

Vulnerable and Unprotected: The Status of Elderly & Disabled Assisted Living Residents in New York State

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Background

Assisted living is the fastest growing type of senior housing. In recent years it has increasingly been seen as an attractive option for people who need or desire the care and monitoring available in a residential setting but want to avoid the institutionalization that most nursing homes provide. Unfortunately, while there are many people who are happy with the quality of life and quality of care in their assisted living, there are increasing reports of problems, some of them quite serious.

Compounding these issues is the fact that there are two very different types of programs labeled "assisted living" in New York State. There is the licensed assisted living residence, catering mainly to the private market, and the Assisted Living Program (ALP), for nursing home eligible individuals on Medicaid. These are in addition to the many licensed adult homes that many consider assisted living which cater to both the private market and individuals on social security. In addition to confusing consumers, this results in a two-tiered system: one for the moderately wealthy and one for the poor or those in the middle class. This two-tiered system is apparent in the differences in terms of amenities and care that consumers can expect, as well as in the laws and minimum standards that apply to the different types of residences.

An overarching problem for consumers is that many of New York's assisted living communities (of all types) do not fulfill the fundamental quality of life principles of assisted living – to provide residents with a good quality of life founded on resident choice, autonomy and self-direction. In fact, though the residences that cater to the private market might appear homelike at first glance, these facilities often wind up furnishing the same kind of institutional lifestyle provided in the traditional nursing home, denying residents choice, autonomy and self-direction.

Increasingly, in New York and across the country, there are problems relating to inappropriate care in assisted living. From the elderly individual with Alzheimer's who turns to an assisted living community for the promise of a safe living environment and professional monitoring but wanders away unnoticed and is hit by a car (because the facility did not maintain sufficient trained staff or was not equipped to manage common issues like wandering) to the diabetic who needs professional monitoring and help with medications, but loses a limb (or even her life) because her assisted living did not employ a professional nurse to properly monitor her and administer medications, elderly and disabled residents are being harmed because of a lack of sufficient care standards.

In addition, as the assisted living industry has grown and become more sophisticated, so too have the ways in which consumers can be taken disadvantage of financially. For example, a few years ago, as NY Attorney General, Eliot Spitzer successfully went after a provider in court for charging exorbitant "community fees" for services that residents were already paying for as part of their other resident fees. While this specific practice was stopped, providers can easily circumvent the ruling simply by creating an exorbitant community fee that does not include services already enumerated in another resident charge. Because residency agreements are typically drafted by the industry, with limited or no means for a potential resident to negotiate, they generally function as contracts of adhesion - the resident can take it or leave it, but they must take it if they want to enter into the community. These contracts are subject to few restrictions or safeguards; providers virtually have carte blanche to put in nonrefundable fees, restrict refunds if a resident chooses to move, is evicted or even dies, or require that the resident agree to a "pre-dispute arbitration" provision. These provisions, which the industry has identified as a major priority¹, require a resident and his/her family to give up their right to make a court claim against the facility for any reason. This means that if the resident is harmed or abused in the future, no matter how egregious, he or she cannot take the matter to court and the facility can never be held legally liable. Any claim must go for arbitration.

Why Are There Still Significant Problems For Elderly & Disabled New Yorkers in Assisted Living?

The advent of New York's assisted living law in 2004² was supposed to put an end to these major issues. Following years of significant and seemingly substantive progress in assisted living policy in New York State, as the law was developed, negotiated and passed and regulations were developed and promulgated, the movement toward meaningful consumer protections and an end to the two-tiered system came to a grinding halt at the end of 2009 when the providers and their lobbying associations

¹ See, "Arbitration Best Practices for Assisted Living Communities, Assisted Living Federation of America" (<http://www.alfa.org/alfa/NewsBot.asp?MODE=VIEW&ID=1060&SnID=1399539740>).

² New York State Public Health Law Article 46-B (http://www.health.state.ny.us/facilities/assisted_living/docs/article-46.pdf).

won their lawsuits that overturned key protections in the assisted living regulations.³ [During the life of the lawsuits, discussions on other issues (such as making assisted living affordable) were put on hold by the state.] Though these regulations were developed after four years of public meetings of the state’s advisory council and two rounds of public comment (all with significant provider input), and with significant compromise throughout that ensured protection of providers’ perceived financial interests, the industry still objected to what remained.

From a consumer perspective, this “win” in court by providers will likely be a major, long term loss for the public. Although the suit only affects the licensed assisted living residences, it effectively stopped discussion of putting in key requirements for programs for low income consumers of assisted living (ALP residents). Following are the key issues identified by LTCCC that will affect consumer safety, quality of life and financial protections in 2010 and beyond. Some of the issues are the direct result of the outcome of the providers’ lawsuits, while others are simply the result of the overall lack of meaningful standards on either the state or federal levels (which the provider lawsuits have, unfortunately, exacerbated).

Key Consumer Safety, Quality of Life and Financial Protection Issues

- No Professional Nurse Required, Even for Facilities With Special Certification to Provide Alzheimer’s/Dementia Care or ‘Aging in Place’

Studies have indicated that the presence of professional nurse staffing in an assisted living facility has a major positive effect on resident health outcomes.⁴ Despite this, in New York, providers succeeded in influencing the development of the regulations so that the final regulations for licensed assisted living residences had no requirement for an RN on staff for a “basic” licensed assisted living residence and only required a facility to have an RN if they are getting special certification to care for people with significant dementia or for those who are “aging in place” (staying in the assisted living as they become increasingly frail and in need of a nursing home level of care). Furthermore, the regulations permitted facilities to have the RN on a full-time basis (no evening, night or weekend coverage) and employ him or her in a non-practicing capacity, such as in an administrative position.

In their lawsuits, the providers succeeded in removing this one safeguard considered essential by LTCCC and many others concerned about resident safety. Now, as the law stands, no licensed assisted living residence– even those holding themselves out as providing special care for dementia and safety for people who wish to age in place and

³ See LTCCC’s dedicated website page on legal and policy developments in NY State at <http://assisted-living411.org/nyassistedliving.php>.

⁴ See, for example, “Effects of Facility Characteristics on Departures From Assisted Living: Results From a National Study,” *The Gerontologist* (2003) 43 (5): 690-696. The authors found that the presence of a full time RN in an assisted living facility resulted in decreased likelihood that resident would go to a nursing home.

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avoid a nursing home as they become more frail – is required to have a licensed caregiver on their staff at any time. This will clearly affect any future discussions on what is needed as we work towards expanding affordable assisted living options.

Though NY Department of Health officials have assured us that facility staffing will still have to be sufficient to meet the needs of each resident’s service plan, LTCCC is deeply concerned that, without specific requirements for professional staff, assisted living residents will now be at risk. The state has created places for New Yorkers to “age in place” (stay in the facility as they become more frail) but will they be safe? Residents who are told they can age in place or are promised safe and appropriate care when they have dementia have lost a critical safeguard for insuring that those promises will be kept.

- A Two- Tiered System: The Medicaid Assisted Living Program and the Assisted Living Residences

The Medicaid Assisted Living Program (ALP) has been around in New York for many years. Since assisted living in New York State mainly caters to a private market, it is (arguably) the best way for people on Medicaid who qualify for nursing home care but could be safely cared for in a less institutional setting to avoid nursing home placement and access the benefits of assisted living. Unfortunately, though there are a number of ALP facilities that provide good quality of life and care for their residents, in too many cases the ALP program has functioned as a means by which adult homes can access much higher reimbursement rates (than the normal licensed adult home rate) without having to show that they are meeting any quality of life criteria associated with assisted living, such as resident dignity and autonomy, a home-like environment, respect for individual preferences, etc... or by classifying residents who are not eligible (do not require nursing home services) as ALP residents. Because ALP providers were never required to meet standards beyond those of the traditional licensed adult home (many of which provide scandalously poor conditions for their residents), consumers are at the mercy of individual providers as to whether or not their facility will provide (or not provide) the home-like environment, quality of life and choices that we consider to be the hallmarks of assisted living. In addition, many of these residents would also benefit from an on-site professional nurse for monitoring, but adult home regulations do not require this.

Rather than dealing with the need to develop affordable assisted living that is consistent with the 2004 assisted living law (and because adult home providers lobbied successfully), the state decided to greatly expand the number of ALP “slots.” With the recent developments in assisted living law and regulation (discussed above) and the state moving forward with plans to increase the number of ALP slots, the disparity in this two-tiered system of assisted living is bound to only get worse. Following the passage of the 2004 law, LTCCC conducted substantial research and

analyses into affordable assisted living.⁵ One of our fundamental recommendations to New York State, as it was considering how to make assisted living affordable through Medicaid, was that, now that the state has legally defined assisted living and established basic criteria, policymakers should first identify a model of assisted living that it wishes to support before putting any more taxpayer funds into a system (the ALP) that was serving many people very poorly. Unfortunately, the state opted instead to perpetuate and expand the ALP and is now moving forward with a plan to increase the number of ALP slots by 6000 over the next five years, while reducing the number of nursing home beds in the state by the same amount. There is nothing that requires that these slots be any better than the nursing home slots they are replacing. In fact, many nursing home facilities are expressing interest in following this money by converting their nursing home slot to an assisted living slot. Thus, despite the mandate that the state provide care in less restrictive and institutional settings and the promulgation of a new assisted living law, the reality is that, without a major change to law or regulation, there is little reason to believe that life for the ALP consumer will be appreciatively better or that real assisted living will be made affordable for the majority of citizens who are in lower and middle income brackets.

- Affordable Assisted Living in New York is at a Stand Still

Ironically, one of the key requirements of the 2004 assisted living law was the mandate that the state take concrete steps toward increasing the availability of affordable assisted living, i.e., assisted living that is accessible to lower and middle income individuals. The state's assisted living advisory council was charged with developing recommendations on how the state can make access to assisted living a reality for lower and middle income New Yorkers. Unfortunately this task has been on hold for years, while the council worked on developing regulations and the council itself has been largely moribund for the last two years as the regulations were promulgated by the Department of Health and then the provider sued to have key provisions overturned. In the meantime, lower and middle income New Yorkers continue to be funneled into the Assisted Living Program (ALP, discussed above), if they have access to Medicaid benefits, while those who do not qualify for Medicaid are on their own. If they need residential care services and cannot afford to pay for assisted living on their own, they can either try to find a decent ALP that has availability or, as is most often the case, wind up being placed in a nursing home.

- The Assisted Living Marketplace is a Mess

One of the goals of the 2004 assisted living law was to make the assisted living marketplace easier to understand and navigate for consumers. At that time, consumers looking for assisted living faced a variety of confusing options: from licensed adult homes and enriched housing (which range from terrible places that had become notorious for providing inhumane conditions to very nice (generally expensive) places that provide a more home-like environment) to unlicensed facilities

⁵ *Making Affordable Assisted Living A Reality*, Long Term Care Community Coalition, 2008 (http://www.assisted-living411.org/documents/WHITEPAPER_001.pdf).

that provide a home and care (often significant care, such as dementia services) to the frail elderly and disabled without any state standards or oversight whatsoever.

Unfortunately, the law and regulations that followed, especially after the result of the provider industry's lawsuits, have made the marketplace even more confusing and unfair for consumers. The law required that all facilities must be licensed under the state's pre-existing adult home law (which, as discussed above, has created an industry that often provides very poor care and quality of life). From there, the assisted living marketplace becomes very complex; it will likely be very difficult for consumers and their families to understand what services they will be getting, what standards will apply and what can be paid for with public funds (or must be covered privately). Once a facility has become licensed under New York's old adult home law and regulation, if it wants to provide "basic" assisted living it can then go for assisted living licensure, with additional criteria, and then call itself "assisted living." A licensed assisted living residence (ALR) that elects to provide aging in place (retain residents who become more dependent) must apply for and receive an enhanced assisted living certificate. Any residence that advertises or markets itself as serving individuals with special needs, including, but not limited to, individuals with dementia or cognitive impairments, must apply for and receive certification as a special needs assisted living residence. ALRs may apply for enhanced and/or special needs assisted living certification for either all or a portion of their licensed beds. And, of course, the ALP program is still functioning as another option, with different rules and regulations.

This range of types of assisted living will likely be extremely confusing to the average consumer who is not fully versed in all of these different types of options and will probably be mostly learning about the lifestyle and services offered by a facility from the facility's sales staff. This problem will only be compounded by the looseness of the regulatory requirements as they currently exist. While a licensed assisted living residence has to obtain special certifications for aging in place and/or special needs, the law does not require any specific number or percentage of slots be certified for aging in place or special needs. Thus, for example, a consumer could enter a facility with a low level of dementia because it has a special needs certificate only to find a year or two later that the facility only certified a few slots for special needs and that those slots are now taken and the person must leave the facility. Where is this resident to go now? What will the impact of this upheaval be for him or her?

In addition, the providers' "win" in their lawsuits have put the residents who do find a place in special needs or enhanced needs at serious risk due to the removal of the requirement that a facility with special or enhanced needs have a registered nurse on staff on at least a full time basis. LTCCC and others thought this was crucial to ensure that there was at least one professionally licensed caregiver on the staff, capable of providing some level of professional monitoring and assessment of these especially frail residents if necessary. With the removal of this requirement, assisted living residences that are caring for people with significant, increasing frailty and/or significant, increasing dementia have no requirement for professional staffing. This "win" also exacerbates the two-tiered system. Those assisted living residences

catering to the rich and moderately wealthy already often have registered nurses on staff; those that cater to the less wealthy or the lower and middle class do not and now will not have to.

Recommendations for State Leaders and Consumers

Recommendations for State Leaders:

- **Move forward on meaningful and equitable affordable assisted living for New Yorkers.** Increasingly in New York State and nationwide, assisted living is seen as an attractive option for those who need or desire long term care in a residential setting. Unfortunately, the state's only affordable assisted living option, the ALP, does not embody current conceptions of assisted living as a place that provides a home-like environment and encourages resident autonomy and independence. The state should either revise the adult home law and regulations to reflect current expectations of assisted living or stop expanding the ALP and identify a model of assisted living that is desirable and meets meaningful criteria for resident services and lifestyle to put public funding into.
- **Vigorously enforce current regulatory requirements, particularly for staffing.** With the loss of the requirement for a professional nurse for facilities with special or enhanced needs certification, it will be especially crucial that the Department of Health (DOH), as well as the other relevant state agencies, ensure that every facility is staffed with sufficient staff, having appropriate training and skills, to meet the needs laid out in each resident's service plan. For instance, if a resident needs to have his or her medication administered, DOH must ensure that the facility is employing an RN to do this, as required by New York's Nurse Practice Act. And the Office of Medicaid Inspector General and NY Attorney General's Medicaid Fraud Control Unit should conduct appropriate monitoring and "data mining" to ensure that this legal requirement is being followed by providers that receive any type of government funding. Vigorous enforcement by DOH is especially crucial, since it is on the front lines of ensuring that every resident's needs, as identified in their care plan, is met appropriately.
- **Ensure adequate funding to support appropriate DOH and Long Term Care Ombudsman staffing levels and training.** Now that the assisted living regulations are in place, more and more residences will be completing the licensing process, including certification for facilities providing special needs and enhanced care, and will thus come under DOH and Ombudsman oversight and monitoring. Assisted living standards, already weakened by the providers' lawsuits, will be rendered meaningless if there is not sufficient survey staff at DOH and Long Term Care Ombudsmen in the counties that monitoring facilities and holding them accountable. New York and other states are currently facing severe budgetary crises just as the need for these agencies is increasing. Despite these fiscal challenges, it is crucial that the state at least maintain levels of staffing for oversight and enforcement in proportion to the numbers of

facilities and residents that it is responsible for. Simply put, it will be catastrophic for residents if the number of state oversight and monitoring staff does not keep pace with the number of licensed facilities and residents in those facilities.

Recommendations for Assisted Living Consumers:

- **Buyer Beware!** As discussed above, current and prospective assisted living residents, and their families, now face a marketplace that is complex and confusing and minimum standards that have been significantly weakened as a result of the provider industry's lawsuits. It is thus crucial to be a knowledgeable and critical consumer. What are the credentials of the staffing of a facility you are considering and what are their staffing levels? To what extent do they provide care for dementia or "aging in place"? Under what conditions will they allow someone to remain in the facility and under what conditions will they require the individual to move out? If they are certified to provide dementia care or aging in place, how many slots do they have? What are the qualifications of the staff providing these service? What are your rights and obligations under the residency contract? These are but some of the important questions to ask about a facility you are considering. [For more information on important quality of life issues and considerations for consumers, go to www.assisted-living411.org for a free copy of our guidebook, "Thinking of Moving to an Assisted Living Residence?"]
- **Take Action.** Since assisted living licensure is new in New York, and facilities are just becoming certified for enhanced and special needs, it is crucial that consumers and their loved ones speak out about any problems that they see. Are residents in their facility receiving appropriate care for their needs? Is the training and accreditation of staff appropriate (i.e., Are only RNs administering medication? Are people with significant dementia receiving appropriate professional monitoring and care?). Speak out if you or someone you know is not receiving appropriate care: inform the NYS Department of Health and the Long Term Care Ombudsman in your county. Email info@ltccc.org to tell us about issues you are seeing. We use information we receive from residents, families, Long Term Care Ombudsman and the public to inform state leaders and work to improve policies and oversight. [Please note that we are not equipped with the staff to help individuals with specific problems.] By speaking out about problems, you can make a difference!