

Office of the D.C. Long-Term Care Ombudsman Program

Overview and Educational White Paper

of

Assisted Living Facilities in the District of Columbia

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Introduction

Like the rest of the nation, the District of Columbia faces challenges as the Baby Boom generation nears retirement. The challenge of finding suitable long-term care arrangements for oneself or a loved one is one that more Americans will need to face as time passes. Between the year 2000 and 2030, the number of elderly persons in the United States will double to 72.1 million people.¹ In the District of Columbia alone, the Census Bureau projects that by 2025 elderly residents (aged 65 years or older) will comprise 14 percent of the total population.² It is critical, therefore, that the District of Columbia government be prepared for this coming shift by enforcing a statutory scheme that will insure that the increasing number of elderly residents of long-term care can age with dignity.³

A relatively new, but important, option for aging Americans is the Assisted Living Residence (ALR). The ideal ALR allows an individual to maintain as much independence in his or her daily activities as possible while providing assistance specifically tailored to his or her individual needs. Unfortunately, as with nursing homes, concerns of neglect, abuse, and fraud arise in the context of ALRs. Thus, it is critical that DC residents educate and inform themselves of their rights and options regarding long-term care for themselves and their loved

¹ <http://www.census.gov/prod/2006pubs/p23-209.pdf>

² Source: U.S. Census Bureau. <http://www.census.gov/population/www/projections/pp147.html#tablea>

³ At the time of this writing, the District of Columbia Office of the Long-term Care Ombudsman has filed and is proceeding in a mandamus lawsuit against the DC Government seeking to correct what it feels is a lack of enforcement of current assisted living statutes.

ones. The following paper is an educational piece intended to serve as a guide to selecting a suitable ALR. To that end, Part I will provide a summary of the Long-Term Care Ombudsman Program (Ombudsman Program) and how the Ombudsman Program is available to [advocate for](#) the rights of long-term care residents. Part II will provide an overview of the services presently available to DC seniors and will further discuss what to look for and questions to ask before moving into an assisted living facility. Part III will conclude that, although there are no current regulations governing ALRs in the District, the District can become a national leader in protecting the rights and well-being of assisted living residents through consumer education and enforcement and licensing regulations.

I. An Overview of the Office of the DC Long-Term Care Ombudsman

The Office of the District of Columbia Long-Term Care Ombudsman (Ombudsman Program) was established in 1975 by the District of Columbia Office on Aging. As mandated by both DC and federal law,⁴ the Ombudsman Program carries out the following responsibilities:

- To serve as advocate for the rights of older persons and other persons who are residents of nursing facilities, assisted living residences, and community residence facilities;
- To investigate and resolve complaints made by or on behalf of an older person or other person who is a resident of a nursing facility, assisted living facility, or a community residence facility;
- To monitor the quality of care, services provided, and quality of life experience by older persons and residents in long-term care facilities to ensure that the care and services conform to District and federal requirements;

⁴ Older American's Act (1965), 42 U.S. C. 3027(a)(12) and Long-Term Care Ombudsman Program Act(1988) DC Code § 7-701.01 et. Seq.

- To establish and conduct a training program for program staff and volunteers; and
- To establish and maintain procedures to protect the confidentiality of information regarding residents.

In order to achieve the above goals, the Ombudsman Program dispatches staff to visit long-term care facilities to monitor care and services and to investigate complaints on behalf of residents, their family members, friends, or legal representatives. Because the Ombudsman Program lacks enforcement authority, Ombudsmen work with facility administrators and staff to resolve concerns regarding care and services, and collaborate with and refer complaints to the Health Regulation Administration (HRA) and, in some cases, Adult Protective Services, and federal and local law enforcement agencies for further investigation and action when laws or regulations have been violated or when fraud, abuse, or neglect are suspected.

The Ombudsman Program performs these responsibilities on behalf of approximately 5,121 residents of licensed nursing facilities and community residence facilities in the District of Columbia.⁵ The focus of this paper, however, will be on assisted living and the approximately 725 residents of those facilities. Pursuant to District law,⁶ the Ombudsman Program has an unfettered right to access all Assisted Living Residences (ALRs) and is responsible for investigating complaints of ALR residents through unannounced visits and chart reviews.

⁵ As of the writing of this paper.

⁶ Long-Term Ombudsman Program Act (1988) D.C. Code §7-703.01

II. Assisted Living in the District of Columbia

A. Assisted Living Facilities

Typically, an ALR is a for profit apartment-style residence that provides one or more daily meals, minimal assistance with activities of daily living (ADLs), and social and recreational activities. Residents typically pay monthly rent in the range of \$3,500 to \$5,500 for their apartment and contract for additional services based on the level of care they require. Generally, ALR residents are more independent than nursing home residents and the majority of the District's Proposed ALRs (P-ALRs)⁷ offer a more upscale environment and more amenities than a nursing home or Community Residence Facility (CRF). Typical of this arrangement is the Methodist Home, which offers essentially private apartment living space with community activities for residents along with prepared meals in a dining hall setting.

In DC, Medicaid reimbursement is not available to ALRs. This is because the Assisted Living Residence Regulation is a statute that requires regulations to enforce it and requires the implementation of a licensing system and fee structure. *Until that happens, no facility can become a licensed ALR.* As a result, P-ALRs are limited to residents with higher incomes or those with more accumulated savings regardless of the Act's mission statement, that affordable ALR care be made available to all residents regardless of income. Because there are no licensed ALRs in the District of Columbia⁸, many of the P-ALRs have policies in place that voluntarily comply with much of the Act. Because the Act protects resident's rights and implements a

⁷ P-ALR This term will be used for ALR type programs not yet able to be certified

⁸ This does not imply that the ALR options available at present are necessarily lacking in quality. It is, however, impossible for any enforcement for resident rights when no licensing schemes are in place. Thus, the consumer seeking assisted living care in the District must arm themselves with knowledge of their rights in order to ensure voluntarily compliance with the spirit of the statute.

progressive philosophy of care, the following serves to guide prospective residents to P-ALRs in the District of Columbia that presently comply with this philosophy.⁹

Using the Act's definition, the District of Columbia currently offers 12 P-ALRs with a capacity of approximately 725 beds. Since the Act has not been implemented and thus, there is currently no regulatory or licensing structure in place¹⁰ these facilities do not require a license and are not monitored by the D.C. Department of Health. Many of these P-ALRs, however, are licensed as CRFs under title 34 of the D.C. Code and others are directly connected to licensed nursing homes.

B. Creating a Balance between Autonomy and Safety

The core philosophy of any given P-ALR or ALR should emphasize the personal *autonomy* of the resident and balance this autonomy against the assistance needed to insure the safety of the resident. Ideally, an ALR should resemble a home more than a nursing home. The safety of the resident should be insured through staff available to provide, or coordinate, 24-hour-a-day assistance with the activities of daily living.¹¹

When searching for a P-ALR or ALR, a prospective resident and his or her family should evaluate it with all the care one would a house or apartment building and should consider factors such as the esthetic and accessibility of the building, the neighborhood surroundings, the

⁹ D.C. Code § 44-101.02 (b) provides a philosophy of care

¹⁰ D.C. Code § 44-101.01 et seq. regulates Assisted Living in the District of Columbia. Currently the Ombudsman Program has filed and is pursuing a Mandamus Lawsuit to force the executive to promulgate regulations to enforce the statute and implement a licensing regime and fee structure. At the time of this writing, this litigation is ongoing.

¹¹ Activities of daily living include "eating, bathing, toileting, grooming, dressing, mobility, and in place transfers". D.C. Code § 44-102.01 (1).

amenities offered, the staffing and the other residents of the facility. Further, the services offered should focus on providing, or arranging for, resident assistance where needed. The resident should be allowed to maintain, to the greatest extent allowed by medical conditions, independence in daily living activities. A prospective resident should consider the policies of the ALR staff and administration regarding autonomy. Examples of questions to ask include:

- Are there restrictions on decorating a resident's unit (e.g. can one bring one's own furniture, or paint or decorate the walls to one's liking)?
- Are there private units available with private bathrooms?
- To what extent can a resident behave in a way to which they are accustomed (e.g. can the resident smoke in his or her unit or have access to a designated smoking area, keep pets, or have access to a stove)?
- Are there community activities available that are interesting to the resident?
- What level of medication supervision is provided?
- Can residents keep their private medical providers?
- Is there transportation available for activities outside the ALR and to medical appointments?
- *What are the fees for additional services not included in the admissions contract?*

The person who is seeking residency in an ALR should tailor questions to his or her individual needs and capabilities.

C. Individualized Service Plans

In order to maintain the balance between the autonomy of a resident of an ALR and the assistance that resident requires, after moving in, the resident (and/or the resident's

representative, either familial or legal) and the staff must work together to create an Individualized Service Plan (ISP). The ISP is a written plan that describes the services that the ALR will provide to the resident based on the current medical and daily life needs of the resident and the services provided by the ALR.¹² The healthcare practitioner¹³ will prepare the plan using an assessment of such factors as the medical, rehabilitative, psychosocial and functional needs of the resident and the reasonable accommodation of the resident in the event those needs change.¹⁴ A thorough ISP will serve to educate the ALR of the resident's needs and will outline the expectations and goals of both the resident and the ALR.

- **Medical Needs.** The facility must provide or facilitate access to all medical care services that a resident requires, including such specialists as chiropractic care. The ISP should also address what laboratory tests the resident requires, the medications he or she is currently taking, and any medical equipment the resident requires.
- **Rehabilitation Needs.** An ISP should also address the therapy services that a resident requires, including physical, occupational, speech and respiratory therapies. The ISP should also address what rehabilitation equipment the resident uses and requires and should address whether a plan is needed to address falls management and prevention.
- **Psychosocial Needs.** This portion of the ISP shall address the cognitive needs of the resident: whether the resident needs supervision or monitoring because of mental health issues or simply needs reminding, cueing, or direction. If necessary, the ISP should address any mental health services provided by the

¹² D.C. Code § 44-102.01 (14).

¹³ "health care practitioner means a person licensed as a physician or nurse practitioner."

¹⁴ D.C. Code § 44-106.04 (a)(7).

ALR or should provide for collaboration with the ALR and the resident's mental healthcare provider. Also, this portion of the ISP will address the social needs of the resident and will address the social, intellectual, recreational, cultural and spiritual accommodations available at the ALR.

- **Functional Needs.** The functional needs of a resident include what assistance the resident requires with eating, bathing, toileting, grooming, dressing, mobility, taking medications and in place transfers
- **Reasonable Accommodation.** Critical to autonomy is reasonable accommodation of residents whose condition changes. An ALR is required to promote "aging in place"¹⁵ by adapting to the changing condition of an individual. This accommodation to changing resident needs should include additional services provided by the ALR, or through coordination with outside licensed healthcare providers such as home health agencies, hospice, and rehabilitation agencies. Only when the condition of the resident reaches a point where the resident's safety is at risk or when the resident chooses to be relocated, should a transfer to another setting be arranged.¹⁶

The ISP will resemble a service contract in that it must include a detailed list of what services will be provided to the resident, when and how often they will be provided, and how and by whom the services will be provided.¹⁷ It is important that the ALR and the prospective resident confer and reach an agreement regarding the responsibilities of both the ALR and the resident

¹⁵ Aging in place means minimizing the circumstances which require a person to move to a different setting when his or her condition changes. D.C. Code §44-102.01 (2)

¹⁶ *Id.* at 106.04 (e).

¹⁷ *Id.* at 106.04 (b).

and the best way of achieving the goals of the resident.¹⁸ After moving in, the resident (or surrogate) and the ALR should reevaluate the needs of the resident and the ISP thirty days after admission and then at least once every six months afterwards. During these reviews, a team including the resident's healthcare practitioner in the facility, the resident (or surrogate if necessary), and the ALR will work together to reassess the needs and services now needed.¹⁹

D. Shared Responsibility Agreements

Sometimes, a resident seeking autonomy in an ALR may want to maintain a lifestyle that could potentially increase the risk of personal harm to the resident and thereby increase the potential legal liability risks to the administrators of an ALR. In a case where such disagreements arise, a shared responsibility agreement can serve as a useful tool to broker a compromise between the administrators and the resident. These agreements are formal written agreements that outline the responsibilities and actions to be taken by both the resident and the ALR and are created with the purpose of resolving conflicts between a resident's right to autonomy and the ALR's concerns for the safety and well-being of the resident.²⁰ The goal is a resolution that is acceptable to both.

In certain instances, resident choices may not be subject to negotiation if they involve such a great risk of harm. Life in an ALR is not fully autonomous, nor can it be. Instead the purpose of these agreements is to increase, to the greatest extent possible, the autonomy of a resident. A prospective resident should obtain all information regarding autonomy of residents from an ALR before the decision to move in is final.

¹⁸ *Id.* at 106.04 (c).

¹⁹ *Id.* at 106.04 (d)

²⁰ *Id.* at 102.01 (22)

E. Dignity and Resident's Rights.

While there are currently no licensing protocols in place that govern assisted living, prospective residents can protect their rights by familiarizing themselves with their rights under the current law. In the current absence of regulations and enforcement of the statute governing ALRs, prospective residents can help create voluntary compliance with the rules by patronizing only facilities that insure the dignity of their residents. Thus, this section seeks to inform the public of their rights under the D.C. Code.²¹

F. Autonomy

The D.C. code provides that a resident of an ALR has a right to live in an environment that fosters self-determination, choice, independence, participation, and privacy.²² The staff must treat the resident with courtesy, respect, and “with full recognition of personal dignity and individuality”. The staff must provide residents with the opportunity to share in decision-making. In addition to promoting the continued social independence of the residents, the ALR must create an environment that combats institutionalization²³ by arranging for transportation to activities and services in the outside community.

G. Dignity²⁴

Residents have the right to maintain their personal dignity. The ALR must develop and enforce policies that prohibit and prevent abuse, whether by physical abuse, neglect or exploitation, of the residents. In addition to developing such a policy, the ALR must conduct a

²¹ See 44 DC Code 101.01 *et seq.*

²² *Id.* at 105.02. Any quotations in this paragraph refer to this section of the code.

²³ I use this term to cover the problems of loneliness, depression, dependence and boredom that can be present in any long-term care setting.

²⁴ D.C. Code §44-105.03; 105.09

thorough internal investigation of any abuse and report these results and actions taken to the Mayor. The ALR must also report any report of abuse to the Adult Protective Services Program as administered by the Family Services Administration of the Department of Human Development.²⁵

Central to personal dignity is the right to remain independent. Accordingly, *an ALR resident has the right to control his lifestyle*. This includes the unrestricted right to send correspondence, to maintain one's own possessions, and to receive visitors of his or her choice. This control also includes the right to participate in social and religious activities that are consistent with their interests.

H. Accommodation of Needs²⁶

Residents also have a right to the reasonable accommodation of their needs. In addition to the obligation of appropriate services dictated by the medical and mental needs of the resident, the ALR must accommodate the preferences of the resident to the extent allowed by their health and safety needs and those of other residents. Never, however, *should the ALR resort to any sort of restraints, either physical restraints or chemical sedatives, as part of the services offered*. Additionally, in cases where a resident's desires and the policies of the ALR are in conflict, the resident has a right to negotiate a shared responsibility agreement that can aid in reaching a satisfactory result.

Foremost among these needs is the right to age in place. Changes in the resident's conditions should not necessarily require the transfer of the resident. To achieve this right, the

²⁵ It is in the reporting and investigation of these allegations that regulations to enforce the law are most needed. As of now, ALR's can only be pressured into self-policing by the resident, a tenant's association, or other third-party advocates, such as the Ombudsman Program.

²⁶ *Id.* at 105.04

resident has the ability to contract with providers of the additional medical services that are beyond the capabilities of the ALR. This includes social services, home health, nursing and rehabilitative services. Aging in place also requires the resident to have the ability to refuse service after the ALR explains the risks and comes to a shared responsibility agreement with the resident.

I. Representation and Resolution of Grievances and Complaints²⁷

Critical to the dignity of a resident is the ability to bring their concerns to the administration and have the right to collaborate with the administration to reach a resolution of these matters without fear of retaliation. To achieve this goal, the ALR has an obligation to have a complaint procedure in place. Before moving in, the prospective resident ought to inquire about the complaint procedures in place, and after moving in, the ALR must provide the resident access to the procedures in place to resolve complaints. When a complaint is filed by the resident, the ALR must keep detailed records of both the complaint and the steps taking to resolve the complaint. In cases where the ALR administration is coercing the resident or retaliating against the resident for complaining, the resident has a right to address his or her complaints to the Ombudsman Program. The Ombudsman Program has the right to review the procedures of an ALR and to investigate and resolve resident complaints. To further protect resident rights, the residents of an ALR have the right to organize and form a Resident's Council or other organization to discuss and propose solutions to resident concerns. Both the Ombudsman program and the formation of Resident Councils can provide outside sources to equalize the balance of power between the ALR administration and the residents.

²⁷ *Id.* at 105.05

If a resident is incapable of acting on his or her own behalf, the resident should be able to designate a surrogate to make decisions and bring complaints on the resident's behalf. If a surrogate is required for a resident, that surrogate must have access to all relevant information and be kept informed regarding decisions that require the consent of the resident. Additionally, the surrogate should be able to act on the behalf of the resident and to coordinate with the ALR to resolve any disagreements.

J. Privacy and Confidentiality²⁸

Also critical to the dignity of a resident is the ability to maintain his or her privacy. However, to provide adequate services to the resident and to develop an individualized service plan, the ALR must have access to the medical records of the resident. The unauthorized disclosure of health information has the great potential to embarrass a resident, and the disclosure of the financial information needed for billing could open the resident to financial exploitation, such as identity theft.

Thus, the ALR and the resident must form a relationship where the resident can trust that his or her personal information is secure. To maintain this trust, the resident has a right to confidential records that are shared only as provided for by federal and state law. A resident should inquire under what circumstances and to whom his or her medical information will be released and that this policy adequately protects the privacy of the resident and the right of the family to protect the identity of the resident.

K. Full Disclosure and Notice of Rights²⁹

²⁸ *Id.* at 105.06

Finally, dignity is achieved by the resident's awareness of the policies that govern his or her stay. Thus, the ALR must prominently post the rights of the residents in their building and also provide a copy of the resident's rights to the resident upon moving in and after any change in the resident's level of care or when new services are available. Additionally, the ALR must disclose all contract terms and billing practices. These terms and practices must be fair and reasonable.

The more information a resident has regarding the policies and procedures of an ALR the better a resident can evaluate prospective ALRs and protect his or her rights after the resident moves in. ALRs should strive to be transparent in their operations. An ALR with a policy of full disclosure will take a large step toward avoiding disputes and in protecting the health, safety and rights of a resident.

III. Conclusion

While the District of Columbia has yet to issue regulations licensing ALRs³⁰, prospective residents can help promote voluntary compliance with the D.C. Code by selecting only P-ALRs that have implemented the protections provided by the statute. This economic pressure can help to ensure that the rights of residents are upheld since non-compliant P-ALRs would be forced to add or increase these resident protections to remain competitive in the marketplace. If prospective residents inform themselves of their rights under the law, they can use their economic leverage to foster a high level of care in the District of Columbia. The DC government is not free from its obligations to enforce the laws, however, and it is critical that the District

²⁹ D.C. Code §§44-105.07-08

³⁰ While creating this document, the D.C. Department of Health has announced that Assisted Living Regulations will be proposed no later than September 2007. The D.C. Long-Term Care Ombudsman Program will revisit and publicly report the progress made by city officials in the upcoming years.

implement regulations and licensing procedures to add government oversight. Once this statute is implemented, the District has the opportunity to be a national leader in the protection of residents' rights. In the meantime, educating residents about the responsibilities of facilities and of their own rights to autonomy and dignity will place economic pressure on the P-ALRs and provide the best insurance for a high level of assisted living care for DC residents.

VI. Definitions:

- (1) "Activities of Daily Living" or "ADLs" means activities including eating, bathing, toileting, grooming, dressing, undressing, mobility, and in place transfers.
- (2) "Assisted Living Residence" or "ALR" means an entity, whether public or private, for profit or not for profit that combines housing, health, and personalized assistance, in accordance to individually developed service plans, for the support of individuals who are unrelated to the owner or operator of the entity.
- (3) "Healthcare practitioner" means a person licensed as a physician or nurse practitioner.
- (4) "Individualized Service Plan" or "ISP" means a written plan developed by the provider, in conjunction with the resident and his or her surrogate, if appropriate, which identifies, among other things, services that the licensee will provide or arrange for the resident.
- (5) "Instrumental Activities of Daily Living" or "IADL" means daily activities such as housekeeping, meal preparation, shopping, money management and travel outside the ALR.
- (6) "Proposed Assisted Living Residence" or "P-ALR" refers to an ALR type program not yet able to be certified.

V. Acknowledgement:

Steve Michael Clark, student intern with Legal Counsel for the Elderly, law intern with American University, Second Year; Joan E. Joseph, MEd in Gerontology and MS in Therapeutic Recreation from Columbia University; Mary Ann Parker, Attorney, Office of the D.C. Long-Term Care Ombudsman Program; Lydia Williams, Board and Care Ombudsman, Office of the D.C. Long-Term Care Ombudsman Program, and Gerald Kasunic, Director, Office of the D.C. Long-Term Care Ombudsman. Without a team approach and their specific knowledge and experience in the assisted living arena, this project would not have been possible.