

HOT TOPICS IN ELDER LAW:

Long Term Care Options, Residents' Rights, and the "Tsunami" of Nursing Home Discharges

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The burgeoning population of older adults and the increased longevity of many younger people with significant disabilities will necessitate a vast expansion of long term supports and services. In 2015, more than 8 million Americans received services from home health agencies, nursing homes, hospices, assisted living facilities, and adult day centers.¹ That number fails to count the legion of people who received informal—but often extensive—assistance with health care and daily activities from friends and families.² Adults age 65 and over face a 68% chance of either needing assistance with at least two activities of daily living or becoming cognitively impaired during their lifetimes.³ By 2050, the number of individuals receiving paid long term care services is likely to reach 27 million.⁴

Although long term care used to be synonymous with nursing home care, there are now a variety of settings and services to meet individuals' needs and preferences. These options can be obtained through both public and private funding. The array of services and supports is not inevitably a continuum in which older adults move through less restrictive and expensive options until they end up at their final stop—the nursing home. In fact, more older adults are choosing to “age in place” or utilize a variety of options to meet their needs at different times in their lives. Moreover, nursing facility transition programs have assisted even long stay and very elderly nursing home residents to return with appropriate supports to their homes and communities.

Although nursing homes remain a Medicaid entitlement while home and community based waiver programs are optional under Medicaid, states across the country have been engaging in “rebalancing” efforts to shift more funding to non-institutional long term care options. The results vary; while one state spends below 15% of its long term care budget on home and community based care, another state spends more than 65% of its state long term care budget on non-institutional options.⁵

The significant expansion of home and community based services is due in part to consumer demand and state efforts to control high nursing facility expenditures. It also results in large

¹ Centers for Disease Control and Prevention Long-Term Care Services 38 (2013).

² 5.8 to 7 million informal caregivers provide assistance to individuals 65 and older who need assistance with everyday activities. See Spector, W.D. et al, Agency for Healthcare Law and Policy, The characteristics of long-term care users 2001 and National Alliance for Caregiving and AARP, Caregiving in the U.S. (2009).

³ AARP, Beyond 50: A Report to the Nation on Independent Living and Disability (2003).

⁴ U.S. Dep't of Health and Human Services and U.S. Dep't. of Labor, The future supply of long-term care workers in relation to the aging baby boomer generation: Report to Congress (2003).

⁵ AARP, Long Term Services and Supports State Scorecard (2017), <http://www.longtermscorecard.org/2017-scorecard>.

part from the 1999 U.S. Supreme Court decision in *Olmstead v. L.C.*⁶ In that case, the Court held that unjustified segregation of persons with disabilities constitutes discrimination in violation of Title II of the Americans with Disabilities Act.⁷ The Court explained that “institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable of or unworthy of participating in community life” and that “confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.”⁸

When choosing long term care options, older adults want to be assured that their choices will be honored, that they will be treated with dignity and respect, and that they will receive affordable, quality care for as long as they require assistance. Since long term care encompasses a broad array of medical, social, personal, and, sometimes, housing services, older adults want to ensure they will have an excellent quality of life as well as high quality care.

Statutes and regulations governing long term care options support consumers’ goals to varying degrees. The federal Nursing Home Reform Act,⁹ enacted in 1987, contains an astonishingly detailed and sweeping blueprint for quality of care and life in the nation’s nursing homes and includes extensive residents’ rights. State laws may provide for additional rights for nursing home residents. Assisted living options are not regulated by federal law and the terminology used to identify these facilities varies from state to state. States also differ in the types of facilities that have to be licensed and the degree of oversight these facilities receive. Most regulated facilities are required to honor enumerated residents’ rights but these provisions are likely not as broad and detailed as nursing facility requirements. Individuals receiving home and community based care tend to have far fewer protections and less oversight. Although grounded in federal Medicaid law, each state home and community based “waiver” program is negotiated with the federal government and may have different eligibility criteria and services and some variation in beneficiary protections.

Among the rights that are protected under federal law for nursing home residents are rights to self-determination and accommodation of individual needs and preferences, rights to information about care and services, the right to receive or refuse care, the right to privacy, and the right to be treated with dignity and respect.¹⁰ In 2016, the federal regulations governing nursing facilities were revised and included additional provisions related to honoring resident choices; protecting residents from abuse, neglect, and exploitation; training requirements for staff, volunteers, and contract employees on issues including dementia and abuse; and additional protections against involuntary discharges and resident “dumping.” These rights are enforced through extensive annual surveys of nursing facilities that determine facilities’ compliance with federal and state requirements and complaint surveys in response to alleged violations. These rights may also be enforceable through contract actions arising from nursing facility admission contracts which may incorporate provisions related to resident rights or through other legal actions.

⁶ 527 U.S. 581 (1999).

⁷ *Id.* at 583.

⁸ *Id.*

⁹ 42 U.S.C. §1396r(b)(4) and 42 U.S.C. §1395i-3(b)(4)

¹⁰ 42 C.F.R. §483.10

Nursing facility involuntary discharges (evictions) are among the most frequent concerns residents raise with representatives of the State Long Term Care Ombudsman program who are funded under the Older Americans Act¹¹ to advocate for residents. In addition to the data compiled by State Ombudsman programs, anecdotally, advocates are reporting a steady increase in involuntary discharges. While some residents receive formal notices and have an opportunity to appeal, other residents are persuaded by facility staff to leave the facility “voluntarily” or are unaware that they have a right to remain. Residents who are most likely to face involuntary discharge include those with mental illness or dementia, aggressive behaviors or a tendency to wander, payment issues, criminal histories, substance use issues, those who require time-consuming or expensive care, those who are perceived as complainers, and those who were homeless before entering the facility.

Involuntary discharges are particularly distressing for nursing facility residents because they lose their home, health care, familiar caregivers, roommates, community, and favorite activities. They usually have little or no input into where they are sent. If they are discharged to another nursing facility, it is often a lower quality facility farther away from their families and communities. And many residents are discharged to lower levels of care, homeless shelters, or the homes of relatives where there may be insufficient supports to care for them. Some residents experience serial discharges when the issues that resulted in their first discharge arise at the new facility.

Federal law provides extensive protections against involuntary discharges which are only permitted if it is necessary to meet the resident’s welfare, the resident’s condition improves sufficiently that he or she no longer needs nursing home care, the resident endangers the health and safety of others in the facility, the resident fails to pay (or have his or her stay paid for by Medicaid or Medicare) after reasonable and appropriate notice, or the facility closes.¹² In most cases, residents must receive 30 days advance written notice of the discharge including the place to which they are to be discharged, the date of discharge, the reason for the discharge, information on how to appeal, and information about available advocacy organizations.¹³ The facility must also document the reasons for discharge, prepare the resident for his or her departure, and retain the resident pending the outcome of any timely request to appeal the discharge.¹⁴ Decisions by administrative law judges on these appeals may in many states be appealed to local courts.

Unfortunately, advocates report that many state licensing agencies are lackluster in enforcing resident rights against involuntary discharges. Even when sanctions are imposed, some facilities assert they would prefer to pay the fine or accept the penalty rather than keep the resident. Residents may be afraid of retaliation if they appeal and are frequently not represented by counsel in administrative hearings or appeals. Moreover, administrative law judges who handle a variety of appeals may not have specialized training in long term care and residents rights. Professional guardians who are responsible for a significant segment of the nursing home

¹¹ 42 U.S.C. §§ 3001 et seq.

¹² 42 C.F.R. §483.15(c)

¹³ Id.

¹⁴ Id.

population may not be energetic in ensuring residents are a good match for a facility, collaborating with the facility about how to meet the resident's more challenging needs, ensuring that the facility is paid promptly and that eligibility for public benefits is maintained, or asserting residents' rights to avoid discharge. Any solution to stem the tide of improper nursing home evictions will require concerted effort by the state and federal governments, the courts and administrative hearing systems, resident advocates, professional guardians and other fiduciaries, and nursing facilities themselves to ensure residents benefit from the breadth and strength of the laws that are supposed to protect them.