0.0%)	2 (10.5%)
Adults Day Care Centers	0 (0.0%)	9 (81.8%)	1 (9.1%)	1 (9.1%)

* The entire facility serves only persons with AD/dementia.

There were differences in average daily charges by type of facility providing care; not surprisingly, the charges for hospital-based care were substantially higher than the charges for care in other types of facilities. The increase in costs for hospitals and NFs compared to HFAs is due to regulatory requirements for staffing, training, equipment and other health related items.

Daily costs for providing special care differed somewhat by type of care. SCUs tend to incur greater average daily costs; the median daily cost was $75.00 for SCUs, compared with $43.00 for SPs and $40.00 for SSs.

As was the case with charges, the differences in costs were greater by type of facility. The costs of providing special care in hospitals ($452.00 per day) were over five times higher than the

costs for providing nursing facility care ($55.00 per day); the costs of special care in NFs were twice as high as care in HFAs. However, in interpreting the cost information, it is important to keep in mind that only 60 percent of the respondents provided any information on this item. Several stated they were unable to separate the costs for their special care from the costs for care in the rest of their facilities. Thus, the data on costs should be interpreted cautiously.

Staffing and Training for Special Care

Nursing assistants were the most commonly employed classification of staff providing special care; they were employed in 71.2% of all facilities, and the facilities that employed them had an average of 9.5 full-time and 4.9 part-time nursing assistants on their staff. Activity coordinators were the second most common occupational group, employed in 60.3% of facilities, although most facilities employed only one full-time or part-time staff person in this position. Less than 10% of all respondents employed either neurologists or psychologists, and professionals in these two categories were only employed on a part-time basis.

Average staff-to-resident ratios varied only slightly by type of care. Facilities offering SSs had slightly higher ratios for all three shifts than did SPs or SCUs. Variations in average staff-to-resident ratios by time of day were greater, with staff providing care to greater numbers of individuals during the night than during the day or evening in all three types of care. The differences in average staff-to-resident ratios were somewhat greater by type of facility than by type of care. The four hospitals that responded to the survey had the highest staff-to-patient ratios (1-to-1 during the day and evening, and almost 1-to-2 at night), and NFs had the lowest staff to resident ratios (about 1-to-6 during the day, 1-to-7 during the evening, and 1-to-11 at night).

There was a wide range of the number of hours of training that staff receive annually in different areas related to special care. There was inconclusive information on the number of hours of staff training received annually.

Characteristics of Special Care

Facilities used criteria to determine appropriateness for admission of individuals to receive special care. Some of the criteria used included diagnosis of AD or dementia, impairments in activities of daily living (ADL functions), the existence of problem behavior, a need for constant supervision, a family interview prior to admission, and contact with an individual's physician as criteria for admission.

Over 75% of all respondents offered reality orientation, reminiscence groups, special physical exercise, music programs or music therapy, and social activities. However, less than 50% offered involvement in household tasks, specialized feeding programs, or feeding/eating skills training.

Most respondents (95.9%) stated family members were involved in the admissions process, treatment planning (84.9%) and discharge planning (78.1%). Others indicated family members were involved in support groups (60.3%) and volunteer activities (57.5%).

The majority of facilities (98.6%) reported they used one-on-one interventions and redirection of the individual's attention to deal with disruptive behavior. Almost as many respondents (89.0%) stated they attempted to anticipate individuals' needs to avoid disruptive behavior. Relatively few (34.2%) indicated they used physical restraints; most of these qualified their responses with additional comments suggesting physical restraints were rarely used. Although a majority of respondents (57.5%) stated they controlled disruptive behavior with psychoactive drugs, additional comments revealed medication was not routinely used, and was always carried out under the supervision of a physician.

Eighty-eight percent of the facilities indicated congregate meals were served to residents. Less than one-third of all facilities served meals to small groups or to individuals in their rooms.

All respondents stated individuals receiving special care could ambulate freely in a secure setting. The majority of respondents also indicated individuals receiving special care could use recreation facilities, sleep and snack at any time. Individuals could leave the facility for outside activities under supervision as appropriate.

Several different types of assessments to monitor individuals to determine the need for revisions in the plan of care were used in facilities providing special care. Both functional and behavioral assessments were used by over 80% of all facilities, and the use of medical assessments was almost as common. Less than 50% of the facilities used psychiatric assessments in the monitoring process. More SCUs than SPs or SSs used all four types of assessments with over 95% of SCUs using functional and behavioral assessments.

Discharge Criteria and Placements

Four facilities (5.5%) indicated they did not discharge individuals from special care. Among facilities from which individuals could be discharged, the majority did not discharge individuals when they became nonambulatory, their private funds were exhausted, or due to scores from a standardized assessment.

Seventy percent (70%) of all facilities indicated the most commonly used criteria for discharge was disruptive behavior. This finding suggests further staff training may be needed in working with individuals with dementia, with an emphasis on techniques for managing disruptive behavior. Individuals were discharged to nursing facilities (78.3%) more frequently than any other setting. Several NFs stated residents could be discharged from SCUs to other units in the facility, if they were no longer benefitting from the special care.

Physical Features of Separate Units

A total of 42 facilities provided care in physically separated units, or were entirely devoted to serving persons with AD/dementia. The most common mechanisms used to secure the units/facilities were security alarms on the exits, used by 69% of respondents, and/or keyed or coded locks on the exits, used by 59.5% of respondents. Less than one-third used visual barriers over the exits, video monitors, security bracelets or sensors worn by individuals linked to a central alarm system. However, many facilities used more than one type of security mechanism; most commonly a combination of locks and exit alarms.

The most common environmental features or modifications in separate units/facilities (80%) were long straight or curved corridors permitting free movement of individuals, and reality orientation boards or large daily calendars on the walls. The majority of facilities (66.7%) had modified communal areas with space for small group activities.

Respondents' Opinions of Required Characteristics of Special Care

Over three-fourths (76.7%) of all respondents providing special care indicated a secure area for moving around inside, specially trained staff, and limited use of psychoactive drugs should characterize special care. Almost as many respondents (72.6%) indicated secured or locked doors and reduced use of physical restraints should be required features. There was little consensus regarding other characteristics which should be required. This diversity of opinion may reflect the fact there is still little agreement on a standard model of special care.

Mechanisms for Advertising Special Care

The most common methods used to inform the community about their special care were "word-of-mouth" referrals from private health care providers and public agencies (80%), brochures (70%) and public education programs (42.5%). Newspaper and radio or television advertisements were used by less than one-third of the facilities.

CONCLUSIONS AND RECOMMENDATIONS

The survey findings indicate differences for costs and charges for special care are greater by type of facility than by type of care. These differences reflect variations in the regulations governing each type of facility, in reimbursement policies of insurers for care in different types of facilities, and differences in the populations each type of facility is designed to serve. However, the data on charges and costs should be viewed cautiously, since not all respondents provided this information, and some facilities indicated they were unable to separate costs for special care from care in the rest of their facilities.

The survey results related to staffing ratios suggest differences may be greater by type of facility than by type of care. The data suggest SCUs may be providing care for persons requiring a higher level of care than SPs or SSs. The charges and costs are higher in SCUs than in SPs or SSs. The admissions criteria tend to be more stringent, a greater variety of services are offered, and the use of psycho-active drugs and physical restraints, although limited, is more common in SCUs. Individuals who can be served in special programs or services should be integrated into the rest of the facility and not placed in a special care unit; they may be able to function independently, may not need as high a level of supervision, and may not engage in as much disruptive behavior. SCUs may be more likely to be utilized in serving individuals in later stages of AD/dementia. It is also possible SCUs are perceived by family members and others as being more appropriate for individuals needing more intensive care than SPs or SSs.

Respondents recommended special care include a greater variety of specific features than they were providing in their own facilities. Perhaps they recognized the limitations of what they were able to provide, especially since many of the facilities were operating relatively new programs. Several respondents indicated their future goals included expanding both the physical environment and the treatment program of special care. However, as has been pointed out by the U.S. Congress Office of Technology in its report, **Special Care Units for Persons with Dementia: Problems and Opportunities**, little research has been done to determine the effectiveness of specific features of SCUs, or of specific interventions and treatments used in them. Thus, it may be premature to require facilities to include specific features in order to be designated as providing special care.

The types of characteristics endorsed by most of the respondents as necessary for special care might require additional expense for facilities. For example, using specially trained staff might result in higher personnel costs, and creating secure areas within the facility might require substantial financial outlays for

physical modifications or renovations of the facilities. Nonetheless, such features may be basic necessities for facilities to be suitably equipped to provide quality care to persons with AD/dementia. The research currently being carried out by nine coordinated projects funded through a special initiative by the National Institute on Aging should provide valuable information on these and other issues regarding SCUs.

The types of services currently being provided in facilities offering special care suggest some facilities may not be aware of the latest information regarding appropriate interventions for persons with AD/dementia. For example, over 80% of respondents indicated they offer reality orientation as part of their services, although leading experts in the care of individuals with AD/dementia suggest reality orientation programs are of minimal usefulness to this population.

Although many facilities require specially trained staff, and provide some additional training for employees who staff the special care, training appears to be limited in many facilities. Staff providing special care should receive state of the art training to remain current in this area of service and research, since the field is changing rapidly.

We have acquired valuable information regarding the nature and extent of special care for individuals with AD/dementia in Virginia, however, it is only a first step. It will be important to gather additional information to obtain a more complete picture of the variations in special care provided throughout the Commonwealth. Detailed interviews with administrators, direct care staff, patients and families would assist in obtaining additional information regarding the provision of special care. Site visits to special care programs and units in different types of facilities would also be invaluable in obtaining information. Thus, further exploration of this issue is recommended to address the complex issues that have been raised.

RECOMMENDATIONS

In response to the issues raised and deliberations of the Special Care Units Study Committee and the Alzheimer's Disease and Related Disorders Commission, the following recommendations are offered:

STANDARDS/REGULATIONS: 1) State standards/regulations for special care units are not recommended at this time due to the lack of agreement among experts about what the particular features of a special care unit should be and the insufficiency of research-based data concerning the effectiveness of various program characteristics.

CONSUMER AWARENESS: 2) The Alzheimer's Disease and Related Disorders Commission and other interested individuals shall develop guidelines and other information such as a brochure regarding special care units, special programs and specialized services to assist and inform consumers in the evaluation and selection of a facility which provides special care. The brochure will include information regarding the state Ombudsman program under the auspices of the Department for the Aging.

> *In order to protect and inform consumers, facilities which advertise or market special care units for individuals with dementia should disclose to consumers in writing specific information about how the unit is special. Information such as admission and discharge criteria, any additional staff training, environmental modifications, special programming, etc. should be described specifically. This disclosure would not in any way restrict what special care units could develop, it would, however, provide more complete information to consumers.*

TRAINING/EDUCATION:3) The Alzheimer's Disease and Related Disorders Commission in conjunction with the local chapters of the Alzheimer's Association and Long-Term Care provider organizations, pharmaceutical companies and other appropriate businesses, shall sponsor a statewide training conference, within the next 18 months, for professionals and paraprofessionals on the characteristics of Alzheimer's disease, current research, innovative approaches to specialized care, and interventions for maladaptive behavior and other relevant information.

4) The Alzheimer's Disease and Related Disorders Commission in conjunction with local chapters of the Alzheimer's Association shall develop a public/private partnership to provide training/ education regarding special care units, special programs and specialized services to professionals, paraprofessionals, family members, caregivers, and the general public.

The Education Committee of the Commission is currently developing a training module on the management of disruptive behavior for staff in nursing facilities and homes for adults. Additional topics for training will cover how to communicate with, and care for individuals with dementia.

DATABASE SYSTEM: 5) The DMHMRSAS shall maintain and expand a database for specialized dementia programs in Virginia using data from the recently completed survey on special care units, special programs, and specialized services.

6) The DMHMRSAS shall conduct a follow-up survey of special care in 1994 to obtain specific data on the characteristics of special care units, programs, services, activities and interventions used to manage maladaptive behavior and criteria for admission of individuals to special care units, special programs and specialized services. The survey should be enhanced by information obtained from site visits and interviews with staff of facilities and families.

7) The Alzheimer's Disease and Related Disorders Commission shall request the Virginia Department of Health and the Department of Social Services to develop a list of facilities with special care units, special programs, and specialized services, based on agreed upon definitions and, data that can be collected within their current reporting mechanisms which would be available to consumers and other interested persons.

APPENDICES

APPENDIX A

GENERAL ASSEMBLY OF VIRGINIA--1992 SESSION

HOUSE JOINT RESOLUTION NO. 51

Requesting the Department of Mental Health, Mental Retardation and Substance Abuse Services to study special care units in long-term care facilities and determine the need for operational guidelines for such facilities.

Agreed to by the House of Delegates, March 5, 1992
Agreed to by the Senate, March 4, 1992

WHEREAS, Alzheimer's disease is one of the more frequently discussed and publicized dementias in recent years; and

WHEREAS, Alzheimer's disease is characterized by a progressive and irreversible deterioration of cognitive functions such as memory, attention and judgment which begins gradually but eventually results in the loss of memory and physical functions and ends in a terminal vegetative state; and

WHEREAS, because of better diagnoses in recent years, the number of Alzheimer's patients have increased dramatically and the demand for long-term care has risen proportionately; and

WHEREAS, Alzheimer's disease accounts for nearly 50 percent of the admissions to nursing homes and long-term care mental hospitals, and it may be the single most important cause of institutionalization for long-term care; and

WHEREAS, other common dementias are brain diseases which result in the progressive loss of mental faculties and include multi-infarct dementia, multiple sclerosis, Parkinson's disease, Pick's disease, Huntington's disease, and Creutzfeldt-Jakob disease; and

WHEREAS, a 1985 joint subcommittee of the General Assembly conducted a study of the phenomenon of Alzheimer's disease and made a number of recommendations, including to: (i) conduct an epidemiological study to determine the true numbers of patients in the state who suffer from this disease; (ii) create five regional dementia centers in the state to better coordinate available services and identify additional needs; (iii) evaluate by professionals and paraprofessionals academic and clinical programs to ensure that adequate instruction about dementias is being provided; (iv) increase curriculum for geriatric nursing assistants to better prepare those who will ultimately deal with these patients; and (v) increase dissemination of information to the public, physicians, and schools; and

WHEREAS, although the 1985 joint subcommittee made a recommendation regarding the use of a secure environment without the use of physical or chemical restraints, an additional study is needed of the entire spectrum of operational guidelines used by the long-term care facilities which provide care for patients suffering from Alzheimer's disease and other dementias; now, therefore, be it

RESOLVED by the House of Delegates, the Senate concurring, That the Department of Mental Health, Mental Retardation and Substance Abuse Services in cooperation with the Virginia Health Care Association, the Virginia Association of Homes for Adults and the Virginia Association of Nonprofit Homes for the Aging be requested to conduct a study of the characteristics of existing specialized care units which care for dementia patients and to determine the need for operational guidelines to be developed for such units. The Department should consider, but not be limited to, issues such as: (i) whether specialized units are providing appropriate interventions specific to the needs and characteristics of people with dementia and how these differ from the standard care provided elsewhere in long-term care facilities; (ii) whether there are identifiable components of the quality care provided by some special care units which should be provided by all; (iii) how specialized care units address the issues of safety, security, and appropriate activities; and (iv) what the basis should be for a price differential for specialized care units compared to standard care units in long-term care facilities. The Department should utilize the information and experience of legislators, family members of clients receiving care, health care professionals specializing in the care of individuals with dementia, representatives of Alzheimer's Association chapters in Virginia, owners and managers of long-term care facilities, representatives of public and private health insurers, and local or state health officials.

The Department shall complete its study in time to submit its findings and recommendations to the Governor and the 1993 Session of the General Assembly as provided in the procedures of the Division of Legislative Automated Systems for the processing of legislative documents.

APPENDIX B

MEMBERS, ALZHEIMER'S DISEASE AND RELATED DISORDERS COMMISSION

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APPENDIX C

SPECIAL CARE UNITS STUDY RESOURCE COMMITTEE

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APPENDIX D

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