

Special Assisted Living Issue

Assisted Living: Federal and State Options for Affordability, Quality of Care, and Consumer Protection

By Sue Seeley

Assisted living is an industry that has shown tremendous growth since its inception in the 1980s. Although largely unregulated and non-subsidized, its performance in the market place has nevertheless established the industry as a significant long-term care option. While assisted living can be a less expensive alternative to nursing home care, it still remains costly and largely privately funded. This precludes many lower- and middle-income older Americans from living in assisted living facilities and forces them, instead, to remain in their homes beyond when they would wish to or to enter a nursing home before they need to.

Exploring affordability options for assisted living is necessary to ensure that older Americans can choose the most appropriate level of long-term care possible. Additionally, as the market for assisted living grows, it becomes even more important to make certain that residents are protected and that facilities are held to a high standard.

Defining “Assisted Living”

The term assisted living covers an extensive range of facilities that provide some form of long-term care to older persons. Broadly defined, an assisted living facility is a residential setting where some level of assistance with daily liv-

ing, sometimes including health care, is provided to persons who can no longer live independently. Assisted living facilities, generally, have certain similar components. Most offer restaurant-style dining,¹ common spaces for socializing, handicapped-accessible facilities in units, and two-way voice communication with staff. Because privacy is a significant issue for residents, the most common unit offered is a one-bedroom apartment or single occupancy living space. Services offered at assisted living facilities range from medication management and personal care to housekeeping, laundry, transportation, and special dietary needs management. They also include health-related and nursing care. The typical assisted living resident is an 83-year-old woman, frail but mobile, who needs help with two or more activities of daily living (“ADLs”), such as bathing or dressing.²

Current estimates of the number of assisted living beds across the country range from 800,000 to 1.5 million.³ Exact numbers are difficult to calculate because of the range of def-

Continued on page 2

Sue Seeley is the Borchard Foundation Center on Law and Aging Legal Intern for the American Bar Association Commission on Legal Problems of the Elderly. She is a third-year law student at the George Washington University Law School in Washington, D.C. Currently, Sue is researching case law, legislation, and policy issues surrounding the U.S. Supreme Court's Olmstead v. L.C. decision and how it addresses the needs of older people.

In This Issue

- 3 **Inside the Commission**
- 5 **Legal Services Delivery: Legal Aid Bureau, Inc.'s Assisted Living Project—Policy Development and Training for Small-Home Providers**
- 17 **Commission Recommends Regulation, Accreditation, and Access in Assisted Living**

Federal and State Options

Continued from page 1

initions of assisted living. In addition, because assisted living in neither defined nor regulated by the federal government, there is no systematic means for counting facilities.

While a number of federal agencies bear some general responsibility for aspects of consumer protection and quality of care,⁴ regulation of assisted living is left primarily to the states' broad discretion. Currently, state approaches to licensure and oversight of assisted living facilities vary widely.⁵ State regulation tends to focus on three areas: requirements for the living unit, admission and retention criteria, and the provision of services.⁶ However, there is wide variation in what states require within these categories, as well as with respect to inspection procedures and frequency, notification requirements, inspector training, and the availability of enforcement mechanisms.⁷

The inconsistency of state regulations poses challenges for residents. First, state regulations regarding the level of care facilities are licensed to provide may conflict with resi-

dents' expectation that they will be able to "age in place," or remain in a single facility for the rest of their lives with services added as their needs increase. Secondly, state regulations may not afford adequate consumer protections for residents. The variety of definitions and regulations of assisted living force residents to rely primarily on information provided by the facility to determine their rights and duties. However, the U.S. General Accounting Office ("GAO") has found that the written materials provided by facilities often lack key information, or that information provided is unclear or inconsistent.⁸ Given the disparity between state regulations, consumers may have to look to other sources—such as the federal and state programs that help them pay for assisted living—to determine their rights and protections.

Making Assisted Living Affordable: Publicly-Funded Affordability Options

Assisted living is, generally, less expensive than nursing home care on a day-by-day cost comparison, but because it is not directly publicly funded it remains out of reach for many low- and moderate-income older persons. Additionally, costs of assisted living facilities vary widely depending on the size and location of the facility, as well as the services they provide.⁹ The private industry has contributed to efforts to create affordable assisted living. The Assisted Living Federation of America ("ALFA"), a provider-based organization, has developed industry initiatives for lowering the cost of assisted living.¹⁰ In addition, some facilities are taking advantage of public programs and private association grants¹¹ to lower the cost of some or all of their assisted living beds.¹² Long-term care insurance is also used by the industry and can help lower costs to residents. While these efforts are commendable, much more needs to be done to increase affordable assisted living industry-wide. It is crucial that advocates, states, and facilities explore and apply any existing publicly-funded affordability options, as well as continue to develop new ones.

The lack of affordable assisted living options often forces low- and moderate-income older persons, who would otherwise require a lower level of care, to enter the institutional setting of a nursing home. Public funds for long-term care, such as Medicaid, cover nursing home care but are not widely accepted at assisted living facilities. In *Olmstead v. L.C.*, 527 U.S. 581 (1999), the Supreme Court held that states are required, under Title II of the Americans with Disabilities Act ("ADA"), to provide community-based services for persons with [disabilities under the Act] under certain circum-

Continued on page 4

BIFOCAL

Bar Associations in Focus on Aging and the Law
Newsletter of the American Bar Association
Commission on Legal Problems of the Elderly

Commissioners

F. Wm. McCalpin, Chair
Hon. J. Joseph Curran Jr.
Pamela M. Dashiell
Nancy N. Dubler
David English
Martha E. Ford
Leslie P. Francis
Roy Hammer
Hon. John H. Kirkendall
Stephen McConnell
Hon. Benjamin Overton
Judith Stein
Joan Teno
Natalie Thomas
Sue Fryer Ward

Special Advisor

Edward Spurgeon

Board Liaison

Victor Futter

Commission Staff

Nancy M. Coleman, Director
Charles P. Sabatino
Erica F. Wood
Stephanie Edelstein
Lori A. Stiegel
Leslie B. Fried
Naomi Karp
Jamie Philpotts
Julie N. Pasatiempo
Melissa Alvarez
Trisha Bullock

Law Intern

Sue Seeley

Editor

Jamie Philpotts

Bifocal, ISSN 0888-1537, is published quarterly (four times a year) by the American Bar Association Commission on Legal Problems of the Elderly, 740 15th St., N.W., Washington, DC 20005. The views or opinions expressed herein do not necessarily represent the policies of the American Bar Association unless specifically adopted as such. Subscription price is \$35 per year. Questions? Contact the commission at (202) 662-8690, or see our Web page at www.abanet.org/elderly. © 2001 American Bar Association.

Inside the Commission

New Appointees Bring Subjectivity, Focus, Experience

The American Bar Association (ABA) Commission on Legal Problems of the Elderly is composed of fifteen members who are appointed on an annual basis by the president of the ABA. As a multi-disciplinary group, the commissioners represent aging experts from a broad spectrum of professions, including law, health care, social work, gerontology, advocacy, and public service. The fundamental diversity of the group ensures a stimulating forum for discussion of the law-related issues facing older Americans. Cooperative efforts between the commissioners and the commission staff have produced numerous publications, as well as research and demonstration projects. To provide our readers with an abbreviated view into the strengths and expertise of our commission, each fall issue of BIFOCAL will feature brief profiles of the most recent appointees.

David M. English is the W. F. Fratcher Missouri Endowed Professor of Law at the University of Missouri-Columbia, where he teaches courses in elder law, federal taxation, estate planning, and property law. Professor English is best known for his work with the National Conference of Commissioners on Uniform State Laws. He was the reporter for the Uniform Health-Care Decisions Act (1993) and Uniform Trust Code (2000), and is currently executive director of the Joint Editorial Board for Uniform Trusts and Estates Acts.



Professor English has long been active in the American Bar Association's Section of Real Property, Probate and Trust Law. He has served as a member of its Supervisory Council since 1997, and was previously chair of its committees on Health Care Decisions, Organ and Tissue Donation, and Long-Term Health Care. He is also a former chair of the Section on Aging and the Law of the Association of American Law Schools. Professor English is a successor co-author of Matthew Bender's *Tax, Estate and Financial Planning for the Elderly* and its companion forms book. Prior to entering law teaching in 1987, he was a partner with the Chicago law firm of D'Ancona & Pflaum. Professor English received his B.A. from Duke University, and his J.D. from Northwestern University.

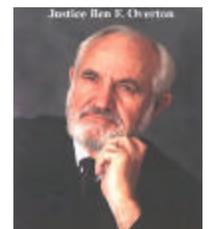
Judith Stein co-founded the Center for Medicare Advocacy, Inc. in 1986, where she is currently the executive director. Ms. Stein has focused on legal representation of the elderly since beginning her legal career in 1975. From 1977 until 1986, Ms. Stein was the co-director of Legal Assistance to Medicare Patients (LAMP) where she managed the first Medicare advocacy program in the country. She has extensive experience in developing and administering



Medicare advocacy projects, representing Medicare beneficiaries, producing educational materials, teaching, and consulting. She has been lead or co-counsel in federal class action and individual cases challenging improper Medicare policies and denials.

Ms. Stein is the editor and co-author of numerous books, articles, and other publications regarding Medicare and related issues, including the *Medicare Handbook* (Aspen Publishers, Inc., 2001). She is the immediate past president and a fellow of the National Academy of Elder Law Attorneys (NAELA), an elected member of the National Academy of Social Insurance (NASI), and a recipient of the HCFA Beneficiary Services Certificate of Merit. Ms. Stein graduated *cum laude* from Williams College in 1972 and received her law degree in 1975 from the Catholic University School of Law.

Hon. Benjamin Overton was the first Florida Supreme Court Justice to be selected under the merit selection process, which was designed to remove politics from the state's judicial system and to improve the quality of the courts. He was appointed by Gov. Reuben Askew on March 27, 1974. He served as Chief Justice from 1976 to 1978, during which time he was a member of the Executive Council of the Conference of Chief Justices and was chair of the conference's special committees on cameras in the courtroom and judicial education. The standards adopted by those two committees have now been implemented in most states.



Justice Overton served 24 years on the Supreme Court and is the named author of over 850 opinions. Before his selection as a justice, he served for nearly ten years as a circuit judge in both the civil and criminal divisions of the Sixth

Continued on page 6

Federal and State Options

Continued from page 2

stances.¹³ The ADA covers any older person with a physical or mental impairment who meets the definition of disabled under the Act, even if their impairment is solely the result of the aging process.¹⁴ The Court held that public entities need to place covered individuals in the “most integrated setting appropriate” when providing community-based services. Unwarranted placement of individuals in an institutional setting constitutes a form of discrimination based on disability prohibited by the ADA.¹⁵

While it is unclear just how *Olmstead* applies to private-sector assisted living facilities,¹⁶ states are directed to provide community-based services under the appropriate circumstances.¹⁷ Assisted living facilities are a good way to provide community-based services, as well as to keep older persons out of institutional settings. Therefore, *Olmstead* creates a “mandate” for establishing affordable assisted living, even in non-covered facilities, such that lower- and moderate-income older persons are not forced inappropriately into nursing homes.

Affordability Options for Services

Affordability options for assisted living can be broken down into two categories: those that cover the services resident may require, and those that will subsidize the cost of housing—room and board—in an assisted living facility. Attempts to lower the costs of assisted living will be most effective if options from both categories are used in concert.

Options to pay for services can be found at the federal and the state level, with most of the options falling under the Medicaid program. They vary in their eligibility requirements, the services they cover, and how they are applied to assisted living facilities. One such option is the Social Security Income Program (“SSI”).¹⁸ Although some states allow SSI to cover more costs than others, SSI alone is unlikely to cover all of the expenses of an assisted living facility. As with other programs, SSI will be most helpful when used in conjunction with additional funding sources.

Most of the options for subsidizing services in assisted living fall under the Medicaid program. Medicaid itself will not pay for assisted living, but there are several waiver options that are currently being used in assisted living facilities to help residents pay for services.

Home and Community-Based Services Waiver

Assisted living is not covered under the regular Medicaid program.¹⁹ However, beginning in 1981 the U.S. Department of Health and Human Services (“HHS”) allowed states to develop community-based service options under the §1915(c) Home and Community-Based Services Waiver (“HCBS waiver”). The waiver allows states the flexibility to develop and implement creative alternatives to institutionalizing Medicaid-eligible individuals. One way states have designed their HCBS waivers is to cover services at assisted living facilities. In order to gain approval for a program proposed under a HCBS waiver, the state must assure the Centers for Medicare and Medicaid Services (“CMS”) (formerly the Health Care Financing Administration (“HCFA”)) that, on average, the cost of providing services under the waiver will not exceed the cost of providing institutional care.²⁰ The state Medicaid agency must also provide other specified assurances, including that there are safeguards to protect the health and welfare of the residents.²¹ Unlike the general Medicaid program, states may explicitly limit participation in the HCBS waiver program to a specific number of people and to a specific geographic area.²² HCBS waiver programs may cover people age 65 and older who (1) would be eligible for Medicaid if they resided in a nursing home, and (2) would otherwise require the level of care furnished in a nursing facility.²³ Requiring that an individual meet state nursing home level of care criteria has the potential to conflict with state licensing and regulation standards.

Recipients under the HCBS waiver must meet financial eligibility requirements just as they would under the standard Medicaid program.²⁴ States have the option of using the same financial eligibility criteria for their waiver programs as they would for Medicaid funded nursing facility services. If an individual is eligible for the HCBS waiver under a special rule²⁵ then states must permit the individual to make deductions from their post-eligibility income (i.e., their income once the individual has become eligible under “the spend down rule” or “the 300 percent rule”) to protect their maintenance needs and remain in the community (or assisted living facility). This is called the Maintenance Needs Allowance (“MNA”).²⁶

All states have some form of a HCBS waiver. They may have more than one waiver, allowing them to tailor each waiver to meet certain services or consumer needs. Most states have three or four waivers.²⁷ Currently 32 states have HCBS waiver programs that cover service costs in assisted living facilities. These waivers provide funds to more than 40,000 assisted living residents.²⁸ One large incentive for the states to develop HCBS waiver programs is that it allows states already paying costs for health care for low- and mod-

Continued on page 8

Legal Services Delivery

Legal Aid Bureau, Inc.'s Assisted Living Project— Policy Development and Training for Small-Home Providers

By Susan Dishler Shubin

Assisted living has emerged on the long-term care spectrum as a rapidly growing and innovative phenomenon. Unlike most senior housing, assisted living residences provide specialized oversight and assistance with daily tasks—bathing, dressing, and personal services—to promote independence. Assisted living can be an important part of a comprehensive long-term care continuum that provides the necessary level of services to a dependent elderly or disabled population in an appropriate environment.

There are currently 14,672 assisted living beds in Maryland trying to meet the needs of the growing number of senior citizens. (*Report of the Task Force on Quality of Care in Nursing Facilities*, December 1999). Low-income seniors make up 13 percent of Maryland's senior population, more than 65,000 people. Resources and housing options must be available for these poor seniors of Maryland. Often the only option for low-income seniors is the small operation run by people with limited means.

Oversight of the assisted living industry occurs at the state level. Many states are currently developing and refining their assisted living rules and guidelines. On January 1, 1999, assisted living regulations took effect in Maryland. Residents, their families, and providers have a tremendous need for education about the services and rights provided in the regulations. Resulting from the collaborative efforts of government, industry, and consumer representatives on the Governor's Assisted Living Task Force, these regulations affect more than 2,000, and possibly as many as 4,000, providers and perhaps as many as 500,000 Maryland seniors.

These new regulations are comprehensive. They address areas such as: food and nutrition; admission agreements (contracts); staff levels; discharge procedures; monitoring of residents and documentation standards; abuse, neglect and exploitation prevention; residents' rights; general physical plant requirements; and fire safety and other emergency precautions. For the first time, providers of assisted living services are being asked to understand and implement intricate

regulatory standards, to help ensure the safety and well being of their residents.

With the passage of the assisted living regulations, Legal Aid Bureau's Assisted Living Project began to get requests from small-home providers for training on how to comply with the new standards. Maryland has many assisted living facilities with 16 or fewer beds (as of March 2001, 1,678 facilities with less than 16 beds have applied for licensure; 487 have been licensed, representing 8,197 beds). Many of the providers run facilities out of their own homes, taking in low-income seniors, and providing care. The providers are often indigent themselves, meeting Legal Aid Bureau's income and asset standards. There is a large segment of untrained, uneducated providers, who, before the passage of the regulations, never wrote policies, procedures, or contracts for their homes. With the onset of the new regulations, they became desperate for information and training.

The Legal Aid Bureau's Assisted Living Project was concerned that if small-home providers did not get the necessary training, they would close their facilities. This would be a disaster for the many poor seniors who do not have other housing options. We quickly realized that by providing the proper training to small-home providers, we would help preserve higher quality housing for Maryland's poor seniors.

A provider in Baltimore was not aware of the regulations governing safe medication management. When the bureau attorney visited the facility, medication was stored in an unlocked closet of a resident's room, easily accessible to any resident, at any time. The attorney educated the facility as to the regulations governing medication storage.

One provider was unclear how to get her staff trained on medication administration and tube feedings. The bureau attorney put her in contact with the Board of Nursing to find out where the staff could receive proper training.

Three new providers in Baltimore say that they do not know how to write policies and procedures and do not understand what types of policies and procedures the state will be

Susan Dishler Shubin is the supervising attorney of the Assisted Living Project of the Legal Aid Bureau, Inc., in Towson, Md.

Continued on page 6

Legal Aid Bureau, Inc.

Continued from page 5

looking for in their investigations. The bureau plans to address this in their training.

One provider called asking for advice on the provisions in the regulations dealing with criminal background checks. The bureau attorney told her what the regulations said and got advice from the attorney general's office on their interpretation of the regulations.

The Legal Aid Bureau was granted \$7,500 from the Partnerships in Law and Aging Program to fund the training. In order to adequately train providers, the first task we needed to complete was to create training material. Because many small-home providers told us that they did not understand how to write policies and procedures, we decided that we should put together a binder with sample policies and procedures that they would need to pass the state survey and that they could use to enhance the care in their facilities. We would help the providers understand the policies and how they could implement the policies in their homes.

Methodology

The Legal Aid Bureau partnered with the Maryland Assisted Living Association (MALA) and Gerontological

Nursing Ventures (GNA), a consulting group that works with assisted living regulations. MALA and GNV assisted Legal Aid in compiling a list of categories for the training. The categories we created included: Managing Your Home, Clinical Resident Care, Emergencies, Physical Plant Requirements, and Food and Menu Requirements. Each category featured a series of policies and procedures. Altogether, the training binder had 54 sample policies and procedures. The Legal Aid Bureau staff wrote the majority of the policies and procedures. GNV wrote the clinical policies and procedures, as their staff had the nursing background necessary for these.

After creating our training binder, the Legal Aid Bureau mailed over 500 letters to small-home providers throughout the state, to the ombudsmen, to group housing coordinators who work with the providers, to adult evaluation review services (social workers and nurses who work out of local health departments and evaluate seniors to help determine the services they need), and to legal service providers. We particularly targeted the group housing coordinators to assist us in setting up training in various counties, to invite providers, and to arrange the training setting.

Training

The Legal Aid Bureau developed a 4-hour training on policies and procedures for small assisted living facilities. The first part consisted of an introduction to the Maryland Assisted Living Regulations. We then spent 45 minutes dis-

New Appointees

Continued from page 3

Judicial Circuit of the state of Florida, and was the chief judge of that circuit for three and one-half years. In 1973, he was chair of the Florida Conference of Circuit Judges.

Justice Overton was an early advocate of the Alternative Dispute Resolution process, and, during his tenure as Chief Justice, 14 Citizen Dispute Settlement Centers were implemented. He is a Certified Civil Mediator in Florida.

In addition to authoring numerous articles, Justice Overton has been involved in a wide range of governmental, legal educational, bar, historical, and professional activities. As a member of the American Bar Association, Justice Overton's participation has included chair of the Task Force on Mental Health Standards for Competency to Stand Trial (standards approved by the House of Delegates in 1985); chair of the Appellate Judges Conference Special Committee on Time Standards for Appellate Courts (standards approved by the House of Delegates in 1987); chair of the Task Force

to Review Criminal Justice Standards on Trial and Discovery (trial standards approved by the House of Delegates in August 1993, and discovery standards approved by the House of Delegates in August 1994); and member of the ABA Joint Committee on Professional Sanctions (developed standards for imposing sanctions in lawyer discipline proceedings, approved by the House of Delegates in 1986).

Justice Overton received his B.A. in Business Administration and his J.D. from the University of Florida, his L.L.M. in Jurisprudence from the University of Virginia, and completed his mediation training at Duke University.

New Liaison

David Powers is the commission's new liaison from the American Psychological Association. He is an assistant professor of psychology in the department of psychology at Baltimore's Loyola College. He is a geropsychologist with expertise in psycholmentric assessment of older adults, caregiving for dementia patients, and death and dying issues.

cussing the policies under the category “managing your home,” including such policies on how residents can file a grievance; the responsibility of staff to report abuse, neglect and exploitation; and residents’ rights, including confidentiality, the right to have visitors, the right to refuse medical treatment, and the right to be treated with dignity and respect.

The next part of the training was on resident care (clinical services). We trained the providers on the necessity of having a compressive service plan for each resident, and how to update the service plan as residents’ needs changed. We discussed the need for incident policies and procedures and the necessity for assisted living staff to understand what constitutes an incident and how to fully investigate it. We discussed the medication management requirements, and the type of nursing oversight needed in assisted living facilities.

The next section of our training focused on emergency preparedness for assisted living homes. We discussed the fire drill requirements, as well as what to do if a resident is missing, what to do if there are weather emergencies, and what to do in the case of a resident’s death.

The final part of the training focused on physical plant requirements, and food and menu requirements. We ended with a closing discussion and time for questions and answers.

Results

Legal Aid Bureau staff trained providers from nine counties and provided training to ombudsmen, social workers, and group housing coordinators who work with small-home providers on a daily basis. We reached all counties but seven. We gave out 250 training binders to managers of assisted living homes and to professionals who assist them. As many as 25 of these professionals have told us that they are reproducing the binders and distributing them to small-home providers, so we have no way of knowing how many of these training binders are actually being used, except that it is far greater than the original 250 we distributed. In addition, the Md. Dept. of Health and Mental Hygiene, Office of Health Care Quality, gives out a packet to all providers who have applied for a license. The sample policies and procedures in the packet, with one exception, are the ones we developed.

One of the things we learned at the trainings, is the diversity in the level of knowledge among providers. A significant number of providers had never read the assisted living regulations, and our training was their first introduction to the regulations. Many providers had basic questions, such as: are fire drills required in assisted living homes? Are windows required in residents’ bedrooms? Can any staff give out medications? These questions are answered in the regulations, and we were able to go through the standards with the

providers, and encourage them to become familiar with the regulations on their own.

Other providers were more sophisticated in their knowledge of the regulations, but had come to the training sessions to get particular questions answered. One of the questions that emerged at every training session was about the role of the RN/Nurse Manager, who needs to supply oversight to certain staff members in assisted living homes. This nurse is called a “delegating nurse,” and she or he must come into the home every 45 days, to review the handing out of medications and review the overall functional status of each resident. There is still a great deal of confusion on the part of the Nursing Board, the Pharmacy Board, and the Office of Health Care Quality as to the role of the delegating nurse, and we were able to discuss with providers the proper standards, to the best of our knowledge.

Another observation we made at the trainings is that certain counties are interpreting standards differently from the state. At various meetings we attended with state officials, we were told that fire drills had to be conducted in each home quarterly, by each shift. During the fire drill, residents have to be removed from the home. However, at two trainings providers told us that in their counties the fire marshalls were not requiring the removal of residents from the home during fire drills. We encouraged these providers to call the state, to determine what they were expected to do.

Another observation we made at the trainings was that providers were experiencing great frustration with the licensing process. Many providers submitted their applications for licensure under the new regulations at the beginning of 1999, and, more than a year later, had not been surveyed by the state. (As of March 2001, 596 facilities have been licensed and 1,224 have applied but are not licensed.) Some had been investigated, but never received their license in the mail. Although the Legal Aid Bureau was unable to help providers receive their license at the trainings, we have subsequently joined committees that are actively trying to address these issues (such as the National Association of Social Workers and the Maryland Chapter Aging Committee).

Feedback from the participants of the trainings was positive. The forms were especially well received, particularly the “Incident Policy and Procedure” form, which helps staff identify what constitutes an incident and to whom the incident should be reported. Also, providers expressed great interest in the “Service Plan” form, which would help them identify when a residents’ needs had changed.

Providers were also grateful for a copy of the “Model Admissions Agreement” (contract form) that we provided. Many providers had never seen one before and had been

Continued on back page

Federal and State Options

Continued from page 4

erate-income older persons to shift those costs to the Medicaid program, where federal matching funds are available.²⁹ The HCBS waiver is the most successful public fund option currently in use for creating affordable assisted living.

Personal Care Services

While the HCBS waiver is the most widely used affordability option, since the 1970s Medicaid has allowed states to offer personal care services (“PCS”) under their state plans. Originally PCS had to be prescribed by a physician, supervised by a registered nurse, delivered in accordance with a care plan, and provided in the individual’s residence. The services were generally tied to assisting individuals with ADLs. However, in 1993, Congress not only formally incorporated PCS into federal Medicaid law, but also gave the states explicit authorization to provide PCS outside the home. In 1994, Congress went even further, allowing states to establish means other than physician prescription of PCS and to use means other than nurse supervision for administering PCS. In 1997, HCFA (now CMS) issued new regulations regarding PCS reflecting these changes. By 2000, 27 states covered PCS under their state plans. Growth in fund outlays has been slow since many states are electing to cover these same services under their HCBS waiver.³⁰ Therefore, while PCS remains a viable option for affordability, it is not used very frequently in assisted living.

There are some key differences between the HCBS waiver and PCS that affect their potential as affordable assisted living options. The HCBS waiver can be limited by the states. States can also set caps on spending under the waiver, limiting the number of people who will receive funds. As a result, some individuals who are eligible for the waiver may not receive funds. The PCS program is an entitlement. Once the state establishes a PCS program it must provide the services, and, therefore, funds, for all beneficiaries who qualify. The HCBS waiver can be limited in its scope to certain geographic areas or groups of individuals. PCS services must be available in the same amount, scope, and duration to all beneficiaries. Recipients under the HCBS waiver must meet the state’s nursing home level of care criteria. PCS beneficiaries must meet state eligibility requirements, usually a less restrictive “medically needy” requirement. Under the HCBS waiver program, states can set special rules for financial eligibility that increase the number of individuals who qualify. Financial eligibility under the PCS program is limited to the SSI income level or a “medically needy” exception.

PCS is a much broader program than HCBS and has the potential to provide assistance to a much larger group of people. However, since its financial eligibility criteria are more stringent, less people may be eligible for PCS than the HCBS waiver.

Private Non-Medical Institutions

Three states—Maine, Vermont, and Florida—have chosen to use private non-medical institutions (“PNMI’s”) as a way to care for older persons in a residential setting. A PNMI is defined as:

an institution that is not, as a matter of regular business, a health insuring organization or a community health center; [which] provides medical care to its residents through contracts or other arrangements with medical providers, and receives capitation payments from the Medicaid agency under a non-risk contract, for its residents who are eligible for Medicaid.³¹

CMS has approved licensing rules for PNMI’s that provide a range of services that include: case management; assistance with performance of ADLs; medication assistance, monitoring, and administration; 24-hour on-site assistive therapy; restorative nursing; health monitoring; and routine nursing tasks.³²

PNMI’s are listed as providers under state plans and are used in a variety of settings: to administer substance abuse treatment, as community residences for those with mental illness, and to provide general services for the elderly. In Maine, PNMI’s are licensed under assisted living facility regulations. Vermont decided to use PNMI’s because their HCBS waiver did not cover as many people as they wanted and it would have been too costly to develop a PCS plan.³³ Since CMS has approved licensing rules for facilities that provide services similar to those received in an assisted living facility, this may be a viable option for certain types of assisted living facilities looking for funding.

Affordability Options for Housing

The HCBS, PCS, and PNMI programs can usually only cover services provided, since Medicaid cannot pay for housing—room and board—outside an institution, except under limited circumstances.³⁴ Residents remain responsible for the portion of the monthly fee attributable to housing costs. This is a potential disincentive for facilities considering applying for an HCBS waiver program. It is low- and moderate-income older people who will qualify for the waiver, and to do so they must have limited income and assets,

except under certain exceptions. Their very eligibility for the waiver (and other options) presumes a limited income and a potential difficulty paying a market rate for room and board. Medicaid typically limits how much a nursing home may charge for room and board, but since Medicaid waivers cover only services with regard to assisted living, there is little need for states to address assisted living housing costs.³⁵ Certain federal options, often implemented on a state or local level, can help lower these costs. Like those covering services, these programs vary widely in their eligibility requirements, scope of coverage, and application to assisted living facilities.

HUD §8 Vouchers

Section 8 is a federal housing assistance program administered through the U.S. Department of Housing and Urban Development (“HUD”) and Public Housing Agencies (“PHAs”), designed to assist low-income families, older persons, and persons with disabilities to pay for decent and safe housing. The voucher provides a “subsidy” for use in the private housing market based on household income and the cost of housing in the area. Residents must pay at least 30 percent, but not more than 40 percent, of their income towards housing costs.³⁶ In order to be eligible for a §8 voucher, a resident’s income must be below 50 percent of the median income of the county or metropolitan area in which the resident chooses to live. A PHA must provide 75 percent of its vouchers to residents with income below 30 percent of area median income.³⁷

Under the standard §8 voucher program, if residents choose to move from one participating unit to another the voucher moves with them. However, in one new §8 program, Project-Based Rental Assistance, the voucher attaches to the facility rather than to the resident. Participants in this program use the subsidy while residing in the unit. While §8 vouchers can be an excellent source of funding to cover housing costs, obtaining a voucher is not that easy. There are often long waiting lists to receive a voucher, and, even then, finding housing that meets the requirements of the program and that accepts the voucher can be difficult. This may make the project-based subsidy more appealing for reducing housing costs, since once a facility obtains the voucher it remains with the facility rather than moving with the resident.³⁸

On September 1, 2000, HUD released a Public and Indian Housing (“PIH”) notice to inform PHAs that §8 vouchers could be used at assisted living facilities. However, the voucher can only be used to cover the housing costs associated with the monthly assisted living fee. The notice specifies that residents in the assisted living facility using the voucher must not require continual medical or nursing care. Additionally, the notice encourages the use of the §8 vouch-

er in conjunction with the HCBS waiver in assisted living facilities.³⁹

Section 8 vouchers clearly have potential to create affordable assisted living. When used in conjunction with an option that covers the services portion of an assisted living monthly fee, such as the HCBS waiver, §8 vouchers can significantly lower the costs to a resident. Section 8 project-based vouchers provide an added benefit. While a normal §8 voucher will lower the cost of assisted living for a particular resident, a voucher that is tied to the assisted living facility unit itself will not only ensure long-term affordability of that unit, but, if the facility has several such units, it may also lower the overall cost to the facility, encouraging the owner to lower fees for all residents.

HUD §202 Conversion Funds

The §202 Program of Supportive Housing for the Elderly provides federal capital advances and contracts for rental assistance, under the Housing Act of 1959,⁴⁰ for housing projects serving older and disabled persons.⁴¹ While §202 funds originally were only used for residents capable of living independently, HUD has gradually recognized that this was unrealistic and, under pressure from Congress, allows the use of HUD-subsidized housing for the provision of assisted living services.⁴² Section 202 funds may now be used for converting housing or other real estate into assisted living facilities for low or very low-income residents.⁴³ As with the §8 voucher, residents in a §202 converted wing must have an income below 50 percent of the area median income, and pay 30 percent of their income towards housing costs.

Unlike §8 vouchers, which provide funds to the resident, §202 funds are obtained and used by the facility. As an affordability option they do not provide direct assistance to the resident, but a facility that uses §202 funds could reduce its overall housing costs and pass this benefit on to residents in lower monthly fees.

HUD §232 Mortgage Insurance

The Housing Act of 1959 established §232 of the National Housing Act,⁴⁴ authorizing a program of mortgage insurance for the construction and rehabilitation of nursing homes. In 1969, intermediate care facilities were added to the program, and, in 1983, board and care facilities became eligible as well. Under §232, any public, proprietary, or private non-profit facility licensed or regulated by the state or municipality that provides accommodation to persons who are not acutely ill or in need of hospital care, but who require skilled nursing care, is eligible to apply for funds. The services must

Continued on page 10

Federal and State Options

Continued from page 9

be provided by licensed professionals, and, while continuous care may be provided, continuous medical or nursing services may not be provided. Facilities must provide room and board, and “continuous protective oversight,” which ranges from simple resident monitoring to assistance with multiple ADLs. Eligible facilities must house 20 or more residents who need continuous care.⁴⁵ It is important to note that unlike §202 funds, §232 does not restrict the benefit to any one particular group, such as older or disabled persons.

Like §202, §232 does not provide a direct benefit to the resident, but as with conversion funds, mortgage insurance can help ensure that facilities that are committed to providing affordable assisted living have multiple sources for subsidizing costs.

Low-Income Housing Tax Credit

The Low-Income Housing Tax Credit (“LIHTC”) program was created by the Tax Reform Act of 1986, and is intended to increase and preserve affordable rental housing by replacing previous tax incentives with a credit directly applicable to taxable income.⁴⁶ LIHTCs are given to owners of qualified low-income buildings over a ten-year period. Only residential buildings are eligible. Eligible facilities for older persons include assisted living, independent living, congregate care, and properties with §8 assistance. Qualified buildings must meet several criteria. Low-income residents must occupy a specified portion of units. These units must have restricted rents and must be rented on a non-discriminatory basis. The units must meet local building, health, and safety codes. The initial lease term must be for at least six months, however, after this time period the lease may go month-to-month.⁴⁷ States have a total amount of credit equal to \$1.25 per state resident, and they evaluate the applicants for the credits based on their service to low-income individuals. States must give priority to plans that serve the lowest income residents for the longest time. While projects can be developed by for-profit and non-profit entities, states must set aside ten percent of their credits for non-profit organizations.⁴⁸

Whereas LIHTCs can be applied to assisted living facilities, and used successfully to lower the facilities’ costs, there are some barriers to using these credits in assisted living. Applicants for LIHTC are evaluated on a per unit cost basis. Assisted living facilities often have higher per unit costs, in part because the costs of common spaces are included in the calculations. Additionally, LIHTC is a program for independent living. Given the range of services an assisted living

facility may provide, they may not be providing services that are limited enough to be considered “supportive services” under the program. If residents receive continual care then the facility is not eligible for the credit. The IRS has outlined a list of services that a facility can provide and still remain eligible. These include meal and laundry service, assistance with medications, and assistance with ADLs. Also, although under the LIHTC rent is limited, calculations of rent must include service and housing costs. This may drive up the “rent” of an assisted living facility past acceptable rates. A final problem is the variations in cost that are found from facility to facility, making it difficult to determine, without specific calculations, if an assisted living facility can benefit from a LIHTC.⁴⁹

The use of LIHTCs has grown, but there has been no corresponding increase in the amount of state funds.⁵⁰ This means that more facilities are competing for the same amount of credits, decreasing the amount of help each facility may receive. This may make the LIHTC a limited success in helping to lower assisted living costs. The LIHTC probably works best for the consumer when coupled with other subsidies for the facility.

Rural Housing Service Funds

The U.S. Department of Agriculture’s (“USDA”) Rural Housing Service (“RHS”) has several low-income housing options that may help lower assisted living costs. First, the RHS provides §515 Rural Rental Housing Loans to covered entities with very low-, low- and moderate-income families. The loans are direct competitive mortgage loans made to provide affordable multifamily housing to very low-, low-, and moderate-income families; older persons; and persons with disabilities. The program is primarily for direct mortgages, but may also be used for land purchase or improvement, or to provide necessary facilities such as water or waste disposal systems. In new §515 projects, 95 percent of the residents must have very low incomes,⁵¹ and in existing projects 75 percent of new residents must have very low incomes.⁵²

A second option offered under the RHS guarantees loans for development of multi-family housing in rural areas of the country.⁵³ Loans are provided for purchase, construction, or rehabilitation of covered facilities. Applicants can include non-profit groups, local governments, or community development groups. Occupants of these facilities must be very low-, low-, or moderate-income families, or older or disabled persons with incomes not in excess of 115 percent of the area median income (“AMI”).⁵⁴

A third option is RHS’s Rental Assistance Program, which may be used in existing and newly constructed §515 RHS Rural Rental Housing. Occupants must be very low- or low-income persons, older persons, or persons with disabili-

ties, as long as they are unable to pay the basic monthly rent within 30 percent of their adjusted monthly income. The RHS and the owner execute a five-year contract in which RHS commits payments on behalf of residents in a designated number of units. If very low-income persons can not cover RHS subsidized rents, then RHS will pay the resident the difference between their 30 percent contribution and the monthly rental rate.⁵⁵ This is very similar to the subsidy calculation under HUD's §8 voucher program.⁵⁶

The RHS programs will probably only prove useful as affordability options for assisted living in a limited number of situations. These programs are restricted to application only in rural areas. Additionally, under the programs there are very strict income requirements that may limit the ability of assisted living facilities to apply for these funds. However, where they are applicable they can provide a benefit to the facility which, if significant enough, can be passed on to the residents through lower monthly fees. As with the other options that aid facilities, these options work best in conjunction with additional options for services.

Quality of Care Standards

While creating affordable assisted living is extremely important, ensuring that residents are protected once they enter a facility is also of paramount concern. Currently, there are no federal regulations regarding the quality of care in assisted living facilities—all regulation has been left to the states.

Testimony at a hearing of the Senate Special Committee on Aging regarding quality of care issues in assisted living indicated that common problems are inadequate care (such as insufficient access to a physician or other medical treatment), insufficient and untrained staff, and problems surrounding medications (such as patients not receiving medications, receiving the wrong medications, or medications being improperly stored).⁵⁷ While this is not an exhaustive list of quality of care issues, it does provide an example of the major areas in which problems arise.

The best way to protect consumers is for the states to develop regulations of assisted living facilities setting explicit standards and requiring resident rights and protections. While state departments of health currently require periodic inspections of assisted living facilities, these inspections vary in their frequency, content, and effectiveness. Enforcement measures for violations also differ greatly. State licensing agencies and adult protective services can investigate complaints, but they may have little authority to resolve them. The Long-Term Care Ombudsman Program,⁵⁸ authorized by the Older American's Act,⁵⁹ is required to investigate and resolve complaints involving residents of assisted living.

However, ombudsman programs, while an excellent source of protection for older persons, are often under-staffed, poorly funded, and may not have the resources to address the myriad concerns raised in assisted living.

Consumer Protection Issues

Consumer protection issues are also a large concern for consumers and advocates. Assisted living remains a privately run industry, and states have little ability, short of licensure and regulation, to force facilities to provide residents with certain protections. As a result, residents are forced to rely almost exclusively on their contract with the facility to determine, protect, and enforce their rights. The GAO has found that, unfortunately, contracts are often lacking in information as to resident rights. Additionally, prospective residents often have a hard time determining what rights and protections each facility offers, since many facilities are reluctant to supply them with a contract or other written materials.⁶⁰

Some of the larger issues that need to be addressed include protections and standards surrounding resident admission and retention, discharge and appeal procedures, services included in the basic fee, and a process for assessing additional charges as services needed increase. Many of the specific concerns that arise out of these broad issues can be addressed through regulation, but this may raise other problems for consumers, facilities, and states. Admission and retention criteria can be imposed by the state through licensing and regulation, but this may inhibit the ability of facilities to accept some affordability options.⁶¹ Moreover, if affordability options carrying added protections for the consumer result in increased operating costs, facilities may be reluctant to participate in these programs.

Costs raise other consumer protection concerns. The GAO has found that facilities offer little protection from eviction if residents can no longer pay their bills. Most assisted living facilities can summarily evict residents if they decide they can no longer afford to care for them. Unfortunately, some assisted living residents may find that they have spent all their money on assisted living and, although they are now eligible for Medicaid, may have difficulty finding an appropriate nursing home to care for them.⁶² This problem demonstrates why it is crucial to provide affordable assisted living options, with attached resident rights and protections, that avoid depleting the resources of older persons.

Certain affordability options may create a starting place for requiring protections. Even if these options are limited in

Continued on page 12

Federal and State Options

Continued from page 11

their ability to impose specific protections, they can serve as a strong point for advocacy.

Affordability Options with Attached Protections

While it is important that states address quality of care and consumer protection issues directly, they face significant challenges in doing so. Certain affordability options, however, carry with them a limited set of rights and protections that states could possibly apply to assisted living facilities accepting federal funds. Even if states are unable to explicitly apply these protections, they may serve as an example for encouraging states to develop, and facilities to accept, regulation. Finally, some options lack explicit attached rights and protections but may provide analogies to similar services offered under similar programs that could prove useful for advocates.

Supplemental Security Income—Keys Amendment

The Supplemental Security Income (SSI) Program carries with it the Keys Amendment, which requires states to regulate residential facilities housing a certain number of SSI recipients.⁶³ Each state must report annually to the Social Security Administration (“SSA”) that it is in compliance with the Amendment. The enforcement measure of the Keys Amendment is a reduction in resident SSI payments to residential facilities that do not meet the standards a state sets pursuant to the Amendment.⁶⁴ This enforcement provision has resulted in the Keys Amendment being largely considered a “meaningless failure.” States are unlikely to report non-compliant facilities since the only penalty is a removal of funds for the resident with no direct penalty to the facility.⁶⁵ However, the Keys Amendment could serve as a precedent for establishing a federal requirement that assisted living facilities meet state (and possibly federal) regulations and standards.

Home and Community-Based Services Waiver

CMS requires states seeking the HCBS waiver to ensure that “necessary safeguards . . . have been taken to protect the health and welfare of individuals provided services under the waiver.”⁶⁶ The corresponding regulations list three required protections. First, adequate safeguards must be established for providers. This could be an incentive for facilities to participate in an HCBS waiver program, as it would assure them

certain rights. Second, assurance must be given to CMS that providers will satisfy all applicable state licensure and certification requirements.⁶⁷ This requires all facilities that participate in the waiver program to be licensed and regulated by the state. While this may be a disincentive to providers who prefer not to be licensed, it could afford needed protections for residents. State licensure and regulation is more likely to afford residents quality of care standards, in terms of the level and quality of services provided, and consumer protections against discharge or breach of contract, than the providers will if left alone.

Lastly, CMS must be assured that assisted living facilities will comply with the state regulations that satisfy the Keys Amendment. While the Keys Amendment has proven to be somewhat of a failure as an enforcement mechanism, it can still act as precedent for developing a federal requirement for federal or state regulation in the areas of quality of care and consumer protection in assisted living facilities. Unfortunately, “[t]here is no indication that [CMS] has taken an active role in advocating for an improved quality of care in residential facilities [operating under the HCBS waiver program].”⁶⁸

Personal Care Services

The PCS program will not provide added protections for the consumer. CMS has declined to establish federal standards for PCS beyond requiring providers to be “qualified.” CMS has stated: “We are not establishing provider qualifications for personal care services. Rather, in the interest of maintaining a high level of flexibility in providing personal care services, we suggest that states develop their own provider qualifications and establish mechanisms for quality assurance.”⁶⁹

Medicaid, Generally

The Medicaid program itself provides certain protections to its participants. Among these are a list of services a state plan must provide to eligible individuals;⁷⁰ regulations concerning the amount, duration, and scope of these services;⁷¹ a general statement of right to a fair hearing for discharge;⁷² and a private right of action to enforce the statute.⁷³ While these rights are not explicitly applied to the Medicaid options for affordability, they do provide a framework for developing future federal and state rights of a comparable nature. The HCBS waiver is a voluntary plan that the states elect to design and implement. It allows the states freedom to allocate certain Medicaid moneys to programs they develop. However, the state is still receiving Medicaid funds to provide health care to eligible individuals. Since they are receiving waiver funds in lieu of nursing home Medicaid funds, which carry with them the above rights, the states should cre-

ate similar protections for the waiver recipients. The point of the HCBS waiver is to allow the state to serve its Medicaid eligible population in a community-based, rather than institutional, setting. Whichever program is used, the individual deserves the same protections they are entitled to under the Medicaid nursing home program.

This is a more difficult case to make with respect to state PCS plans. Although PCS plans were formally incorporated into federal Medicaid law in 1993, they still remain a part of the state Medicaid plan.⁷⁴ This formal incorporation does provide some basis for arguing that states using PCS plans should afford recipients the same rights and protections they would receive under the federal Medicaid plan.

Nursing Home Reform Act

There are also certain protections afforded individuals under the 1987 Nursing Home Reform Act. These rights include the right to be fully informed; the right to participate in one's own care; the right to make independent choices; the right to privacy and confidentiality; the right to dignity, respect, and freedom; the right to security of possessions; the right to remain in the facility; and the right to raise concerns or complaints.⁷⁵ The right to remain in the facility and the right to raise complaints are of particular importance for assisted living consumer protections. As with the rights provided under the general Medicaid program, these rights and protections do not apply directly to assisted living residents. However, the HCBS waiver does require that eligible individuals be eligible for nursing home level of care.⁷⁶ Since many waiver programs have the same financial eligibility requirements as Medicaid does generally,⁷⁷ many residents of assisted living facilities receiving HCBS waiver funds are eligible for nursing home care. This can serve as a strong basis for a policy argument creating an analogy between residents in assisted living and Medicaid recipients in nursing homes. Consumer advocates can point out that it seems somewhat incongruous to provide protections to nursing home residents that are not afforded assisted living residents, when both require similar care.

HUD §8 Voucher Program

Section 8 housing must meet several criteria: it must meet HUD's Housing Quality Standards ('HQSs'), it must have rent that is reasonable in comparison to comparable housing units, PHAs must allow residents with vouchers 60 days to find housing after being awarded the voucher, and owners and managers of the unit the resident wishes to obtain must be willing to participate in the program.⁷⁸ While this makes §8 a voluntary program, once a facility accepts the voucher they are bound by the program's regulations. At least once per year, a PHA must re-inspect the housing unit to

ensure it passes HUD's HQS, reevaluate the resident, and adjust the subsidy as necessary. The §8 program may require housing providers to give additional notice of an intention to evict residents, and provide for certain appeals. Currently these protections are likely to exceed those provided by state regulations and facilities. Additionally, federal financial assistance may carry the requirement that PHAs cover the costs of "reasonable accommodations" in their policies and programs to ensure participation by persons with disabilities, including frail older persons.

Other Housing Options

The remainder of the housing options do not carry any specific rights regarding quality of care or consumer protections, beyond those imposed by the states. The rights and protections available to residents under these programs are the same rights they have, generally, as tenants, most of which exist through the lease contract with the landlord. However, since these are federal programs, residents may have the added protections afforded to tenants under federal law, such as §504 provisions and an increased requirement for notification of eviction.

Conclusion

Recently, the U.S. Senate Special Committee on Aging has begun a series of hearings on increasing access to affordable long-term care options for older persons. At a June 28, 2001, hearing, members of the committee made very strong statements in support of shifting the emphasis from institutional care to community-based care. Additionally, HHS Secretary Thompson argued for a restructure of the Medicaid waivers. NCB Development Corporation commented:

These two areas of emphasis at the hearing indicate a strong and growing commitment at the federal level to increase Medicaid funding and flexibility to provide home and community-based care options. This movement will greatly benefit efforts to increase the quality and availability of [affordable assisted living].⁷⁹

In addition, the GAO has noted:

[A]s the states increase the use of Medicaid to help pay for assisted living, the contribution of federal financing will grow as well. These trends will likely

Continued on page 14

Federal and State Options

Continued from page 13

focus more attention from consumers, providers, and the public sector to where assisted living fits on the continuum of long-term care, on the standards the states use to ensure quality of care and protect consumers, and on the approaches states use to ensure compliance with these standards.⁸⁰

States face a daunting task in implementing the various affordability options in their efforts to make assisted living a viable long-term care choice for more older persons. States could regulate the initial rates of assisted living facilities, either by requiring them to be lowered or setting caps on rates for licensed facilities. States could also lower assisted living costs by promoting affordability options, either by creating options for residents to meet the rates set by assisted living facilities or by utilizing affordability options to control costs as residents “age in place.” Existing affordability options are much more likely to be successful if states take this second approach to regulating assisted living. It is important that states bear in mind the effects of regulating costs of assisted living. Residents will have varying needs in terms of affordability alone, and states should endeavor to create a regulatory system that addresses as many of these needs as possible. The more options a state extends to residents and facilities, the better able they will be to create affordable assisted living for as many older persons as possible.

Once a state determines which options will best meet consumer needs, they still face a challenge in getting private-sector assisted living facilities to accept these sources of income.⁸¹ While there may be certain incentives both to states (using federal funds rather than state funds) and facilities (solving their problem of empty beds) to accept federal funds in assisted living facilities, there is little incentive to push these affordability options further to protect consumers. If a facility faced a reduction in profit by becoming licensed, many facilities might choose to remain unlicensed, thereby affecting the states ability to apply quality of care standards or consumer protections. In addition, assisted living facilities may be reluctant to participate in programs that require more rules, procedures, and resident protections.

Assisted living has emerged as an important component on the continuum of long-term care for a growing population of older Americans. It can provide older persons with a non-institutional environment where they can receive needed assistance, while maintaining their independence for as long as possible. By pursuing affordability options and investigating their attached rights and protections, con-

sumers, advocates, and states can assure assisted living a strong future.

Notes

1. A la carte services are often offered for residents who wish to eat in their rooms, although this may be an additional cost.
2. See BARBARA ENGLISH, CONGRESSIONAL RESEARCH SERVICE REPORT FOR CONGRESS, ASSISTED LIVING: BACKGROUND AND ISSUES 2 (April 6, 2001) [hereinafter CRS REPORT].
3. See U.S. GEN. ACCT. OFFICE, ASSISTED LIVING: QUALITY-OF-CARE AND CONSUMER PROTECTION ISSUES IN FOUR STATES 1, n.1 (1999) [hereinafter GAO, ASSISTED LIVING].
4. See U.S. GEN. ACCT. OFFICE, LONG-TERM CARE: CONSUMER PROTECTION AND QUALITY-OF-CARE ISSUES IN ASSISTED LIVING 4 (1997) [hereinafter GAO, LONG-TERM CARE].
5. See STEPHANIE EDELSTEIN, AMERICAN BAR ASSOCIATION COMMISSION ON LEGAL PROBLEMS OF THE ELDERLY, ASSISTED LIVING: STATE CRITERIA FOR ADMISSION AND DISCHARGE 2-3. See GAO, LONG-TERM CARE, *supra* note 4, at 4-5.
6. See *Id.* at 5.
7. See GAO, ASSISTED LIVING, *supra* note 3, at 13.
8. See CRS REPORT, *supra* note 2, at 3. Rates can range from \$1,000 to more than \$4,000 per month. There are certain basic services that are included by most assisted living facilities in their monthly fee, but the number and frequency of these services vary by facility. Examples of these basic services include meals (although the number of meals served per day and the location of service varies), bathing, and medical reminders. Services such as a la carte meals and medication dispensing are often extra costs. Assisted living facilities may increase their fees if an individual's condition worsens or they require additional services or staff time.
9. See *www.alfa.org*.
10. The Robert Wood Johnson Foundation and the NCB Development Corporation have a “Coming Home Program” that provides risk capital and technical assistance to providers for developing affordable assisted living. See *www.ncbdc.org*.
11. See DAVID TILSON, ASSISTED LIVING FOR VERY LOW-INCOME ELDERLY: NEW PUBLIC POLICY?, BIFOCAL, Volume 21, Number 2, 3-4 (ABA Comm. on Legal Problems of the Elderly Spring/Summer 2000) (describing the success of one assisted living facility in Northern Virginia in using public and private funds to create a wing of affordable assisted living beds). See *infra* p. 14 note 43.
12. See *Olmstead v. L.C.*, 527 U.S. 581, 587 (1999). The state is required to provide community-based services when “the state’s treatment professionals have determined that community placement is appropriate, to transfer from institutional care to a less restrictive setting is not opposed by the affected individual, and the placement can be reasonably accommodated, taking into account the resources available to the state and the needs of other [individuals with a covered disability].” *Id.*
13. The ADA defines “disabled,” with respect to an individual as, “(A) a physical or mental impairment that substantially limits one of more of the major life activities of such individual.” 42 U.S.C. §12102(2) (1994). The Act also states that “(B) a record of such impairment; or (C) being regarded as having such an impairment” on the part of an individual would make them “disabled” within the Act. *Id.*
14. See *Olmstead*, 527 U.S. at 601.
15. An assisted living facility would need to be an entity covered by the ADA in order for the Act, and, therefore, *Olmstead*, to apply.
16. There are questions as to whether *Olmstead* can be applied to assisted living facilities, since it is yet to be determined whether assisted living constitutes institutional or community-based care.

18. See ERIC M. CARLSON, LONG-TERM CARE ADVOCACY 5-21 (Matthew Bender 1999).
19. Under Medicaid, states are required to cover nursing home care for “categorically eligible” persons age 21 and older. This mandate entitles these persons to nursing home care. States have the option to cover nursing home care for other Medicaid beneficiaries as well, including those under age 21 and the “medically needy.” See DEPARTMENT OF HEALTH AND HUMAN SERVICES, UNDERSTANDING MEDICAID HOME AND COMMUNITY SERVICES: A PRIMER www.hhs.gov [hereinafter HCBS PRIMER]. “Medically needy” would cover those persons under 65, and therefore not categorically eligible, but who otherwise need nursing home level-of-care. However, being entitled to nursing home care is not sufficient to receive it. An individual must also meet eligibility requirements for nursing home care. Individuals must fall within one of Medicaid’s designated categories, one of which is the “elderly,” defined by Medicaid as “people age 65 and older.” See ENID KASSNER & LEE SHIRLEY, MEDICAID FINANCIAL ELIGIBILITY FOR OLDER PEOPLE: STATE VARIATIONS IN ACCESS TO HOME AND COMMUNITY-BASED WAIVER AND NURSING HOME SERVICES 3 (AARP 2000).
20. See ROBERT MOLLICA, STATE ASSISTED LIVING POLICY: 2000, www.nashp.org/salp2000 (NASHP 2000). In 1998, the average cost per person under the HCBS waiver was \$14,950. However, there were large differences in cost among different populations receiving services under the waiver. HCBS waiver programs that served seniors had an average cost of \$5,362 per participant. Some of the factors that can affect cost include: the difference in intensity of services required and the extent to which other state plan services can meet these needs. See HCBS Primer, *supra* note 19.
21. See MOLLICA, *supra* note 20.
22. See JOSHUA M. WIENER, THE URBAN INSTITUTE, NEW FEDERALISM—ISSUES AND OPTIONS FOR STATES: YOUNGER PEOPLE WITH DISABILITIES AND STATE HEALTH POLICY, Series A, No. A-9, 5 (May 1997). In order to allow the states to set caps, CMS waives the requirements of comparability (that services be provided to all groups equally) and statewideness (that all benefits be covered in all parts of the state). See *id.* This allows states to isolate application of the HCBS waiver to a certain population, in a certain geographic location.
23. See MOLLICA, *supra* note 20. If a state licenses a facility only for certain care needs, a specified number of ADLs, that does not rise to their definition of nursing home level of care, then the facility will be unable to accept residents eligible for Medicaid HCBS waiver funds without violating the state licensure requirements. Additionally, if a state requires a facility to discharge a patient when they reach a nursing home level of care, the facility will again be blocked from accepting HCBS waiver-eligible residents. Therefore, since the use of HCBS waiver funds is an excellent way to create affordable options, the decisions a state makes in designing its HCBS waiver can greatly affect how successful the waiver will be in creating affordable assisted living.
24. Older persons are categorically eligible for Medicaid, but they must also meet financial eligibility before they will receive funds for nursing home care. Financial eligibility is comprised of both income and assets. Income eligibility “includes both the income standard that an individual must meet and the methodology that each state uses to determine whether an individual meets the standard.” In order to be income eligible an individual’s income must (a) meet the SSI limit, (b) equal 100 percent of the poverty level, (c) meet a special rule. KASSNER & SHIRLEY, *supra* note 19, at 4.
25. There are three types of special rules. The spend down method allows an individual to deduct medical expenses from their gross income. The individual pays the balance of the medical expenses with Medicaid paying the rest until the individual meets the income eligibility level. A problem with the spend down method is that it requires an individual to deplete their resources in order to be eligible, resources that could help cover long-term costs. The 300 percent rule allows states to set an income standard of 300 percent of SSI to allow more people to be eligible. The special rules increase the potential for an individual to be eligible for Medicaid. While the 300 percent rule will make more people eligible, a combination of the spend down rule and the 300 percent rule will maximize eligibility. Individuals can spend down to a higher level to become eligible, therefore depleting less of their income or wealth. Finally, there are “medically needy” provisions that allow otherwise financially ineligible individuals to become eligible. If an individual is income eligible under a special rule they must also satisfy asset eligibility requirements. As with income eligibility this has two components: the state’s standard and the methodology the state uses to determine whether their standard is met. States will set a certain limit on the assets an eligible individual may retain. This varies widely from state to state. See KASSNER & SHIRLEY, *supra* note 19, at 4 – 5.
26. See KASSNER & SHIRLEY, *supra* note 19, at 5 – 6, 8, 10. The state determination of the MNA, which can be used for rent or food or other expenses, can have a crucial effect on whether an individual can remain in the community or facility. However, if a waiver participant is eligible under a state’s special rule of “medically needy,” then the state must establish a Medically Needy Income Level (“MNIL”). The MNIL is a level of income that can not be exceeded after allowable deductions from gross income for the individual to remain eligible. In certain cases the MNIL may remove any additional cushion the MNA established.
27. See HCBS PRIMER, *supra* note 19.
28. TILSON, *supra* note 12, at 7.
29. See WIENER, *supra* note 22, at 5.
30. See HCBS PRIMER, *supra* note 19.
31. See MOLLICA, *supra* note 20.
32. See *id.*
33. See *id.*
34. Medicaid may cover housing costs under certain limited circumstances. If residents are eligible for Medicaid funds under a special rule, such as the 300 percent rule, the states are required to establish an MNA. The MNA allows residents to retain enough money to remain in the community, and, thus, could be used to cover room and board expenses in an assisted living facility. See MOLLICA, *supra* note 20. See also *infra* p. 5, p. 13 n.25. The level at which the state sets the MNA will affect a resident’s ability to cover assisted living expenses. *Id.* States need to set the MNA high enough to allow individuals to pay these expenses. “Inadequate MNAs may be a crucial factor leading to an institutional bias in the Medicaid program.” KASSNER & SHIRLEY, *supra* note 19, at 10. Under §1915(c) post-eligibility treatment of income rules, states are allowed to use reasonable standards in establishing the MNA. Additionally, the state is allowed to vary the MNA based on the individual’s circumstances. See MOLLICA, *supra* note 20. This flexibility allows states to set different MNAs for assisted living residents versus those living in private homes, allowing the former to cover their housing expense and the latter their rent or mortgage payment. The state could also vary the MNA based on the type of assisted living facility an individual is entering.
35. See MOLLICA, *supra* note 20.
36. See ANN O’HARA, USING THE SECTION 8 VOUCHER PROGRAM FOR RENTAL HOUSING (U.S. Dept. of Health and Human Services, Office of Civil Rights 2001). The subsidy is calculated in a series of steps. First HUD publishes a list of fair market rents for “modest” rental housing by locality. Then each local PHA establishes a payment standard that is between 90 percent and 110 percent of the HUD determined fair market rent. The monthly subsidy given to the resident is the difference between the 30 percent of the resident’s monthly adjusted income that they must pay towards rent, and the PHA determined payment standard. See *id.*
37. HUD’s HOUSING CHOICE VOUCHER PROGRAM FACT SHEET, www.hud.gov/section8.

Continued on page 16

Federal and State Options

Continued from page 15

38. See O'HARA, *supra* note 36. See also Jane Adler, *Tough Search: Section 8 Apartments are Affordable but Difficult to Obtain*, CHI. TRIB., May 16, 1999.
39. Despite this encouragement, as of July 2001 HUD was aware of only one program that has combined the §8 voucher and the HCBS waiver, administered by the Michigan State Housing Development Authority ("MSHDA"). According to Mr. Larry Valencic at MSHDA, they worked in conjunction with the local Area Agency on Aging to identify the population who were eligible for §8 vouchers, among those already in a HCBS waiver program. MSHDA currently has 17,000 vouchers, and they have set aside 50 of these for use with a HCBS waiver. Of the 50 vouchers they set aside, 13 participants are living in assisted living facilities. The remaining participants are in private housing receiving community-based care there.
40. See 42 U.S.C. 1701q §202.
41. See 24 C.F.R. §891.100.
42. See TILSON, *supra* note 12, at 7.
43. See www.hud.gov. One very successful example of the use of §202 funds is the Culpepper Garden facility in Arlington, Virginia. Culpepper Garden was the pioneer in using §202 funds to build assisted living. The grant made to Culpepper Garden was the first made with the explicit understanding that the facility would be licensed and used for construction of an assisted living wing for low-income older persons. In 2000, Culpepper Garden opened their new wing with 73 units for assisted living for residents with a median income of \$1,000 per month. In order to maintain long-term affordable care for their assisted living residents Culpepper Garden has had to address the issue of operating their facility while keeping costs low. To do so Culpepper Garden has relied on several sources of funding: a §202 construction grant, a county construction grant to modify and expand common spaces, private non-profit contributors, HUD §8 rent subsidies, a county grant to subsidize care services for very low-income residents, and a private grant to subsidize their first year of operation. However, as residents' needs increase, Culpepper Garden will have to continue to find sources of funding. Culpepper Garden is an excellent example of how facilities can combine multiple programs to reduce the cost of assisted living. See TILSON, *supra* note 12, at 7 – 8.
44. See 12 U.S.C. §1715(w).
45. See www.hud.gov.
46. The owner of a covered facility is given a tax credit based on a percentage of the proportion of rental housing the owner agrees to maintain as both rent and income restricted for at least eighteen years. At least 20 percent of the units must be set aside for residents whose incomes do not exceed 50 percent of the area median income ("AMI"), or 40 percent of the units set aside for residents whose income does not exceed 60 percent of AMI. See MICHIGAN STATE HOUSING DEVELOPMENT AUTHORITY, LOW INCOME HOUSING TAX CREDITS, www.mshda.org.
47. See AASHA DEVELOPMENT CORPORATION, USING TAX CREDITS FOR HOUSING OLDER ADULTS: A RESOURCE GUIDE FOR NON-PROFIT PROVIDERS 2 - 3 (October 1997) [hereinafter AASHA].
48. See Katherine M. O'Regan and John M. Quigley, Federal Policy and the Rise of Non-Profit Housing Providers, JOURNAL OF HOUSING RESEARCH, Volume II, Issue 2 300 (2000).
49. See AASHA, *supra* note 47, at 1 - 3.
50. See *id.* at 1.
51. Under RHS programs "very low-income" is defined as persons with an income below 50 percent of the AMI, "low-income" is defined as persons with income between 50 percent and 80 percent of AMI, and "moderate-income" is capped at \$5,500 above AMI. See www.usda.gov/rhs.
52. See www.usda.gov/rhs.
53. Eligible communities generally have populations less than 10,000 people. See www.usda.gov/rhs.
54. See www.usda.gov/rhs. See also *infra* n.51.
55. See www.usda.gov/rhs.
56. See *infra* n.36.
57. See CRS REPORT, *supra* note 2, at 4, citing U.S. SENATE SPECIAL COMMITTEE ON AGING, Shopping for Assisted Living, Hearing, Testimony of Consumer Consortium on Assisted Living. See also GAO, ASSISTED LIVING, *supra* note 3, at 24 – 27.
58. See Older Americans Act of 1965, 42 U.S.C 3001 *et seq.*, as amended Nov. 13, 2000, Pub. L. No. 106-501.
59. 42 U.S.C §3001, as amended § 712 .
60. See GAO, ASSISTED LIVING, *supra* note 3 at 13-15. See also *infra* p. 2.
61. For example, states may license a facility to care for residents within a certain level of ADL's, but an affordability option, such as the HCBS waiver may have conflicting requirements that preclude the facility from accepting the public funds. States need to be aware of these potential conflicts when designing licensing requirements.
62. See GAO, ASSISTED LIVING, *supra* note 2, at 5.
63. See 42 U.S.C. §1382e(e).
64. See 42 U.S.C. §1382e(e)(3)-(4).
65. See CARLSON, *supra* note 18, at 5-21.
66. *Id.* at 5-23.
67. See *id.*
68. *Id.*
69. *Id.*
70. See 42 U.S.C. §1396d(a).
71. See 42 C.F.R. §440.230.
72. See 42 U.S.C. §1396(a)(3). See also 42 C.F.R. §431.200 *et seq.* These regulations outline what the notice given to the resident should contain, reasonable times for request for hearing, right to continued benefits pending a hearing decision, right to a timely hearing, rights before and during the hearing, and specifics of the hearing.
73. 42 U.S.C. §1983.
74. See HCBS PRIMER, *supra* note 19. See also *infra* p. 6.
75. See SARAH GREENE BURGER, VIRGINIA FRASER, SARA HUNT, AND BARBARA FRANK, NURSING HOMES: GETTING GOOD CARE THERE, THE NATIONAL CITIZENS' COALITION FOR NURSING HOME REFORM 23 – 38, 142 – 143 (1996).
76. See MOLLICA, *supra* note 20. See also *infra* p. 13, n.19.
77. See MOLLICA, *supra* note 20. In order to gain approval from CMS, a state must demonstrate that its proposed HCBS waiver program does not cost more, on average, than the services provided in an institutional setting. See *infra* p. 5.
78. See O'HARA, *supra* note 36.
79. NCB DEVELOPMENT CORPORATION, AFFORDABLE ASSISTED LIVING E-NEWSLETTER, <http://pull.xmr3.com/469-A7B3/16800538/logotan.gif> 1 (July 19, 2001).
80. GAO, ASSISTED LIVING, *supra* note 3, at 29. See also *infra* pp. 10 – 11 (discussing the potential of these options to carry with them quality of care standards and consumer protections).
81. One inducement to assisted living facilities to adopt affordability options may be the recent discovery that many assisted living facilities are overbuilt for demand. See NCB DEVELOPMENT CORPORATION, AFFORDABLE ASSISTED LIVING: BACKGROUNDER, www.ncbdc.org. While the expected future growth of the older American population may eventually take care of this problem, in the short-term it may be an excellent way to persuade facilities to fill currently empty beds.

Commission Recommends Regulation, Accreditation, and Access in Assisted Living

Report and Recommendation on Assisted Living to the American Bar Association House of Delegates

RESOLVED, that the American Bar Association supports uniform and comprehensive state and territorial standards, regulation, and oversight of facilities and programs, commonly referred to as “assisted living,” offering to persons in a residential setting some degree of supervision or assistance with personal services and health care, sufficient to (a) enable consumers to make informed choices about their care options; (b) provide residents’ rights and legal protections; and (c) ensure resident safety and appropriate, high quality care.

FURTHER RESOLVED, that the American Bar Association opposes state, territorial, or federal agencies granting “deemed status” (the recognition of private accreditation as meeting government regulatory standards) to assisted living programs or providers accredited by private organizations unless (a) state monitoring and enforcement functions are effectively integrated and strengthened under the deeming process; (b) results of the state and territorial monitoring and enforcement process are fully accessible to the public; and (c) the deeming process is closely monitored and evaluated.

FURTHER RESOLVED, that the American Bar Association supports initiatives to increase the availability of affordable assisted living options and access to those options by persons of low and moderate means.

Introduction

Advertisements for assisted living facilities offer comfortable residences, social opportunities, freedom from housekeeping and health care worries, and the prospect of never having to move again. However, consumers seeking a residence to meet both their current and future needs face a daunting task. Those looking at programs in more than one state are likely to be even more confused. Unlike nursing homes, there are no federal regulations governing assisted living, no uniform standards, and no mechanism for ensuring resident safety and quality of care. Each state has its own definition of assisted living, its own guidelines for resident eli-

gibility and for the services that can be offered, and its own system of regulating facilities. In most states, oversight of assisted living is minimal; in some states, it is non-existent.

Broadly defined, assisted living offers supervision, assistance with some activities of daily living and other personal services, and sometimes health care, in a residential setting, to persons who can no longer live independently. The following definition is one of the more comprehensive, although variations abound:

Assisted living is a residential setting that provides or coordinates flexible personal care services, 24-hour supervision and assistance (scheduled and unscheduled), activities, and health-related services; has a service program and physical environment designed to minimize the need for tenants to move within or from the setting to accommodate changing needs and preferences; has an organizational mission, service programs and a physical environment designed to maximize residents’ dignity, privacy, and independence; and encourages family and community involvement.¹

The Assisted Living Federation of America (ALFA) estimates that approximately one million people live in an assisted living environment today (compared to an estimated 1.5 million who live in nursing homes).² The majority of these residents are female and very frail, with an average age of 84. Indeed, one in four assisted living residents requires the same level of assistance as the typical nursing home resident.³ Consumer demand for assisted living is expected to continue, as the number of older Americans is projected to more than double by 2030, when people age 65 and older will make up 20 percent of the population.⁴

Assisted living providers may be individuals who were formerly in the board and care industry; entrepreneurs with real estate backgrounds but no health care expertise; owners of nursing homes or hospitals adding assisted living within existing buildings or converting entire buildings; or former nursing home or other health care providers. They may be for-profit or not-for-profit. They may also be members of the “hospitality” industry (i.e., the Hyatts and Marriotts).

Report and Recommendation

Continued from page 17

Assisted living facilities range in size from “mom-and-pop” homes with fewer than five residents, to apartment-style complexes housing several hundred persons. They may be freestanding, or one part of a continuing care retirement community.⁵ Costs vary depending on size, location, and services, as well as the particular facility’s pricing plan. Such a plan may be all-inclusive, a la carte, or a combination of the two in which residents pay a basic monthly fee plus additional charges for other services. Some plans also require a substantial down payment. Most residents pay out of personal resources.

Assisted living first emerged in the late 1980s as a housing option for older people who were generally healthy and financially comfortable. At that time, it was virtually unregulated. Providers objected to regulation, contending that the market would direct what services were provided in assisted living, and the quality of those services. However, the industry burgeoned, resident needs changed, and the issues grew more complex. In recent years, states have responded to those changes and have taken steps to regulate these facilities. The problem is that state approaches differ considerably, and significant issues of uniformity, consistency, safety, and quality of care remain. In 1999, the U.S. General Accounting Office studied 721 assisted living facilities in four states with very different systems (California, Florida, Ohio, and Oregon). The GAO reported that in general, state regulation of assisted living focuses on three main areas: living accommodations, admission and retention criteria, and the types and levels of services that may be provided. Investigators observed that even within these three categories, states rarely address how services are to be provided, how quality is to be ensured, or what legal protections should be given to residents.⁶

Need for Uniform and Comprehensive Regulation

Lack of Uniform State Definitions

For consumers, the inconsistency and confusion in assisted living begins with terminology. In developing regulations for assisted living, some states renamed as assisted living such facilities as residential care, personal care, board and care, domiciliary care, sheltered housing, adult congregate living, or rest homes. Some added assisted living to the existing scheme. Others developed new definitions and regulations for the emergent models, either to replace existing programs or as a separate program. There are currently more

than two dozen designations for facilities that could be called assisted living, with more than one such designation in some states. In California, for example, these programs are known as residential care facilities; in New Mexico, they are called adult residential shelter care facilities. Michigan licenses homes for the aged and adult foster care. New York licenses assisted living programs, adult care facilities, adult homes, and enriched housing programs. This range of designations can be particularly confusing for people considering a move to an assisted living facility in a state other than where they currently reside, or for family members exploring assisted living options for an out-of-state parent.

To further complicate matters, some states permit certain categories of assisted living to operate unlicensed and without oversight. Kentucky’s new assisted living regulations exempt facilities that existed when the new law took effect in July 2000. In Michigan and New York, some assisted living programs do not fit within the categories that are licensed and regulated, and are therefore not subject to state oversight. It is highly unlikely that the average consumer would understand these distinctions.

Lack of Consumer Protection in Marketing and Contracts

More confusion derives from the services that are offered, or that appear to be offered, and their costs. Sales pitches and marketing materials may lead consumers to believe that they can remain in a facility for the rest of their lives, glossing over the fact that either facility policy or state regulation may require discharge if the resident’s needs exceed certain limits, or that the cost of services increase far beyond the basic fees originally quoted. Marketing claims may conflict with the terms of the contract, or fall short of what is actually provided. No state statutory and regulatory schemes address marketing issues; none require use of a standard contract; and of those states that even require a written contract, few specify what disclosures that contract should make. Accordingly, assisted living contracts range from single, sparsely worded pages that commit a facility to providing nothing more than a roof over the resident’s head, to multi-page documents packed with detailed, often confusing, and, sometimes, inconsistent information.

In a 1995 examination of 13 assisted living contracts, the ABA Commission on Legal Problems of the Elderly found vague language and stark omissions on issues as important as the kind, frequency, and cost of services offered by the facility, resident rights, and discharge policies and procedures.⁷ The situation had changed little by 1999, when the GAO reported that contracts lacked essential information, were vague or even misleading, and were not routinely provided to prospective residents. The GAO findings were reinforced

recently by the AARP Foundation, which compared marketing materials and admission contracts from 80 facilities. AARP discovered that significant discrepancies between marketing materials and contracts are common; that marketing materials frequently provide more information than contracts; and that many contracts include a caveat that the contract supercedes any other oral or written representations made to the consumer. The most frequent discrepancies between marketing and contracts involved supervision, nursing care, assistance with medication, and transportation. For example, marketing materials promised 24-hour nursing care, or assistance with taking medication three times a day, but the contract itself was vague, or even silent, on these issues.⁸

Unfortunately, consumers are likely to believe what they read in brochures and what they are told by sales representatives, whom they may mistakenly assume to be nurses or social workers. It is not until later that consumers discover that the services they expected are unavailable, or that they are available but for an additional fee. For example, a facility may offer “assistance with medication,” which, to a consumer, is likely to mean hands-on help taking medicine in the doses prescribed (opening the container, removing the appropriate amount, and handing it to the resident to swallow), at the appropriate times. The facility, however, may be licensed only to give reminders, not to administer the medication.

Need for Recognition of Resident Rights and “Aging in Place”

In some respects, assisted living residents have fewer legal rights than nursing home residents or apartment dwellers. Some states, e.g., Mississippi, provide no rights at all in the regulations, leaving this issue to the discretion of the facility. In other states, different rights attach in different programs, although consumers are unlikely to realize this distinction because the facilities appear so be so similar.⁹ Even in states where residents do have legal rights and protections, inconsistency reigns. Some regulations give residents only a right to privacy. Others provide for specific protections, such as freedom from abuse and restraints, privacy, confidentiality, and accommodation of individual needs. Still others establish a full set of rights more akin to those of a nursing home resident, plus a grievance procedure.

Almost all states require regulated facilities to provide residents with notice of a pending transfer or discharge, although that notice may be as little as five to ten days. Some states have established, or require facilities to establish, guidelines and procedures by which residents can object to the action. Few states specify that the notice should contain the grounds for discharge, and not all states direct how notice is to be provided, or to whom.¹⁰ There is also little uniformity in the degree to which residents may challenge a discharge.

In at least two states (Massachusetts and Minnesota), assisted living discharges fall under landlord-tenant law. Some states require facilities to establish their own appeals mechanisms, which could result in nothing more than a meeting with the staff member or administrator who made the initial decision. Other states have established guidelines for internal procedures, and/or provided recourse to an outside agency (usually the agency that licenses the facility).

What about those advertisements that claim a facility will care for residents for the rest of their lives? Unfortunately, they are not always accurate, and they create more confusion. Although assisted living is frequently touted as enabling people to “age in place,” in reality, many residents do not live out their lives in the facility of their choosing. They may need services beyond those the facility is licensed to provide, or they may not be able to meet the costs of their care. Sometimes, the resident’s own behavior might be the basis for discharge. The rate at which residents move out of assisted living, and the reasons for these moves, are difficult to determine. They vary significantly from one state to the next due to differences in state law, limits on allowable conditions or services, and facility choice of whom to serve, which services to provide, or which to make available through outside programs, e.g., home health and other community-based care.

Some states prohibit facilities from providing certain services, but allow residents to obtain the same services from an outside agency. Mechanisms to ensure the quality of care for residents who remain in a facility under these circumstances vary from non-existent to relatively involved. In Maryland, for example, the licensing agency must approve retention of residents with needs higher than a facility’s licensure would permit.¹¹ Michigan’s homes for the aged may retain residents who need care beyond that which the facility is licensed to provide, if the resident, resident’s family, physician, and facility agree, and the facility assures the state that the resident will receive the necessary services.¹²

Need for Comprehensive State Regulation

Unlike nursing homes, which must meet staffing standards and other strict regulations, and submit to regular inspections, there are no uniform standards or federal regulations to protect assisted living residents.¹³ The industry has argued that resident autonomy and flexibility can be attained only if providers do not have to comply with the kind of extensive regulations governing nursing homes. Many providers contend that the contract, and the market, should direct what services are provided, and the quality of those

Continued on page 20

Report and Recommendation

Continued from page 19

services. Consumer advocates respond that providers have significantly greater bargaining power than elders made vulnerable by physical frailty, diminished mental capacity, or anxiety about an impending move to a new environment, or by families under pressure to find a quick placement for a parent. Moreover, they argue that the history of resident abuse and neglect in the board and care and nursing home industries lend strong support for government oversight of the services and care provided.

States have begun to examine issues of oversight and enforcement, but regulations vary tremendously in the frequency and content of inspections, and in mechanisms for enforcement. States are more likely to focus on required disclosures of information, e.g., living arrangements, admission and retention criteria, scope of services, and facility design, than on the quality of services and care provided. They rarely prescribe staffing ratios or specific staff training. The result is that services and quality vary from one state to the next and even from one facility to the next.

Each of the four states investigated by the GAO in 1999 licensed some form of assisted living, and inspected or surveyed the licensed facilities. The licensing agency or other appropriate state program, such as adult protective services or the long-term care ombudsman program, also responded to complaints about potential violations or allegations of abuse or neglect. Even so, there was great variation in the rate and content of inspections, and in tools for ensuring compliance with the regulations. Moreover, those states still experienced inadequate or insufficient resident care; insufficient, unqualified, and untrained staff; and inappropriate medication administration.¹⁴

In states where unlicensed facilities are permitted to operate, the issue is further complicated. Testifying before the U.S. Senate Special Committee on Aging, Sen. Hillary Clinton (D. N.Y.) described how consumer misunderstanding can lead to disaster. In New York, unlicensed assisted living “look-alike” facilities contract with a licensed home care organization for provision of health services to residents. In this case, the resident’s daughter, unaware that she was dealing with two separate providers, gave instructions about her mother’s medication only to the assisted living program. The instructions were not followed, and the mother died.¹⁵ Other serious incidents have been reported in the national media.

u In New York, an 82-year-old assisted living resident died from congestive heart failure a few days after an inexperienced aide (the only staff member on duty despite

promises of 24-hour care) walked him down a long hallway to a waiting ambulance.¹⁶

u Residents of a Minnesota assisted living facility resorted to calling 9-1-1 on behalf of residents who needed help the staff was not providing. When one resident was taken to the emergency room, hospital workers telephoned the facility for her medical history, but no one answered. Police who went to the facility were met by the sole staff person on duty—a cook who barely spoke English and who had not been taught how to use the phone.¹⁷

u For the second time in a month, an 80-year-old man with Alzheimer’s disease wandered out of an unlocked door in a North Carolina assisted living facility marketed as providing dementia care. By the time staff realized the man was gone, he had walked half a mile down a dark highway, been hit by a car, and died.¹⁸

u An 83-year old frail female resident of a Virginia assisted living facility died two days after being assaulted in a day room by a 55-year old male resident.¹⁹

Although these incidents may not be the norm, they cannot be ignored. While assisted living regulations may establish minimum guidelines and parameters within which facilities are to operate, few states have mechanisms for monitoring quality, or holding assisted living providers accountable for poor care. Providers may appreciate a hands-off approach, but lack of oversight makes it more likely that they will not be held accountable for meeting resident expectations, or worse, that resident safety will be compromised by a failure to meet minimum care standards.

Unrestrained advertising hype, opaque—or missing—contracts, the lack of standards and oversight of assisted living leads to confusion for frail older consumers, their families, and those who seek to advise them, and may even put residents at risk of harm. For the reasons described above, there is a need for state standards, regulation, and oversight of assisted living facilities and programs that will allow consumers to make informed choices about their options, give residents legal rights and protections, and ensure that residents receive appropriate, high quality care.

Accreditation and Deemed Status

As an alternative to regulation, the assisted living industry encourages private accreditation as a tool for measuring quality. Two industry-sponsored groups are offering to accredit assisted living facilities, in much the same way that hospitals and nursing homes are accredited. The Assisted Living Federation of America and the American Association of Homes and Services for the Aging have designated the Rehabilitation Accreditation Commission (CARF) as the accrediting body for their member facilities. The Joint

Commission on Accreditation of Healthcare Organizations (JCAHO) has also entered this assisted living arena.

The JCAHO standards are organized around six functions of resident care (consumer protection, rights, and ethics; continuity of services; assessment and reassessment; resident services; resident education; and health and wellness) and six on management (improving performance; managing the environment; leadership; managing human resources; managing information; and infection control). To earn and maintain JCAHO accreditation, a facility must have an on-site survey by Joint Commission surveyors at least every three years.²⁰ The CARF standards include: assisted living core values and mission; input from residents, families, and other stakeholders; disclosure of information; outcomes management; individual-centered planning, design, and delivery of services; and resident rights.²¹ Neither the CARF nor the JCAHO criteria are specific. Rather than setting measurable requirements for key areas, they offer a more general objective, are designed for flexibility, and focus on quality improvement.

In some circumstances, when facilities meet private accreditation standards, they are considered to meet government licensure or regulatory requirements. This process is known as deeming.²² Deeming, or deemed status, has existed since 1965 as an option for certifying hospitals for the Medicare program. In 1982, when the Health Care Financing Administration proposed to extend deemed status to nursing homes participating in the Medicare program, advocates for nursing home residents identified such significant problems that the proposal was withdrawn. Similar concerns arise in the assisted living context.

While accreditation is fine as an industry tool for quality improvement, it becomes problematic when states substitute what is essentially self-evaluation, for compliance with regulatory standards and state oversight. Moreover, the assisted living accreditation is performed by a private organization supported by facility fees; licensure is undertaken by a government agency not subject to outside influence. Accreditation visits are usually announced; licensing agency inspections are not. Accreditation is based on a set of private criteria developed by the industry without public input; licensure is based on regulations adopted by the state. Accreditation takes an educational and consultative approach; licensure aims to determine compliance with state regulation and to identify and remedy deficiencies. Accreditation criteria leave much to the subjective opinion of surveyors, offer little opportunity for facility comparisons by consumers and others, and detract from accountability. They should not substitute for uniform standards with measurable requirements to guide consumers and ensure high quality care, and they should not be the basis for granting of deemed status.

Industry standard setting and accreditation are certainly to be encouraged, but they are not adequate substitutes for public accountability, especially given the vulnerability of assisted living residents. Accordingly, accreditation and deemed status should not be a substitute for regulation by state or federal agencies, unless state monitoring and enforcement functions are effectively integrated and strengthened under the deeming process, results of the state monitoring and enforcement process are fully accessible to the public, and the deeming process is closely monitored and evaluated.

Need for Affordable Options

The cost of assisted living depends on the facility and the needs of the resident. Costs vary not only from one facility to the next, but from one resident to the next. Common fee arrangements include a substantial entrance deposit, or none at all, plus 1) a basic rate for room and board, with services available on an a la carte basis, or 2) a basic rate for room, board and a standard package of services, with other packages or additional services available at extra charge. In a 1993 AARP survey of 63 assisted living residences, only seven utilized a single rate within the same facility.²³

The cost of assisted living ranges from approximately \$1,000 to more than \$4,000 per month.²⁴ Costs are generally paid out of personal resources by residents and their families, which places this option beyond the reach of many older Americans. For those without families to help, the situation is even more acute. The U.S. Bureau of the Census reports that in 1997, 84 percent of persons aged 75 and older had incomes less than \$25,000 per year, and 40 percent had incomes of less than \$10,000 per year.²⁵ There is no way that they will be able to afford assisted living without some assistance. Unfortunately, some people find out after they have moved in, that they cannot afford the cost of the care they need, and they must leave. As many as two-thirds of current residents have incomes that are too low to cover the typical cost of a year's stay without using up their savings.²⁶

For those who can afford the premiums, long-term care insurance may subsidize the cost, although coverage is limited and premiums are high unless the policy is purchased well in advance. Medicare does not pay for assisted living. It may, however, cover skilled nursing care or services provided to assisted living residents by licensed home health care agencies. Some residents receive financial assistance through state Medicaid waivers.²⁷ These Medicaid waivers are of limited value, however, as coverage is limited, facilities must agree to participate in the program, and residents must meet income and medical eligibility guidelines.

Continued on page 22

Report and Recommendation

Continued from page 21

The U.S. Department of Housing and Urban Development offers some federal funding for the development of assisted living for low-income persons age 62 and older who need assistance with at least three activities of daily living, e.g., eating, dressing, bathing.²⁸ Another source of assistance is the Supplemental Security Income state supplement for persons with mental or developmental disabilities.²⁹ States may also offer their own subsidies to individuals directly to pay for care. Some segments of the assisted living industry are exploring affordable options. One church-affiliated group is structuring fees so that the market rent covers an in-house subsidy for low-income residents. The Robert Wood Johnson Foundation and a non-profit lender have joined forces with some non-profit senior housing and service providers to develop affordable assisted living for very low-income (Medicaid eligible) persons in several states.³⁰

Despite the significant growth of the assisted living industry, opportunities are limited for persons of modest means. The high cost of market-rate facilities forces many people who need long-term care to forgo services, to move away from their communities, to rely on family members, or to enter the more restrictive setting of a nursing home unnecessarily. Others are forced to leave their assisted living homes when they can no longer pay the cost of their care. Initiatives to increase the availability of affordable assisted living options and to support access to those options by persons of low and moderate means will help to alleviate this situation.

Existing Association Policy

The American Bar Association has a long history of support for consumer protections and quality in health and long-term care.

In 1983, the Association went on record in support of effective enforcement mechanisms to ensure adequate quality of care in nursing homes participating in the Medicare and Medicaid programs, and expressed concern over proposals that included granting of deemed status to nursing homes.³¹ In 1987, the House of Delegates supported federal and state legislative and regulatory standards to improve the quality of home care, including provisions to involve consumers directly in the evaluation and monitoring of home care, provide them with clear and consistent information about services, consumer rights, and simple and effective means of redress should problems arise. This resolution also included support for monitoring systems and enforcement mechanisms aimed at ensuring quality of care for older persons and persons with

disabilities. It opposed the granting of “deemed status” under federal and state programs to home health providers who are accredited by private accrediting bodies unless certain conditions are met.³² These conditions are included in the recommendation under consideration at this time.

In 1989, the Association expressed support for federal oversight and state legislation requiring licensure and regulation of board and care facilities for adults who need personal assistance, lodging and meals, consistent with eight specified principles, (state licensing, contractual protections and resident rights, regulation to prevent abuse and neglect, minimum standards to ensure resident safety and protection, enforcement to assure quality, development of a plan of care, sanctions against unlicensed homes, and living arrangements consistent with principles of least restrictive environment and treatment).³³ While this policy still stands with regard to board and care homes, assisted living covers a wider range of facilities and provides a higher level of care than the institutions that were the subject of the 1989 policy.

Also in 1989, the Association recommended that federal and state legislation provide a coordinated and comprehensive system of care for Americans of all ages with long-term care needs, consistent with principles of equity and procedural fairness, and consumer choice with respect to the nature and setting for delivery of care.³⁴ The Association supported universal access to quality health care that includes, among other characteristics, mechanisms for assuring the quality and appropriateness of care.³⁵

The recommendation under consideration fits squarely within Goal III of the Association’s mission and goals: to provide ongoing leadership in improving the law to serve the changing needs of society. It builds upon the foundation created by existing policies, extending their principles to assisted living, the newest and fastest growing member of the continuum of long-term care. It would permit the Association to advocate for standards, regulation, licensure and oversight, to improve the current patchwork of laws affecting assisted living, to enable consumers to make informed choices, to protect the rights of residents, and to ensure that they receive appropriate, high quality care. It would also allow the Association to raise concerns about deemed status, and to promote affordable assisted living options for those who cannot afford to pay the high costs of most facilities.

Conclusion

The assisted living industry has received a great deal of negative publicity in recent months, which has led to increased activity at the federal and the state levels. At the federal level, Rep. Fortney Pete Stark (D. Ca.) has introduced H.J. Res. 13, calling for a White House Conference on

Assisted Living. While there are several co-sponsors, as of this writing no action has been taken on the bill. At an April 26, 2001, hearing convened by the U.S. Senate Special Committee on Aging, several senators expressed concern about quality of care and a great deal of interest in working with consumer advocates and provider organizations to develop model standards that could be adopted by states.³⁶ Most of the activity has been at the state level, and states that were initially reluctant to regulate assisted living, are beginning to consider mechanisms for addressing quality of care and consumer protection. The Association's involvement would be particularly timely.

Notes

1. Keren Brown Wilson, ASSISTED LIVING: RECONCEPTUALIZING REGULATION TO MEET CONSUMERS' NEEDS AND PREFERENCES 10 (AARP 1996).
2. Assisted Living Federation of America, <http://www.alfa.org>.
3. Catherine Hawes, A NATIONAL STUDY OF ASSISTED LIVING FOR THE FRAIL ELDERLY: RESULTS OF A NATIONAL SURVEY OF FACILITIES, DHHS/ASPE, 2000.
4. U.S. ADMINISTRATION ON AGING, DHHS, A PROFILE OF OLDER AMERICANS: 2000, <http://www.aoa.gov>.
5. Continuing care retirement communities offer independent living, assisted living, and skilled nursing home care on a single campus.
6. U.S. GEN. ACCT. OFFICE, ASSISTED LIVING: QUALITY-OF-CARE AND CONSUMER PROTECTION ISSUES IN FOUR STATES, GAO/HEHS-99-27 (1999) [hereinafter GAO Report].
7. See John Buck, *Assisted Living: An Uncharted Course*, BIFOCAL, Winter 1996, at 1.
8. This information was gathered in preparation of the consumer education brochure, NAVIGATING YOUR WAY TO A QUALITY ASSISTED LIVING FACILITY, AARP, 601 E. Street, NW, Washington DC 20049 (D17037-1200).
9. E.g., in Hawaii, residents of Adult Residential Care Homes (housing plus personal and health care services "to residents who do not need the professional health services [of] an intermediate, skilled nursing or acute care facility") may be discharged with two weeks notice because "the operator wishes to ... discharge the resident." Haw. Rev. Stat. 19, §321-15.1, Haw. Admin. R., 11-100-19. This reason is not acceptable in Assisted Living facilities (housing plus "health care ... personalized support services ... health monitoring... and routine nursing tasks..."). Haw. Admin. R. 11-90-10(b). Consumers, however, might not realize the difference.
10. Common grounds include nonpayment, resident behavior, and resident health needs. States that regulate the content of the discharge notice may require the reason for the action, effective date of the transfer or discharge, where the resident is to be moved, appeal rights, and a contact for the long-term care ombudsman.
11. Md. Reg. Code tit.10.07.14.10 (2000).
12. MAC §333.21325 (Jan. 9, 2001).
13. Nursing homes provide residents with room, board, nursing services, and assistance with activities of daily living. Nursing homes participating in the Medicare or Medicaid programs must comply with the federal Nursing Home Reform Law, 42 U.S.C. §1395i-3 (Medicare certified facilities) and 42 U.S.C. §1396r (Medicaid certified facilities). For a discussion of nursing home law, see Eric Carlson, LONG-TERM CARE ADVOCACY (1999).
14. See GAO Report.
15. Testimony of Hillary Rodham Clinton (D. N.Y.) before U.S. Senate Special Committee on Aging, April 26, 2001.
16. Jennifer Steinhauer, *As Assisted Living Centers Boom, Calls for Regulation Are Growing*, NEW YORK TIMES, Feb. 12, 2001, at A1.
17. Amy Goldstein, *Assisted Living: Helping Hand May Not Be Enough*, WASH. POST, Feb. 18, 2001, at A1.
18. *Id.*, at A1.
19. Ian Shapira, *Fauquier Patient's Death Ruled a Homicide*, WASH. POST, Mar. 28, 2001 at B1.
20. JCAHO website at <http://www.jcaho.org>.
21. CARF website at <http://www.carf.org>.
22. PRESIDENT'S ADVISORY COMMISSION ON CONSUMER PROTECTION AND QUALITY IN THE HEALTH CARE INDUSTRY, QUALITY FIRST: BETTER HEALTH CARE FOR ALL AMERICANS, 1998.
23. Rosalie A. Kane & Keren Brown Wilson, ASSISTED LIVING IN THE UNITED STATES: A NEW PARADIGM FOR RESIDENTIAL CARE FOR FRAIL OLDER PERSONS? 48 (1993).
24. CRS REPORT FOR CONGRESS, ASSISTED LIVING: BACKGROUND AND ISSUES, April 6, 2001, at 3.
25. See NCB DEVELOPMENT CORPORATION: AFFORDABLE ASSISTED LIVING BACKGROUNDER, <http://ncbdc.org>, citing U.S. Bureau of the Census, <http://www.census.gov>.
26. Amy Goldstein, *Assisted Living: Paying the Price*, WASH. POST, Feb. 20, 2001, at A1.
27. At least 38 states cover some assisted living services through Medicaid waivers and/or other state-funded programs. See Mollica, STATE ASSISTED LIVING POLICY 2000, at <http://www.nahsp.org>.
28. The HUD Assisted Living Conversion Program (ALCP) provides grants to convert §§202, 202/8 and 202 Project Rental Assistance Contract projects to Assisted Living Facilities for the frail elderly. 42 U.S.C. §3545.
29. See Eric Carlson, LONG-TERM CARE ADVOCACY §5.05[2] (1999).
30. See David Nolan and John Rimbach, *A Model of Affordable Assisted Living*, PROVIDER, Oct. 1997, at 73.
31. ABA Resolution No. 104 (February 1983). This resolution urged retention of effective enforcement mechanisms to ensure adequate quality of care in nursing homes participating in the Medicare and Medicaid programs, and expressed "concern over possible changes which may substantially weaken existing enforcement procedures and limit public access to the enforcement process." It responded to proposed regulations that would have allowed accreditation by the Joint Commission on Accreditation of Hospitals (JCAH, later to become JCAHO) to be sufficient to demonstrate compliance with Medicare/Medicaid standards. The accompanying report argued that deemed status would "place an accreditation body into an enforcement role which can only be properly carried out by the state survey agency and HHS." Report at 2.
32. ABA Resolution No. 106 A (August 1987). The conditions are identical to those listed in the attached Recommendation. They would require that a) state monitoring and enforcement functions [be] effectively integrated and strengthened under the deeming process; b) results of the state monitoring and enforcement process [be] fully accessible to the public; and c) the deeming process [be] closely monitored and evaluated.
33. ABA Resolution No. 121 (August 1989). The accompanying report describes board and care homes as including a "wide variety of non-medical, community-based residential facilities." These homes are defined in the Older Americans Act as institutions regulated by the states pursuant to 42 U.S.C. §1382(e). While there is some overlap, board and care and assisted living are not always the same. For example, depending on the state, assisted living may provide medical care to residents.
34. ABA Resolution No. 106A (August 1989).
35. ABA Resolution No. 105 (February 1994).
36. See U.S. Senate Special Committee on Aging, <http://www.senate.gov/~aging>.

Legal Aid Bureau, Inc.

Continued from page 7

struggling with how to write a contract that both protected the residents and themselves.

Obstacles to the Training

One of the greatest obstacles we came across in arranging the trainings was the inability of providers to leave the homes they manage and attend the trainings. Many of these providers run small homes, without staff other than themselves, and have no one to leave the residents with during the day. Some providers told us that a two-hour training would have been more feasible for them, while others thought the four-hour training better met their needs.

Another obstacle was adequate outreach. Many small assisted living facilities are not on any state list and are, in essence, “underground homes.” These providers would be the ideal audience for a training such as ours, yet they are the providers who are hardest to reach. One small-home manager on the eastern shore of Maryland told us that she knew of ten different homes that were going underground, and she could not convince the managers to come to our training.

Replication of the Project

Over the past several years, many states have revised their assisted living laws, and those states that had no assisted living laws have begun the process of writing and passing them. Therefore, it is possible that a project such as the one

Legal Aid performed could be replicated in other states. Additionally, in Maryland, new providers are opening homes on a daily basis. We periodically get calls from providers asking us when we will be offering additional trainings. Therefore, as homes continue to open, trainings such as ours would be a good source of information for providers trying to comply with regulations. It is also possible that these types of trainings could be replicated outside of the assisted living arena. In Maryland, group homes for those with developmental disabilities have their own sets of governing regulations. Providing comprehensive training for those providing the care could enhance the quality of care in these homes, and give the providers confidence that they can follow the regulations in a feasible and cost effective manner.

Conclusion

The Legal Aid Bureau staff know that the project has helped many small-home providers of assisted living care understand the regulatory standards and, in some situations, given them the confidence to keep their homes open. This can only benefit the low-income seniors who depend on these homes and who could be homeless, but for these homes. We continue to be concerned about the providers who have gone underground and are trying to run homes without state oversight and without adequate training. Additionally, we are concerned about the licensing process and the slow pace of state licensure. We are hopeful that, as more homes get licensed under the new standards, the quality of care in assisted living homes will improve. This project could be replicated in other states and with other types of providers.

BIFOCAL

American Bar Association
Commission on Legal Problems of the Elderly
740 15th St., N.W.
Washington, DC 20005-1022

www.abanet.org/elderly