REPORT OF THE
JOINT COMMISSION ON HEALTH CARE

STUDY OF WHETHER THERE ARE ABUSES IN INDEPENDENT LIVING ARRANGEMENTS FOR THE ELDERLY OR DISABLED PURSUANT TO HJR 637 OF 1995

TO THE GOVERNOR AND
THE GENERAL ASSEMBLY OF VIRGINIA

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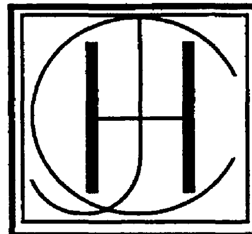

Preface

House Joint Resolution (HJR) 637 of the 1995 Session of the General Assembly directed the Joint Commission on Health Care to study whether there are abuses in independent living arrangements for the elderly and disabled; and, if so, to recommend ways of addressing and correcting these abuses without curtailing the independence of persons who are fully capable of living without regular medical or ambulatory assistance.

In Virginia, there are several different types of long-term care/aging facilities or housing in which elderly citizens can reside. In addition to private housing such as apartments and single family homes, elderly citizens also reside in nursing homes, adult care residences, continuing care retirement communities (CCRCs), and independent living arrangements.

Nursing homes, CCRCs and adult care residences are regulated and licensed by the Commonwealth. Because these facilities provide for the "maintenance or care" for their respective residents, the state has a responsibility to the residents to assure that certain standards of care and levels of service are met. This assurance is provided through the licensing and regulatory reviews performed by the Department of Health for nursing homes, the Department of Social Services for adult care residences, and the Bureau of Insurance for CCRCs.

Independent living arrangements, however, do not provide for the "maintenance or care" of the residents. Independent living arrangements, which provide only housing services, are not regulated or licensed by the state. In most independent living arrangements, housing is provided under the terms of a lease, similar to that in other apartment dwellings. There are no provisions in the contract for providing "maintenance or care" services to the residents.

Because independent living arrangements provide only housing services, some residents contract on their own for home health care services to help them remain independent. These services may include personal assistance (e.g. reading, ironing, showering or companionship) or limited medical services such as drawing blood, changing a catheter and providing durable medical equipment. Often, independent living arrangements are located in retirement communities which also include adult care resident and nursing home facilities.

Some residents of independent living arrangements located in certain retirement communities have complained that frail residents with medical

infirmities, disabilities and limitations are being accepted into independent living arrangements rather than being required to live in a higher level of care (i.e. adult care residence or nursing home). The residents that have voiced these complaints argue that this constitutes an abuse of the independent living arrangements and has an adverse impact on their lifestyle. These residents identified the following concerns regarding the frail elderly being allowed into independent living arrangements:

* frail elderly do not receive the level of care they need;
* persons who provide home health care services to these frail elderly use common rooms and facilities and disrupt the "independent lifestyle" other residents desire and expect;
* residents' use of wheelchairs, walkers and other medical equipment diminish the "sociability" of the independent living lifestyle; and
* retirement communities which allow frail elderly into independent living avoid state licensing requirements for adult care residences.

Through the course of our study, we conducted a broad review of the issues raised in HJR 637, including interviews with administrators of several retirement communities, residents of independent living arrangements, state and local government long-term care and aging officials, long-term care industry officials, senior citizen advocacy groups, and others. Our study found that while the concerns of some independent living residents are understandable and legitimate, they do not constitute an abuse of the Commonwealth's regulations regarding long-term care facilities or independent living arrangements. Moreover, federal and state laws prohibit discrimination against elderly persons with medical disabilities or other limitations. Based on these laws, if retirement communities were to prohibit residents from moving into or remaining in independent living arrangements, they likely would be in violation of these anti-discrimination laws.

In addition to federal and state laws which protect the rights of the frail elderly, the long-term care and elderly communities as well as state policy place emphasis on keeping the elderly as independent as possible. In the context of the issues raised in HJR 637, this policy direction would argue that if frail residents can contract for services they need in order to stay as independent as possible, they should have the freedom to do so. Conversely, prohibiting the frail elderly from residing in an independent living arrangement would be in conflict with this policy.

The concerns raised by some independent living residents about allowing the frail elderly into these arrangements may be due in part to confusion about how the various retirement communities operate with respect to the rights of

residents (e.g., a certain facility's policy regarding frail elderly in independent living units). Currently, there is little consumer information available on the specific administrative and resident policies of retirement communities to educate senior citizens on how issues such as the frail elderly are handled at each facility. Additional consumer information and/or a voluntary counseling service may be effective in this regard.

Three policy options were presented in the draft issue brief for consideration by the Joint Commission.

Option I: Maintain the status quo.

Option II: Request the Department for the Aging, the Area Agencies on Aging and the Department of Social Services to Consider the Feasibility of Developing and Publishing Additional Consumer Information on Independent Living Arrangements, and Establishing a Voluntary Counseling Service Similar to the Virginia Insurance Counseling and Advocacy Program.

Option III: Introduce a Resolution Encouraging Retirement Communities Offering Independent Living Arrangements to Take All Appropriate Actions to Advise Those Applying for Residence in an Independent Living Unit About the Facility's Policies and Procedures Regarding Frail Elderly In These Accommodations.

Our review process on this topic included an initial staff briefing which you will find in the body of this report followed by a public comment period during which time interested parties forwarded written comments to us on the report. In many cases, the public comments, which are provided at the end of this report, provided additional insight into the various topics covered in this study.

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Executive Director

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I.
Authority for Study

House Joint Resolution (HJR) 637 of the 1995 Session of the General Assembly directed the Joint Commission on Health Care to study whether there are abuses in independent living arrangements for the elderly and disabled, and, if so, to recommend ways of addressing and correcting these abuses without curtailing the independence of persons who are fully capable of living without regular medical or ambulatory assistance. A copy of HJR 637 is provided at Appendix A.

II.
Background

Adult Care Residences and Nursing Homes Are Regulated and Licensed by the Commonwealth

Adult Care Residences: The Department of Social Services (DSS) regulates and licenses Adult Care Residences (ACRs). As defined in § 63.1-172 of the Code of Virginia, an ACR ". . . means any place, establishment, or institution, public or private, operated or maintained for the maintenance or care of four or more adults (emphasis added) who are aged, infirmed or disabled and who are cared for in a primarily residential setting..." Maintenance or care is defined in the Code to mean "the protection, general supervision and oversight of the physical and mental well-being of the aged, infirmed or disabled individual."

The State Board of Social Services adopted new standards and regulations for Licensed Adult Care Residences on November 16, 1995. These regulations, which became effective on February 1, 1996, provide for two levels of care within a licensed ACR: **residential** and **assisted living**. Residential living means a level of service provided by an ACR for adults who have physical or mental impairments and require only *minimal* assistance with the activities of daily living (e.g., bathing, dressing, toileting, transferring, bowel control, bladder control, and eating/feeding). Assisted living is a higher level of care provided by an ACR for adults who require *moderate* assistance with activities of daily living.

Nursing Homes: Section 32.1-125 of the Code of Virginia requires nursing homes to be licensed by the Department of Health. Nursing homes, which include convalescent homes, skilled nursing facilities, intermediate care facilities and extended care facilities, are defined as any facility whose primary function is the provision, on a continuing basis, of nursing services and health-related services for the treatment and inpatient care of two or more non-related individuals. In the continuum of long-term care services, nursing homes provide the highest level of care; and, accordingly, services are provided in a more restrictive environment.

Continuing Care Retirement Communities (CCRCs) Provide a Continuum of Care and Are Regulated and Licensed by the State Corporation Commission

CCRC Services: While adult care residences and nursing homes provide long-term care services to specific populations of elderly citizens based on their care needs, Continuing Care Retirement Communities (CCRCs) provide a continuum of board, lodging and nursing services to an individual for life or for a period of at least one year. Typically, the CCRC resident pays an entrance fee plus an additional monthly fee. In exchange, the CCRC provides a package of services, including nursing care, based on the needs of the individual. Residents are placed in the care setting suited to their needs. Accordingly, persons with fewer disabilities or limitations typically are placed in an independent living or assisted living setting, whereas those with greater limitations or needs may receive nursing care services. As CCRC residents "age-in-place," become more dependent, and need greater services, they move to a higher level of care.

CCRC Regulation and Licensure: CCRCs are regulated and licensed by the State Corporation Commission (SCC) pursuant to §38.2-4900 et. seq. of the Code of Virginia. The SCC regulations: (i) seek to ensure the financial stability of the CCRC, (ii) protect the consumer's investment; and (iii) set requirements regarding financial disclosure and contract requirements. As noted above, CCRC residents move to higher levels of care when they age and need additional services. Section 38.2-4905, subsections (4) and (5) require CCRC resident contracts to describe the physical and mental health and financial conditions upon which the provider may require the resident to relinquish his place in the designated facility and to continue as a resident. This requirement is intended to

ensure the resident is aware of the process that may be used to require him/her to move to a higher, more restrictive level of care.

"CCRC Look-Alikes:" In addition to those retirement communities that are licensed as a CCRC, there also are communities referred to as "CCRC Look-Alikes." These facilities offer an array of services similar to that available in a CCRC, but rent their apartments on a monthly, fee-for-service basis, with no assurance of access to additional services. A 1992 study by the Department for the Aging (1992 House Document 46) found that these "CCRC Look-Alikes" may cause confusion among consumers.

Independent Living Arrangements, Which Include a Wide Range of Housing Alternatives, Do Not Provide for the Maintenance or Care of the Residents; and, Therefore, Are Not Regulated or Licensed by the Commonwealth

Elderly persons who do not need the services provided by an adult care residence (ACR) or nursing home live independently. Independent living arrangements include a wide range of housing alternatives for the elderly and disabled, including private homes, congregate housing, apartment dwelling, and independent living units which typically are part of a larger retirement community. Unlike adult care residences (ACRs), nursing homes and CCRCs, independent living arrangements are not regulated or licensed by the Commonwealth because no "maintenance or care" is provided to the resident.

In most independent living arrangements, except a resident's private home, housing is provided under the terms of a lease, similar to that used in other apartment dwellings. Other types of services may be provided such as meals, security, hospitality, and social and recreational activities. However, there is no contract between the resident and the property owner/lessor to provide for the "maintenance or care" of the resident. The fact that no "maintenance or care" is provided to residents of independent living arrangements differentiates these facilities from adult care residences (ACRs).

Because residents of independent living arrangements are not dependent upon the facility for their care, the Commonwealth does not require licensure of these types of arrangements. Conversely, ACRs, which do provide for the

maintenance and care of residents, are regulated and licensed to assure a minimum level of safety and well-being of vulnerable adults in out-of-home placements. To provide this assurance to ACR residents, the regulations include requirements for the safety and appropriateness of the physical facility, the qualifications and appropriateness of the providers of care and the adequacy of the program of care.

Some Residents in Independent Living Arrangements Contract for Home Health Care Services

As noted previously, residents of independent living arrangements do not rely on the facility to provide for their maintenance and care. For the most part, persons living in independent living arrangements are healthier and do not require assistance with activities of daily living. However, some independent living residents contract with home health care agencies and other providers for various services. Some residents contract for personal assistance such as reading mail, ironing, showering and companionship. Others contract for limited medical services such as drawing blood for medical testing, changing a catheter, and providing durable medical equipment. Some need more extensive care and contract with agencies to provide home care on a day-to-day basis (i.e., 8 hours/day). These residents prefer to contract for these services on their own so that they can retain their independent living status and have fewer restrictions on their day-to-day activities.

Retirement Communities Which Arrange for Contracted Home Health Services Are Subject to State Adult Care Residence Regulations and Licensure

If the retirement community arranges for or coordinates the delivery of home health services for independent living residents, Department of Social Services' regulations would consider the community to be providing maintenance and care; and, thus, would be subject to licensure as an ACR. However, if the residents contract for the home health services on their own, the independent living units are not subject to state licensure or regulation.

III.
Potential Abuses in Independent Living Arrangements

Some Independent Living Residents Have Complained that Residents with Medical Infirmities, Disabilities and Limitations Are Allowed to Remain in Independent Living Arrangements Rather Than Being Required to Move to a Higher Level of Care

House Joint Resolution 637 directs the Joint Commission on Health Care to study whether there are abuses in independent living arrangements, and, if so, to recommend ways of addressing these abuses. Based on interviews conducted with the resident of an independent living facility who requested that HJR 637 be introduced, it was learned that the primary concern for potential abuse was that some independent living residents with medical infirmities, disabilities or limitations are being accepted into independent living arrangements. Further, the resident cites concern that, in some instances, persons who are healthy when first admitted to independent living are allowed to remain in these units after their health deteriorates to the point that they need a higher level of care.

Scope of Review Limited to Certain Retirement Communities: The potential abuses cited by this resident were identified in retirement communities in which both independent living arrangements and higher levels of care (such as residential or assisted living levels of care provided by a licensed adult care residence) are offered. The potential abuses identified for study do not apply to other forms of independent living arrangements such as persons living in private homes or separate apartment dwellings. Also, continuing care retirement communities (CCRCs), in which residents sign a contract which stipulates how and when residents are moved to higher levels of care, are not within the scope of the study.

Some Residents Argue that Abuses of Independent Living Arrangements Have an Adverse Impact on Their Lifestyle

The following concerns were identified regarding retirement communities which allow frail elderly residents (i.e., persons with medical infirmities, disabilities or other limitations) to remain in independent living arrangements:

* frail elderly residents may not be receiving the level of care necessary to meet their needs;
* many of these residents contract with home health agencies and other providers to provide personal and medical care services; these home health providers use the retirement community's common rooms and facilities, and disrupt the "independent lifestyle" other residents desire and expect from the community;
* residents' use of wheelchairs, Amigo-style motorized carts, walkers and other medical equipment diminish and ultimately destroy the "sociability" and desirability of the independent living lifestyle;
* by permitting residents to contract for home health services, the retirement community avoids state licensing requirements for adult care residences imposed on facilities which provide for the "maintenance and care" of residents; and
* retirement communities which allow this practice breach their "marketed promise" of providing different levels of care for residents based on their needs.

Retirement Communities State that They Seek to Place Residents in the Most Appropriate Setting and Attempt to Meet the Desires of the Residents

Several retirement communities, including the community where the issues of potential abuse arose, were interviewed to obtain their views on these issues and ascertain how residents are placed within their respective communities. The administrators of these retirement communities all indicated that they attempt to place residents in the most appropriate setting based on their health needs. Moreover, they attempt to meet the desires of the resident as to where they feel most comfortable living. Several administrators noted that they would rather "err on the side of meeting the resident's wishes" than forcing them to accept a level of care or type of housing that they do not want.

Each of the administrators stated that when a resident's health status is such that a higher level of care is indicated, they counsel the resident that it is in his/her best interest to receive additional services or move into a higher level of care (e.g., an assisted living unit). Often, the administrator will contact the resident's family and consult with the resident's physician to discuss the situation

and seek their assistance in explaining to the resident the need to obtain additional care.

All of the administrators noted that, in the vast majority of cases, the resident, often with the urging of his/her family and physician, will agree to the recommended changes. According to these administrators, the number of instances in which a resident absolutely refuses to move is extremely rare.

There Are Differences in How Retirement Communities Place and Transfer Residents in Independent Living Arrangements

Based on interviews conducted with the administrators of several retirement communities with independent living and assisted living units, there are differences in how residents are placed in and transferred to different types of living arrangements.

U.S. Fair Housing Laws Cited as Reason for Allowing Frail Elderly in Independent Living Arrangements: At the retirement community where the potential abuses were raised by the residents' council, the administrators indicated that the U.S. Fair Housing Amendments Act prohibits them from refusing independent living arrangements to persons with health disabilities, infirmities or limitations. In addition, the facility believes this law also prohibits them from requiring independent living residents, who have "aged-in-place" and have developed significant health needs, to move out of their dwelling and into a higher level of care. (The impact of the U.S. Fair Housing Amendments Act as well as other federal and state laws on independent living arrangements is discussed later in this report.)

This facility requires persons applying for residence to complete a medical evaluation form describing their physical/medical condition. However, the form is used only in the event the facility has to respond to an emergency involving the resident. The information is not used to require a person to live in either independent living or assisted living units. The resident contract for independent living arrangements used at this facility does not include any provisions requiring the resident to maintain a certain degree of health or independence. The resident contract is a simple lease agreement. Thus, there is

no restriction on the medical/health status of an individual in an independent living unit either at the time of initial placement or during the time the individual resides in the unit.

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Approval of Physician Required at Another Facility: In another similar retirement community, the facility places more restrictions on who is placed and allowed to remain in the independent living units. The resident contract at this facility includes a provision that, in order to reside in an independent living unit, the resident's physician must indicate that he/she is capable of living independently and is able to remain on the property. Without a physician's approval, the resident is not placed in an independent living unit. The resident contract also stipulates that the facility can require the resident to have a physical examination, and that if the resident refuses, the facility can require the resident to leave the premises following 30 days written notice. The facility staff indicate that while it is seldom necessary to do so, it does require persons to leave independent living when it is determined to be in the best interest of the resident.

There is Limited Consumer Information Available to Educate the Elderly on How Specific Facilities Operate Their Independent Living Arrangements

As illustrated in the preceding section, retirement communities which offer independent living arrangements have different policies as to how persons are admitted to these units. Residents often are not aware of these policies until after they reside at the community. There are long-term care consumer guides published for the elderly (e.g., Department for the Aging's Consumer Guide to Long-Term Care); however, very little information regarding independent living is included in these materials.

Consumer information on specific aspects and policies of each retirement community (e.g., policies on independent living) in a given region would help educate the elderly <u>before</u> a decision is made regarding where to live. Another method of educating consumers about independent living arrangements is a counseling service. The Department for the Aging coordinates the Virginia Insurance Counseling and Advocacy Program (VICAP) to counsel senior citizens about health and life insurance issues. A similar program to provide information

on retirement communities may help educate consumers on how specific facilities operate their independent living units.

State Long-Term Care and Aging Officials and Long-Term Care Industry Associations Are Aware that Allowing Frail Elderly Residents in Independent Living Arrangements is an Issue of Concern with Some Residents; However, They Believe it is not a Significant Problem

To determine the extent of the potential abuses in independent living arrangements giving rise to this study, interviews were conducted with staff of the following state agencies and several long-term care/aging industry associations:

* Department of Medical Assistance Services
* Department of Social Services
* Department for the Aging
* Department for the Rights of Virginians with Disabilities
* Virginia Association of Area Agencies on Aging
* Three Local Area Agencies on Aging
* Virginia Long-Term Care Ombudsman Program
* Virginia Health Care Association
* Virginia Association of Nonprofit Homes for the Aging
* Virginia Association for Home Care
* Virginia Adult Home Association

Representatives of these entities indicated that they have been aware of the issues/concerns regarding placing and retaining frail elderly persons in independent living arrangements. The consensus of these representatives was that while these concerns have been voiced by some residents in various retirement communities, it is not a significant medical or long-term care issue that needs legislative or regulatory action to correct.

Regional Department of Social Services Offices Report Few Complaints Regarding Independent Living Arrangements

The central office of the Department of Social Services (DSS) contacted the regional office administrators throughout the state to ascertain whether any of the offices had received complaints regarding persons with medical disabilities or limitations residing in independent living arrangements. While there were no specific written records kept on such complaints, the regional offices reported very few, if any, complaints. The DSS regional office that oversees the region where the complaint giving rise to this study originated, reported that they have not received any other such complaints.

Concerns Regarding Independent Living Residents with Medical Disabilities and Limitations Likely Are a Natural Part of the "Aging-In-Place" Process

In general, the aging and long-term care representatives agreed that the concerns regarding independent living residents with medical disabilities or limitations is a reflection of the "aging-in-place" process. They explained that it is natural for elderly persons to want to share facilities, socialize and interact with persons who are healthy, active and reflect a "youthful" style of living. Persons who have medical disabilities and limitations, and live in independent living arrangements sometimes are viewed by the healthier residents as detracting from the independent living lifestyle. Also, aging experts note that it can be disconcerting to healthier residents to interact with persons who have medical disabilities because it can serve as a reminder that they may face similar health problems in the future.

IV.
The Impact of Federal And State Laws on Independent Living Arrangements

Independent Living Arrangements Must Comply with the Federal Fair Housing Amendments Act of 1988; The Americans with Disabilities Act Has Less Application to this Issue

U.S. Fair Housing Amendments Act: The Fair Housing Amendments Act (FHAA) of 1988 prohibits discrimination in almost all housing activities or transactions, whether in the public or private sector; in the provision of services or facilities in connection with a dwelling; and in the application of zoning, land use, or health and safety regulations. (Edelstein, 1995).

Specifically, §804. [42 U.S.C. 3604] (d) states that it is unlawful: "to represent to any person because of race, color, religion, sex, *handicap* (emphasis added), familial status or national origin that any dwelling is not available for inspection, sale, or rental when such dwelling is in fact so available." Subsection (f)(1) states that it is unlawful: "to discriminate in the sale or rental, or to otherwise make unavailable or deny, a dwelling to any buyer or renter because of a *handicap* (emphasis added) of: (A) that buyer or renter, (B) a person residing in or intending to reside in that dwelling after it is sold, rented, or made available; or (C) any persons associated with that buyer or renter." Subsection (f)(2) provides it also is unlawful to discriminate against any person in the terms, conditions, or privileges of sale or rental of a dwelling or in the provision of services or facilities in connection with such dwelling because of a handicap.

An attorney with the American Bar Association's Commission on the Elderly, who has expertise in the FHAA, states that while the law precludes retirement communities from denying independent living status for persons with medical disabilities or other limitations, there is very little case law which has addressed this specific topic. Nonetheless, she indicated that the intent of Congress was clear that the law applies to all housing.

An April, 1995 report entitled "Fair Housing Laws and Group Residences for Frail Older Persons" was published by The Public Policy Institute of the American Association of Retired Persons (AARP). This report, which addresses

the impact of the FHAA on housing for the elderly, states that the FHAA "...makes it clear that the decision to accept a particular applicant must be based only on the applicant's eligibility for the program in question. . . [Q]uestions about *disability* (emphasis added) are legitimate only to determine an individual's eligibility for housing for persons with disabilities, or, if special programs or services are provided, to determine which ones will be needed." Implicit in the report is a finding that considering a person's disability to exclude them from various housing is prohibited under the FHAA.

In summary, it appears that the FHAA prohibits retirement communities from precluding persons with medical disabilities or other limitations from residing in independent living units.

The Americans with Disabilities Act (ADA): The ADA also protects persons with disabilities, including older frail persons. However, it is generally agreed that the ADA does not have direct application to the issue of denying certain housing opportunities to frail elderly persons. Moreover, the ADA specifically excludes entities covered by the FHAA. (Edelstein, 1995). The ADA is applicable primarily to non-housing functions of a facility, such as access and accommodations in meeting rooms, meal sites, etc.

The Virginia Fair Housing Law and The Virginians with Disabilities Act Mirror Federal Anti-Discrimination Laws

Virginia Fair Housing Law: Section 36-96.1 et. seq. of the Code of Virginia states that it is the policy of the Commonwealth to provide for fair housing to all citizens regardless of race, color, religion, national origin, sex, *elderliness*, familial status, or *handicap* (emphasis added). The Virginia Fair Housing Law mirrors the key provisions of the Federal Fair Housing Amendments Act (FHAA). Similar to the FHAA, §36-96.3 (8) and (9) of the Code of Virginia state it is illegal to refuse to sell or rent, or refuse to negotiate for the sale or rental of, or otherwise discriminate or make unavailable or deny a dwelling because of a handicap.

The Virginians with Disabilities Act: Section 51.5-45 of the Code of Virginia provides that "...all persons with disabilities shall be entitled to full and equal opportunity to acquire, as other members of the general public, any housing accommodations offered for sale, rent, lease, or compensation, subject to

the conditions and limitations established by law and applying alike to all persons."

A comprehensive legal analysis of the Virginia Fair Housing Law and the Virginians with Disabilities Act was not conducted as part of this study. However, given the similarity of Virginia's Fair Housing Law to the FHAA, and the provisions of the Virginians with Disabilities Act, it appears that Virginia state law mirrors federal anti-discrimination laws and precludes retirement communities from denying independent living status to residents with medical disabilities.

State Laws and Regulations Regarding Adult Care Residences Do Not Apply to Independent Living Arrangements

As noted in the Background section of this report, state laws and regulations regarding adult care residences (ACRs) do not apply to independent living arrangements. State ACR laws and regulations apply only to those facilities which provide for the "maintenance or care for four or more adults who are aged, infirmed, or disabled and who are cared for in a primarily residential setting..." True independent living arrangements do not provide "maintenance or care" for the residents; they simply provide housing and perhaps other "hotel-type" services such as meals, cleaning services, hospitality, etc.

DSS Investigated the Complaints Regarding Potential Abuses of Independent Living Arrangements That Gave Rise to This Study

The Department of Social Services (DSS) investigated the complaints of potential abuses of independent living that gave rise to this study. DSS found the retirement community to be operating in accordance with state laws and regulations. In correspondence with the complainant, DSS advised that the independent living units at the facility did not provide maintenance or care; and, thus, were not subject to state licensure. The regional licensing administrator who conducted the review indicated that if the facility were to require persons to leave the independent living arrangements because of medical limitations, the facility may be viewed as assuming responsibility for the maintenance or care of the residents, which could lead to a requirement that the units be licensed.

V.
Public Policy Issues Regarding Long-Term Care, Aging and Independent Living

The Issues Regarding When an Elderly Person Should be Moved to a Higher/More Restrictive Level of Care, and Who Should Make the Decision, Pose Difficult Public Policy Questions

The issues of when a frail older person should move to a higher level of care, and who should make this determination pose difficult public policy questions. Clearly, these issues should be decided in the best interests of the individual. The AARP report referenced earlier concluded that health care providers, state and local licensing agencies and some members of the aging network, all of whom are acutely aware of the potential neglect of frail older persons, have worked for many years to protect these individuals and ensure that they are not put at risk. However, the report goes on to say that this approach may be deemed overprotective by those who prefer more autonomy, and it may conflict with anti-discrimination laws and court cases.

The authors of the report conclude that the disability community and others in the aging network advocate strongly and compellingly for the right of persons with disabilities to make their own decisions about where and how they live, even if those choices place them at risk. In the context of the frail elderly residing in independent living arrangements, this approach would argue that even if residents have medical disabilities and limitations which require additional services, they should be able to live as independently as possible. Moreover, any attempts to force an alternative lifestyle on these residents likely would violate anti-discrimination laws.

Current Policy Direction is to Have Long-Term Care Residents and Elderly Persons Remain as Independent as Possible

In recent years, aging and long-term care policy has emphasized keeping elderly persons as independent as possible and in environments with as few restrictions as possible. Not only are such arrangements often less expensive; they also are thought to provide a higher quality and more desirable lifestyle.

This movement toward independence and increased autonomy applies to the frail elderly as well as the disabled population.

The Commonwealth's Long-Term Care Policy, as Expressed by the 1993 General Assembly, Emphasizes Independence of the Elderly

The national trend of emphasizing independence for elderly persons was adopted as a formal long-term care policy by the Commonwealth. House Joint Resolution 602, which was adopted by the 1993 General Assembly, stated that elderly citizens should receive necessary care and services in the least costly and least confining situation. The resolution further stated that "... in keeping with the preferences of most elderly and disabled Virginians, a long-term care system should: (i) *provide maximum independence for older and disabled adults;* (ii) maximize community based care alternatives for publicly funded long-term care services; (iii) ensure a continuum of long-term care services in each locality; (iv) *allow individual choice in the selection and provisions of long-term care services;* and (v) support families and other informal caregivers (emphasis added)."

HJR 602 declared that "... the Commonwealth be committed to providing services to elderly individuals through programs and in settings which *maximize their ability to function as independently as possible* (emphasis added) given their physical limitations and which encourage principles of personal dignity, individuality, privacy and the right to make choices and the right to a decent quality of life."

The Department of Social Services' Adult Protective Services Program Serves as a Safety Net in Extreme Cases When Elderly Persons Become Unable to Care for Themselves; Also, Section 63.1-55.3 of the Code of Virginia Requires Certain Health Care Providers and Others to Report Cases of Neglect, Abuse or Exploitation

One of the arguments for requiring the frail elderly to move into a higher level of care is the possibility that the individual's health will deteriorate significantly and/or the person will be living in an unsafe environment. This is one of the concerns voiced by those independent living residents who requested that this study be conducted. While this is an issue of concern, the Department of Social Services' (DSS) Adult Protective Services Program functions as a safety net to identify and remedy cases of severe neglect.

Adult Protective Services Program: Section 63.1-55.1 establishes the Adult Protective Services program at the DSS . This program provides protective services for persons who by reason of advanced age, impaired health, or physical disability cannot take care of themselves or their affairs and have no relative or other person to handle their affairs. When an incident is reported to a local department of social services, a social worker conducts an investigation to determine the need for services. To the degree he/she is capable, the affected adult participates in the decision-making regarding the care and services needed. Adults are helped to remain as independent as possible.

Certain Persons Are Mandated to Report Suspected Neglect, Abuse or Exploitation of Adults: Section 63.1-55.3 mandates the following persons to report suspected abuse, neglect or exploitation of adults: physicians, including hospital residents and interns, persons employed in the nursing profession, persons employed by a public or private agency or facility and working with adults, persons providing full-time or part-time care to adults for pay on a regularly scheduled basis, social workers, mental health professionals, and law-enforcement officers. This mandated reporting works in concert with the Adult Protective Services Program to provide protection for elderly persons who may have fallen into self-neglect and need additional health care services.

Home Health Care Providers Have a Professional Responsibility to Report Cases in Which They Can No Longer Adequately Provide the Necessary Care for a Client

Many of the frail elderly residing in independent living arrangements contract with home health agencies or other providers for certain home health services. The providers who deliver this care are licensed through the Department of Health Professions and/or the Department of Health. The home health providers deliver services as prescribed by the resident's physician. Therefore, a physician is monitoring the care provided to these persons. In addition, while there is specific no licensure requirement that home health providers report cases of clients whose health care needs are beyond the services the provider is able to provide, there is a professional and ethical responsibility to report such cases to the resident's physician. This also helps to identify frail elderly persons who may need to be placed in an assisted living unit within the retirement community.

VI.
Independent Living Arrangements in Other States

There is Very Little Information Available Regarding Independent Living Arrangements in Other States

Because independent living arrangements are considered primarily to be private residences and outside of the regulated long-term care system, there is very little information available on how other states address the issue of frail elderly residents. Another complicating factor is the variation in definitions used in other states for independent living, congregate housing, board and care homes, and assisted living.

While no written reports or documents were found that describe how independent living arrangements operate in other states, the consensus of the long-term care and aging experts interviewed through the course of this study was that no state requires independent living arrangements to be licensed. They also agreed that, in most states, the trend is to keep residents as independent as possible. More importantly, the provisions of the U.S. Fair Housing Amendments Act would have the same impact on independent living arrangements in other states as it does in Virginia.

VII. Conclusions

The Concerns of Some Residents Regarding the Frail Elderly Who Reside in Independent Living Units Are Understandable and Legitimate; However, This Issue Does Not Appear to be an Abuse of the Commonwealth's Long-Term Care Regulations or Independent Living Arrangements

The issues raised by residents of independent living arraignments reflect legitimate concerns regarding elderly persons with medical disabilities or limitations residing in this setting. Clearly, it is reasonable to question whether the frail elderly could be cared for more appropriately in a higher level of care, such as assisted living. It also is a legitimate and understandable concern of healthier residents to feel that the presence of the frail elderly in independent living arrangements detracts from the "independent lifestyle" that persons expect and desire from these accommodations. However, this issue does not appear to be an abuse of independent living arrangements or the Commonwealth's long-term care statutes and regulations regarding licensure of adult care residences. The Department of Social Services' review of the retirement community where this issue was raised found that the facility was in compliance with state laws and regulations regarding adult care residences.

While there are some retirement community residents who believe the practice of allowing the frail elderly to remain in independent living is an abuse of these accommodations, aging and long-term care officials and retirement community administrators do not believe this issue represents an abuse or major problem. These officials agree that this issue is a real concern among some residents and can sometimes be problematic. However, they indicated that, in the vast majority of cases, residents whom they believe need to be moved to a higher level of care agree to do so after consultation with family members and their physician. Only in rare instances do these residents completely refuse to move.

Federal and State Housing Laws Prohibit Discrimination Against Elderly Persons with Medical Disabilities or Other Limitations

While there has not been specific case law regarding the application of the U.S. Fair Housing Amendments Act of 1988 to independent living arrangements,

legal experts believe the law prohibits retirement communities from denying independent living arrangements to the frail elderly. Virginia's Fair Housing Law and the Virginians with Disabilities Act appear to mirror federal law in this respect.

The Long-Term Care and Elderly Communities as well as State Policy Place Emphasis on Keeping the Elderly as Independent as Possible

As noted earlier, the aging and long-term care communities have emphasized keeping elderly persons as independent as possible and in environments with as few restrictions as possible. The disability community and others in the aging network advocate strongly and compellingly for the right of persons with disabilities to make their own decisions about where and how they live, even if those choices place them at risk. The emphasis on independence for the frail elderly is consistent with the broader public policy of including persons with handicaps and limitations as much as possible and allowing them to remain as self-sufficient as possible. In the context of the frail elderly remaining in independent living arrangements, this policy direction would argue that if these residents can contract for services they need through home health care, they should have the freedom to do so.

The Commonwealth's long-term care policy, as stated in House Joint Resolution 602 of the 1993 General Assembly Session, is consistent with the policy direction of emphasizing independence and self-sufficiency of elderly citizens.

Requiring Licensure of Independent Living Arrangements Does Not Appear to be Warranted

Independent living arrangements include numerous types of accommodations including private homes and apartments, congregate housing, and retirement communities. These living arrangements provide alternatives to the elderly beyond the scope of state long-term care licensure and regulation. Currently, independent living arrangements in retirement communities are almost identical to private apartment dwelling, and provide residents a secure place to live with few if any restrictions on their activities and lifestyle. To subject certain of these independent living arrangements to state licensure and

regulation would narrow the alternatives available to the elderly and likely would impose certain requirements/restrictions on the accommodations. Moreover, given the broad range of independent living arrangements it would be difficult to decide "where to draw the line" with respect to which types of independent living would and would not be subject to licensure.

Additional Consumer Information on the Different Types of Facilities, Services, and Resident Policies in Retirement Communities and Independent Living Arrangements May Help Reduce the Confusion Among the Elderly About How These Arrangements Function

The different types of retirement/long-term care communities (e.g., independent living, congregate housing, adult care residences, nursing homes, continuing care retirement communities, and "CCRC Look-Alikes") and the various levels of long-term care services (i.e., residential, assisted living, intensive assisted living, and nursing care) is confusing to senior citizens. Confusion about how these various types of retirement communities operate with respect to the rights of residents (e.g., a certain facility's policy regarding frail elderly residing in independent living units) is a contributing factor to the problems being reviewed in this study.

Currently, there is little consumer information on the specific administrative and resident policies of retirement communities to educate senior citizens on how issues such as the frail elderly in independent living units is addressed at each facility. While producing this type of information will not eliminate these types of problems, it would help reduce the confusion among the elderly, and they would be aware of the facility's policies on independent living and other important aspects of the community prior to making a commitment to reside there. Regional consumer publications and/or a voluntary counseling service similar to the Virginia Insurance Counseling and Advocacy Program (VICAP) may be effective in this regard.

VIII.
Policy Options

Option I: Maintain Status Quo

Option I recognizes that while the concerns of some residents regarding the frail elderly remaining in independent living arrangements are legitimate, they do not represent an abuse of the state's adult care residence regulations and licensure requirements. Additionally, Option I recognizes that, while these concerns exist among some residents, they do not represent a significant enough problem to warrant legislative action.

Option II: Request the Department for the Aging, the Area Agencies on Aging and the Department of Social Services to Consider the Feasibility of Developing and Publishing Additional Consumer Information on Independent Living Arrangements, and Establishing a Voluntary Counseling Service Similar to the Virginia Insurance Counseling and Advocacy Program

Under this Option, the Department of Aging, the Area Agencies on Aging and the Department of Social Services would be requested to consider the feasibility of developing and publishing consumer information that provides more detailed information on independent living arrangements. Publishing such information on a regional basis with specific details about administrative and resident policies in each retirement community would help educate consumers about how each facility addresses issues such as frail elderly residing in independent living units. In addition to considering the merits of publishing consumer information, these entities would also be requested to evaluate the feasibility of establishing a voluntary counseling service similar to the Virginia Insurance Counseling and Advocacy Program as a means of educating the elderly about various aspects of the long-term care system and independent living arrangements.

Option III: Introduce a Resolution Encouraging Retirement Communities Offering Independent Living Arrangements to Take All Appropriate Actions to Advise Those Applying for Residence in an Independent Living Unit About the Facility's Policies and Procedures Regarding Frail Elderly in These Accommodations

As noted in this issue brief, there is confusion among the elderly regarding how independent living arrangements operate, particularly with respect to allowing the frail elderly to remain in these units. Through Option III the General Assembly would encourage retirement communities to take all appropriate actions to advise persons applying for residence in an independent living arrangement about the facility's policy regarding the frail elderly in these accommodations. Proactive steps such as counseling the applicant and the applicant's family about these policies, and including information in the resident contract on this topic (as required by law for CCRCs) would help ensure that residents who choose to live there are aware of these policies and have accurate information as to how independent living arrangements are operated.

APPENDIX A

GENERAL ASSEMBLY OF VIRGINIA -- 1995 SESSION

HOUSE JOINT RESOLUTION NO. 637

Directing the Joint Commission on Health Care to study whether there are abuses in independent living arrangements for the elderly or disabled.

Agreed to by the House of Delegates, February 23, 1995
Agreed to by the Senate, February 21, 1995

WHEREAS, the number of elderly persons residing in the Commonwealth is expected to increase dramatically in the next 20 years; and

WHEREAS, housing is a major issue for the elderly, and most of the older citizens in the Commonwealth desire to remain as independent and self-sufficient as possible; and

WHEREAS, it is to the advantage of the Commonwealth and its citizens to avoid placement in more expensive care, not only in terms of dollars but also in terms of individual dignity and self-sufficiency; and

WHEREAS, because of improved medical technology and changes in population demographics, longevity and morbidity, long-term care has become the fastest growing component of the health care industry; and

WHEREAS, the Commonwealth regulates various types of care for the elderly, including adult care residences which are licensed by the Department of Social Services and nursing facilities which are licensed by the Department of Health; and

WHEREAS, adult care residences provide for the maintenance or care of adults who are aged, infirm or disabled but who do not require nursing facility care; and

WHEREAS, although the assisted living level of care offered by adult care residences requires licensure if the residence offers care to four or more adults, independent living, which is offered by many retirement communities, does not require licensure; and

WHEREAS, some retirement communities in the Commonwealth have allowed persons with significant medical needs to move into independent living or have allowed persons whose health has seriously deteriorated to remain in independent living; and

WHEREAS, in some retirement communities not required to be licensed, medically needy independent living residents may contract with home care organizations for their medical care; and

WHEREAS, if the retirement community assumed responsibility for providing, maintaining, and supervising this same care, the retirement community would be required to be licensed; and

WHEREAS, some retirement communities house both independent living residents and assisted living residents; and

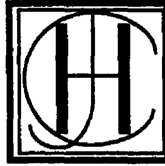
WHEREAS, although some persons in independent living have greater medical needs than those in assisted living, current law does not address this situation; now, therefore, be it

RESOLVED by the House of Delegates, the Senate concurring, That the Joint Commission on Health Care be directed to study whether there are abuses in independent living arrangements for the elderly or disabled and, if so, to recommend ways of addressing and correcting these abuses without curtailing the independence of persons who are fully capable of living without regular medical or ambulatory assistance.

The Department of Social Services and Department of Health and any other agency of the Commonwealth shall assist the Commission in the study, upon request.

The Joint Commission on Health Care shall complete its work in time to submit its findings and recommendations to the Governor and the 1997 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



Joint Commission on Health Care

Summary of Public Comments on Draft Issue Brief I: Potential Abuses in Independent Living Arrangements

Comments regarding the Potential Abuses in Independent Living Arrangements Issue Brief were received from the following 4 interested parties:

Virginia Health Care Association (VHCA)
Virginia Association of Non-Profit Homes for the Aging (VANHA)
Department for the Aging/Department of Social Services
Residents' Council Chambrel-at-Williamsburg

Policy Options Presented in Issue Brief

Three policy options were presented in the Issue Brief for consideration by the Joint Commission on Health Care.

Option I: Maintain the status quo.

Option II: Request the Department for the Aging, the Area Agencies on Aging and the Department of Social Services to Consider the Feasibility of Developing and Publishing Additional Consumer Information on Independent Living Arrangements, and Establishing a Voluntary Counseling Service Similar to the Virginia Insurance Counseling and Advocacy Program

Option III: Introduce a Resolution Encouraging Retirement Communities Offering Independent Living Arrangements to Take All Appropriate Actions to Advise Those Applying for Residence in an Independent Living Unit About the Facility's Policies and Procedures Regarding Frail Elderly in These Accommodations

Summary of Individual Public Comments

Virginia Health Care Association

Mary Lynne Bailey, Vice President of Legal and Government Affairs, commented in support of Option I. She stated that consumers contemplating a move to an independent living arrangement should investigate the appropriate arrangement for themselves and directly satisfy any concerns that they may have.

Virginia Association of Nonprofit Homes for the Aging

Marcia A. Melton, Director of Legislative Services, commented that they supported Options I, II and III. They support Option I because it suggests that no additional legislation or regulation is necessary in independent living arrangements. They believe that consumer empowerment is also key in the long term care industry. They support Option II because it would request various state agencies to examine the development of useful consumer information and felt that this approach would enhance the public's awareness regarding long-term care options in a specific community. VANHA supports Option III because it encourages independent living facilities to provide consumers with an appropriate level of disclosure regarding facility policies as they relate to the frail elderly.

Department for the Aging/Department of Social Services

Thelma E. Bland, Commissioner of the Department for the Aging, coordinated her response with Clarence Carter, Commissioner of the Department of Social Services and commented that they recommended Option III as the most feasible.

Residents' Council, Chambrel-at-Williamsburg

James K. Schmidt, President, commented in support of the recommendation that the facility should have the responsibility for advising applicants on its policy regarding independent living for frail elderly senior citizens rather than doing it by legislation. Further, he commented that the current legislation provided sufficient definition of the terms and stated that any difference in their interpretation in specific cases could be challenged in the courts.

JOINT COMMISSION ON HEALTH CARE

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