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Policies to Protect Persons With Dementia in Assisted Living: Déjà Vu All Over Again?

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Continued growth in the number of individuals with dementia residing in assisted living (AL) raises concerns about their safety and protection. In this Forum, we review current AL practices relevant to residents with dementia and present a rationale for examining the government role in protecting these individuals within this context. Since public oversight of AL is currently a state prerogative, we assess states' regulatory activity across 3 domains closely related to safety and protection of persons with dementia: environmental features, staffing, and use of chemical restraints. We then step back to consider the state policymaking environment and assess the feasibility of developing a minimum standard of regulations from one state to the next. This Forum concludes with a historical comparison between the contemporary AL market and the nursing home care market prior to the Nursing Home Reform Act of 1987, and we discuss how an increased amount of federal interest could improve existing state efforts to protect persons with dementia residing in AL.

Key words: Residential care, Health policy, Federalism, Nursing Home Reform Act

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In the last 20 years, assisted living (AL) has become a principal component of the American residential long-term care system. The number of state-licensed AL facilities has grown from 16,000 in 1995 to more than 39,000 in 2010, and these facilities currently house as many as one million people (Mollica, Sims-Kastelein, & O'Keefe, 2007;

National Center for Assisted Living, 2014; Park-Lee et al., 2011). The National Center for Assisted Living suggests that the number of AL residents may be higher because AL is defined differently across states, and any count of state-licensed facilities may under-represent the actual market supply of AL. Indeed, facilities take on a variety of forms

including some small homes inhabited by fewer than 10 older adults, others embedded within large Continuing Care Retirement Communities which feature independent apartments and skilled nursing facilities (SNFs), and many standing alone on their own campus (Zimmerman & Sloane, 2007).

One reason for the phenomenal growth has been tied to how AL is distinguished from other residential long-term care facilities by promoting a philosophy of resident autonomy and independence. AL fosters a home-like environment where residents often import their own furniture and other personal effects and are encouraged to choose among services that best accommodate their needs and personal budgets (Wilson, 2007). AL has also benefitted from advances in medical technology, changes in Medicaid payment policies that recognize AL as an alternative place for residential long-term care, and changes in Medicare payment policies that have contributed to altering the resident mix among many SNFs (Levinson, 2012; Medicare Payment Advisory Commission, 2013). Individuals with less intensive care needs, who previously may have been qualified for admission into a SNF, increasingly have chosen to enter AL because the availability of services other than for post-acute medical care is relatively comparable and living environments are more attractive.

As the AL model has flourished, these facilities have become a primary place of residence for older adults with cognitive impairment. Current estimates suggest that up to 70% of AL residents experience a diagnosable form of Alzheimer's disease or another dementia, evenly divided across the mild, moderate, and severe stages of disease progression (National Center for Assisted Living, 2014; Zimmerman, Sloane, & Reed, 2014). At least half of these residents exhibit affective disturbances, such as depression; problematic behaviors, such as wandering and inappropriate aggression; and disrupted thinking processes, including visual and auditory hallucinations (Leroi et al., 2007).

Quality of Life for Persons With Dementia in AL Facilities

Recognizing the unique challenges presented by the growing number of residents with dementia, an increasing number of AL facilities offer special care units and dementia-specific services (Zimmerman & Sloane, 2007). These units often feature modified environments including exit controls, safety accommodations, and other designs that promote security and safety; employ a comparably higher number of staff who have completed training in dementia; and offer specially designed services such as medication management. Targeted dementia care has been associated with improved individual outcomes such as reduced

depression, better medication adherence, and decreased emergency room use (Zimmerman et al., 2005). However, most AL residents with moderate or severe dementia do not live in special care units or receive any type of targeted care (Zimmerman et al., 2014).

Elder abuse increasingly has been observed among persons with dementia (Dong, 2014; Dong, Chen, & Simon, 2014), and evidence suggests that an unconscionable number of persons with dementia in AL experience some form of neglect, abuse, or harm. Castle, Wagner, Sonon, and Ferguson-Rome (2012) surveyed 572 AL facility administrators and 3,620 direct care workers (DCWs) and found the majority (54%) of DCWs reported having observed other staff taking shortcuts in completing work assignments that place residents at risk for neglect or harm. The majority of survey respondents also indicated that facility leadership pays little attention to safety issues, does not provide any formal staff training concerning resident safety, nor facilitate any sort of reporting system that could help identify cases of neglect, abuse, or harm. Castle and his colleagues surmised that the safety culture in AL is low and not an administrative priority; with the potential for neglect of residents with dementia as high.

Castle (2013) then examined the incidence of explicit acts of elder abuse in AL that could result in harm and/or contribute to decreases in resident health and welfare. Using data from a nationally representative survey of 12,555 DCWs, Castle calculated that the annual incidence of verbal abuse was 13%, physical abuse reached 7%, and more than 3% of residents may have experienced some sort of harm. Since the AL industry serves almost a million people, this suggests that tens of thousands of AL residents annually experience harm or physical abuse, while hundreds of thousands may suffer verbal abuse.

Others have suggested these rates are higher (Cooper et al., 2009; Wigglesworth et al., 2010). The long-term care ombudsman program reported that abuse in AL is commonly reported (Administration on Aging, 2006), and Dyer, Connolly, and McFeeley (2002) found that residents with dementia are more likely to be abused than persons without dementia. Still, with absence of a national standard or corresponding surveillance effort to authenticate claims of neglect or abuse, it is difficult to make more precise calculations.

A closer examination of a few select individual incidents offers another way to demonstrate how this issue has become a matter of public concern. In 2013, a facility in San Diego was exposed for overmedicating its residents, neglecting them, and not providing proper nutrition (McDonald, 2013). In 2014, an 87-year-old man with dementia died of hypothermia in the parking lot of a New Jersey AL facility after wandering away from the facility (NBC10.com Staff, 2014). In a particularly disturbing incident, an AL resident

with Alzheimer's disease in Florida was torn apart by an alligator after wandering away from the assisted living facility (ALF) ([Florida Committee on Health Regulation, 2011](#)). Since AL has largely been marketed as a private pay, consumer-driven alternative to nursing facilities, it is incomprehensible that residents receive anything less than the best of care ([Castle, 2013](#)). AL appears to be failing when it comes to protecting residents with dementia, and an examination of the public policy response is warranted.

The Need for Government Oversight of AL

Arguably, such an examination is required by federal law. In passing the Americans with Disabilities Act (ADA) in 1990 (42 U.S.C.A. § 12102), the U.S. Congress assured equal protections guaranteed under the Fourteenth Amendment were extended to all persons with disabilities including those with degenerative neurological conditions ([Rempfer, 1997](#); 42 U.S.C.A. § 12101). Through the ADA, the federal government specifically requires businesses and nonprofit service providers including AL facilities, day care centers, hotels, and recreational facilities to comply with basic requirements that prohibit unequal treatment of "protected classes" such as persons with dementia (42 U.S.C.A. § 12182). AL also has been included as a place of service subject to the Fair Housing Act (FHA), and for nearly 10 years, AL has been required to provide safe and accessible care settings for their residents ([National Senior Citizens Law Center, 2005](#); [U.S. Securities and Exchange Commission \[SEC\], 2006](#)).

The need to extend equal protection to persons with dementia in AL becomes particularly compelling as intellectual functions deteriorate to the point when individuals can no longer engage in reliable decision-making needed to self-direct care in the manner AL promotes as a philosophy ([Alzheimer's Association, 2009](#); [Bynum, 2014](#)). Persons with dementia should be protected from exploitation which may occur while executing a routine contract renewal featuring complex fee structures. Residents with dementia should be protected from neglect, abuse, and harm, especially as the capacity for self-care diminishes and responsibilities for an individual's well-being increasingly are assumed by DCWs. Environments should be safe and free of hazards that may not be known or recognized by persons with dementia. Staff should be sufficient in number and adequately trained as to provide programs and services that facilitate an individual's well-being. While ADA requirements are well-specified in some instances, such as the accommodations hotels must make for physically disabled guests ([U.S. Department of Justice, Civil Rights Division, 2014](#)), the systematic application of these requirements for AL residents with dementia appears lacking, despite the prevalence of dementia in AL.

State Legislative and Regulatory Activities

Historically, there has been limited federal involvement in the oversight of AL, and public responsibility for the protection of AL residents, including those with dementia, has been left to the states ([Assisted Living Workgroup, 2003](#); [Wilson, 2007](#)). While this sort of decentralized model of federalism is commonplace in American health policy because it is considered practical and responsive to state preferences, how this cooperative federalist arrangement impacts persons with dementia living in AL remains generally unexplored ([Cox, Eldridge-Houser, Hasken, & Temme, 2011](#); [U.S. Government Accountability Office \[GAO\], 2012](#)).

Most state AL policymaking efforts initially focused on definitions of facility licensure ([Kaskie & Kingsley, 2009](#)). Some states included AL in licensure categories with small board and care homes, while others classified AL as institutional facilities. Consequently, variation in AL policy activities reflect what states elect to address, how they actually choose to do so, and which authorities assume oversight responsibilities ([Mollica et al., 2007](#); [Zimmerman & Sloane, 2007](#)). Kaskie and Kingsley also reported that, when it comes to oversight, state surveillance efforts often were lacking staff support and rarely applied any significant penalties or sanctions.

With regard to regulations specifically addressing residents with dementia, [Kaskie and Kingsley \(2009\)](#) found only eight states that require a dementia-specific admission policy and three require a dementia-specific discharge policy. Despite the industry emphasis on consumer autonomy and the positive impact that the availability of public information has on the quality of care provided in nursing facilities ([Castle & Sonon, 2006](#)), [Kaskie and Kingsley \(2009\)](#) reported fewer than half of states had adopted any kind of public disclosure policies concerning the type of care provided to persons with dementia in AL.

In a more systematic effort to determine how state policy addresses the challenges in protecting the increasing number of residents with dementia in AL ([Mollica et al., 2007](#)), we focused our attention on those policies pertaining to environmental safety, staffing, and use of chemical restraints. Our objective was to evaluate these policies in terms of rigor, as their delineation is more likely to correspond with increased protection and more desirable resident outcomes ([Mollica et al., 2007](#)). Using LexisNexis and WestLaw, we identified all state statutes and regulations that addressed these issues in AL through 2013. We then rated the rigor of each type of AL policy in each state using an additive scale. A score of 0 indicates that the state has no policies, while higher scores indicate policies covering a greater range of required activity or other forms of

compliance. The statutes and regulations were identified and coded by the second and third authors, with any coding disagreements being decided by the first author. Such an approach to measuring a key qualitative aspect of state policy has become increasingly common (Kaskie, Knight, & Liebig, 2001; Woodruff et al., 2007).

Environmental Safety

Given their impact on outcomes such as resident elopement (Moore, Algase, Powell-Cope, Applegarth, & Beattie, 2009) and accidents, we evaluated policies concerning physical environments and other efforts to assure resident safety in AL. These included laws and regulations concerning secured perimeters, resident access to sharp and toxic objects, and additional fire alarms in dementia care units. We also considered policies that pertained to resident quality of life and identified state policies pertaining to visual accommodations (e.g., minimized glare), personalized rooms, and well-appointed common areas.

The average safety score in this domain was 3.06 on a scale from 1 to 10. Oregon, with a score of 9, had enacted the most delineated environment policies while 10 states including Arkansas and Wisconsin had no policies concerning the physical environment for AL residents with dementia. Thirty state regulations called for inhibited resident access to sharp, toxic, or hazardous materials. Facility administrators in Arizona had to ensure that all poisonous or toxic materials are labeled and kept in a locked location, separate from the food preparation areas. In addition, 10 states required licensed facilities to maintain secure perimeters (e.g., locked doors and gates) for residents with dementia. The regulations in Texas specified door type, locking mechanisms, and outdoor gate and fence features. Twelve states have policies focusing on the quality of life of persons with dementia that require certain lighting conditions, and seven of these states require that AL interiors maximize floor and stairwell surface contrasts. It is worth noting that, in contrast to SNFs, AL facilities have comparably few requirements concerning facility safety, even though nearly 70% of residents experience some form of dementia and are at greater risk for harm (42 CFR §483.75(d)(2)).

Staffing

Given how staff training and other requirements have been tied to the protection of SNF and AL residents alike (Castle, 2013; Harrington, Mullan, & Carrillo, 2004), we examined dementia staff training efforts and accounted the required number of training hours. States that required specific training topics (e.g., aggression control) and more hours of required training were considered to have more

rigorous policy than states without such explicit policies. We also evaluated policies requiring staff to pass criminal background checks, minimum resident-to-staff ratios, and the employment of medical professionals.

Among these, 38 states required some amount of special training in dementia for AL staff while 26 states required staff to pass criminal background checks. State staffing policy scores averaged 3.49 on a scale of 1–10. Georgia and Rhode Island had the highest scores, while seven other states had no dementia-specific staffing policies. The extent of training requirements varied considerably. Twenty-six states require staff to participate in dementia training programs, but only 17 specify a minimum amount of time ranging from 2 to 12 hr annually. In addition, 19 states required AL staff to complete dementia training upon hire, ranging from 2 hr in Massachusetts to 30 hr in Arkansas. Nine states established requirements concerning staff professions. For example, in Alabama, each specialty care AL must have at least one registered nurse available to assess residents with dementia and, in Arkansas, a registered nurse, psychologist, or physician must be on staff to coordinate and evaluate individual care plans for residents with dementia. In addition to criminal background check requirements, 24 states require an “adequate” number of staff be available to provide care to residents; 10 states went as far as to specify minimum staffing requirements. In Alabama, specialty care ALFs were required to have at least two dementia-trained staff members on duty at all times.

It is worth noting how none of these policies addressed the training of AL administrators. In contrast to nursing homes, in which administrators must obtain a state license (42 CFR §483.75(d)(2)), there is no certainty that AL administrators are sufficiently trained in issues concerning resident rights, wandering/egress control, or dealing with difficult behaviors as they pertain to residents with dementia. We recognize that AL administrators have ample opportunity to participate in continuing education and training but the lack of a minimum standard is striking. A management system where administrators are not required to be familiar with dementia care principles may not be as likely to assure DCWs receive the requisite amount of support in providing care to persons with dementia.

Freedom From Chemical Restraints

Given that Zimmerman et al. (2014) observed evidence of an unexpectedly high number of ALF residents with dementia being prescribed psychotropic medications and Castle, Handler, and Wagner (2014) found that staff training in medication management was reported as poor in 52% of the facilities surveyed, we considered state policies limiting the use of chemical restraints, sedatives, and psychotropic medications. States that prohibit the use of

chemical restraints under any circumstance were coded as having more rigorous policy environments than states that allow chemical restraints under certain conditions (e.g., physician authorization) and states without such policies. We also searched for policies which indicate residents have the right to be free of chemical restraints.

The AL medication policies averaged 1.61, with 10 states obtaining a maximum score of 3 by prohibiting the use of chemical restraints, sedatives, and psychotropic medication under any circumstance. Regulations in 24 states permitted to use chemical restraints when certain conditions were met, such as physician authorization or during an emergency. Thirteen states, including Utah and Hawaii, had no policies in place regulating the use of chemical restraints in AL. In some states, such as Arizona and Indiana, AL residents had the “right” to be free from chemical restraints. In Colorado, psychotropic medications were only prescribed with residents’ consent and request. This regulatory landscape contrasts with the increasing amount of federal attention being directed toward the resurgence of inappropriate antipsychotic prescribing practices in SNFs across the United States and the implementation of policies designed to minimize negative outcomes (Briesacher, Tjia, Field, Peterson, & Gurwitz, 2013; U.S. GAO, 2012).

The State of State AL Policies

Many states ($N = 40$) have taken at least one clear step to maintain a safe environment for persons with dementia, even more ($N = 44$) had enacted at least one policy concerning AL staff who work with residents with dementia while 30 states made some effort to regulate the use

of chemical restraints. However, the median level of effort and variation in policy activity offers a compelling exhibit of how the states have fallen short in successfully assuring that AL residents with dementia are protected from neglect, abuse, or harm (Figure 1).

For example, while 40 states have enacted some type of environment safety policy, only 15 of those received a score above 5 and no state reached the maximum of 10 points. Similarly, of the 44 states with some staffing requirement, only 14 states reached at least half of the total possible score with no state reaching the maximum value of 10. While 33 states regulated the use of chemical restraints in AL, only 10 completely prohibited their use. We found no particular state that stands far above any other in terms of providing an exhaustive and exemplary set of dementia-specific AL regulations concerning the physical environment, staffing, and use of chemical restraints (Table 1). In addition, states that have developed rigorous regulations in one area have not always developed rigorous regulations in another.

Such variations in state policy are not necessarily worrisome. In fact, this sort of public policy landscape could be lauded as a triumph of the new federalism, as states have elected to adopt different AL policies in response to local circumstances. Moreover, since we have not empirically established that such differences in environmental safety, staffing, and medication management policies actually cause individual residents to experience more positive or negative outcomes (Castle, 2013), some may argue that having few if any policies may be no different than having more. A research study contrasting resident outcomes in those states that prohibit all chemical restraints from those with less stringent approaches certainly would provide

Figure 1. Overall rigor of state dementia policies for assisted living: statutes and regulations through 2013.

Table 1. 2013 State ALF Policy Scores

State	Staffing (0–10)	Environment (0–10)	Clinical care (0–3)	Total score
AL	7	5	2	14
AK	0	0	3	3
AZ	4	2	3	9
AR	7	7	0	14
CA	4	3	1	8
CO	3	3	3	9
CT	4	0	2	6
DC	4	0	3	7
DE	3	1	1	5
FL	5	1	2	8
GA	8	6	3	17
HI	1	0	0	1
ID	4	5	2	11
IL	7	2	0	9
IN	1	3	2	6
IA	3	6	2	11
KS	2	2	0	4
KY	3	0	0	3
LA	4	7	2	13
ME	4	6	1	11
MD	4	1	3	8
MA	5	2	3	10
MI	0	0	0	0
MN	2	0	2	4
MS	7	7	3	17
MO	5	5	2	12
MT	2	4	1	7
NE	4	5	0	9
NV	4	4	2	10
NH	0	2	2	4
NJ	0	2	0	2
NM	3	5	3	11
NY	0	4	2	6
NC	6	4	0	10
ND	0	0	2	2
OH	4	2	2	8
OK	1	0	2	3
OR	3	9	0	12
PA	4	3	3	10
RI	8	3	2	13
SC	6	3	0	9
SD	1	3	2	6
TN	2	0	1	3
TX	5	7	2	14
UT	4	5	0	9
VT	3	3	2	8
VA	7	6	2	15
WA	3	4	3	10
WV	0	3	0	3
WI	1	0	2	3
WY	6	1	2	9

great insight about the role of state policies in improving resident care. Until such research is completed, some may maintain there is no urgency to establish a national

standard for state protection policies pertaining to AL residents with dementia.

Notwithstanding this need to generate more empirically derived guidance about AL policy, the issue of providing adequate protection remains. Given how many states impose few requirements to maintain a safe environment for residents with dementia, the horrific stories about AL residents who wander seem more plausible. In the absence of consistent staffing requirements across states, it becomes more clear why the results of a national survey revealed that less than half of AL staff could differentiate between the symptoms of dementia from the characteristics of normal aging, let alone communicate effectively with residents experiencing dementia (Gurnik & Hollis-Sawyer, 2003; Zimmerman et al., 2014). Similarly, the variation in state chemical restraint policies may provide insight into the large number of residents with dementia experiencing harmful outcomes corresponding with inappropriate prescribing (Hyde, Perez, & Forester, 2007).

We contend that a comprehensive, well-enforced set of dementia-specific regulations are necessary in ensuring the implementation of organizational AL practices that promote the provision of high-quality care to persons with dementia. At a minimum, states should establish a baseline for public standards concerning environmental safety, staffing, and chemical restraint use, and periodically revisit these regulations and related enforcement strategies to ensure that such policies coincide with evolving industry practices (Table 2).

Has the New Federalism Run Its Course?

We now turn our attention to whether the contemporary state policymaking landscape is likely to achieve this goal. In regard to AL policies generally, we find them to be comparatively more technical, and reliant on regulatory rule-making and discretionary budgeting to advance legislative intent. We also recognize these sorts of policies more often are influenced by narrowly defined interests relative to contextual factors such as population demand for AL, market supply of AL units, prevailing state political ideologies, or current policy climates (Kaskie et al., 2001; Imhof & Kaskie, 2008).

Within this framework of state policy making, the Alzheimer's Association, a highly visible national organization that advocates on behalf of persons with Alzheimer's and other forms of dementia, would seem likely to be involved with advancing AL policies. However, with the Association's 2014 public policy agenda to "rid the world of Alzheimer's disease," advocacy efforts largely have focused on increasing federal appropriations for basic research activities designed to identify and stop the progression of

Table 2. Recommended Minimum Standards for Dementia Policies in Assisted Living

Policy construct	Minimum features for effective policies
Staffing	Initial and ongoing staff training Using Arkansas' policy as a model, assisted living staff should be required to have at least 30 total hours of dementia-specific training upon hire in the following topics: • 1 hr of the facilities dementia policies • 3 hr of etiology, philosophy, and treatment of dementia • 2 hr on the stages of Alzheimer's disease and other forms of dementia • 4 hr on behavior management • 2 hr on use of physical restraints, wandering, and egress control • 2 hr on medication management • 4 hr on communication skills • 2 hr of prevention of staff burnout • 4 hr on activity programming • 3 hr on ADLs and Individual-Centered Care • 3 hr on assessments and creation of individual service plans • Assisted living staff should receive at least 8 hr of annual dementia-specific training in topics that include: - Development and new trends in the field of dementia therapy - Development of individual service plans - Communication skills - The stages of Alzheimer's disease and other forms of dementia Minimum staffing requirements 1. Before hire, all staff should undergo a criminal background check. 2. As required in Mississippi, all assisted living facilities should, at the very least, have a registered nurse on duty at all times. 3. At least, one staff member with dementia-specific training should be available for every 10 residents with dementia at all times.
Environment	Securing toxic and sharp objects As in Arizona, poisonous or toxic materials should be labeled and stored in a locked area separate from where food is prepared. Locked doors, secure perimeters, and outdoor wandering space Borrowing from Texas, all assisted living facilities should have outside areas of at least 850 sq. ft. enclosed in tall walls or fences to inhibit elopements. In addition, the facility should have electronically controlled locks that automatically unlock in times of emergency (e.g., fires). Facilities designed to maximize contrast and minimize glaring Since persons with dementia often have difficulties with vision, assisted living facilities, like those in Utah, should design an environment that minimizes glaring (e.g., low lighting) and maximizes the contrast between walls, furniture, flooring, and the stairs.
Chemical restraint use	Under no circumstances should a resident be sedated or chemically restrained.

Note: ADLs, activities of daily living.

Alzheimer's disease. In comparison, we found little evidence of state-level advocacy efforts focused on policies to protect persons with dementia who reside in AL ([Alzheimer's Association, 2014](#)).

Another possible interest that may work to establish and expand state AL policies consists of state ombudspersons and other individuals who are authorized to represent and protect all older persons, including those older adults living in residential care facilities and persons with dementia residing in AL ([Estes, Zulman, Goldberg, & Ogawa, 2001](#)). In fact, the critical role of ombudspersons in advancing protection policies for persons with dementia certainly was evident at the federally convened Assisted Living Workgroup (ALW). At this meeting, ombudspersons consistently were on record as supporting more rigorous regulations concerning

environmental safety, staff training, and medication management in AL; recognizing how similar efforts to expand federal and state SNF regulations were instrumental in improving resident quality of care. However, given how ombudsmen largely rely on support from state executive and legislative branches, and that support could be characterized as inconsistent at best ([Estes et al., 2001](#)), we are not certain how well this narrow interest can positively shape AL policies from one state to the next.

Alternatively, without a clearly defined constituency or public interest, the state policy landscape is more likely to be shaped by organizations and lobbyists representing those with financial interests in providing AL care. In one study, [Boehmke \(2008\)](#) linked the rigor of states' long-term care policy activity with the contributions made

by professional provider organizations to state legislators and governors. In regard to the AL industry, provider associations and lobbyists routinely proclaim how federal and state policy making is contrary to the spirit of AL. In fact, as a participating member in the ALW, the Assisted Living Federation of America (ALFA) cast the only dissenting vote against a seemingly uncontroversial recommendation that Congress fund long-term care ombudsmen at a level that allows them to perform their responsibilities under the Older Americans Act. When faced by a multi-billion dollar industry that publicly proclaims an aversion to policy making of any kind and demonstrates its influence by effectively blocking the advancement of a national policy recommendation endorsed by every other known interest in AL, it seems unlikely that each state government will be able to guarantee a minimum amount of public protection for persons with dementia in AL.

What about state courts with jurisdiction over AL? The high cost of defending against consumer litigation might spur providers to unilaterally improve care, or even to lessen their opposition to more stringent laws and regulations. However, after surveying the judicial landscape, we do not find much reason for optimism. While some providers have implemented internal organizational initiatives to improve quality of care and, thereby, have moved to reduce liability for incidents of neglect, abuse, and harm, other AL providers have taken a different tack. These providers use legal arbitration as a strategy to deflect liability or simply absorb the costs of litigating with the small number of residents who have sufficient resources to retain their own counsel and engage with AL corporate counsel (Thompson & Jones, 2013). By way of evidence, the Emeritus Corporation (2013), which recently was involved in a multi-million dollar settlement for failing to provide adequate care to AL residents, included the following statement in its annual disclosure to the Securities and Exchange Commission:

“[Emeritus] has been and is currently involved in *litigation and claims incidental to the conduct of its business that are comparable to other companies* in the senior living industry, including professional and general liability claims and regulatory and other governmental audits and investigations arising in the normal course of business. Certain claims and lawsuits allege large damage amounts and may require significant costs to defend and resolve. As a result, *we maintain a combination of self-insurance reserves and commercial insurance policies in amounts and with coverage and deductibles that we believe are adequate*, based on the nature and risks of our business, historical experience and industry standards.” (*Emphasis added*).

As long as such corporate legal strategies remain cost-effective relative to implementing protection policies, it is doubtful that minimum standards addressing the safety and welfare of AL residents with dementia can be advanced through the state courts.

A Call for Federal Policy

In 2001, the U.S. Senate Special Committee on Aging created the aforementioned ALW, a national stakeholder process that eventually produced a set of more than 100 recommendations for Congress to consider. More recently, in November of 2011, the Committee convened a hearing concerning the quality of care provided in AL. However, the U.S. Congress has failed to advance any national policy for AL, even as the number of residents with dementia has grown and it has become clear that facilities are unevenly equipped to protect them.

At this point, we find it useful to consider the similarity of circumstances in contemporary AL to those preceding the passage of the Nursing Home Reform Act (NHRA) of 1987 (Public Law 100-203; OBRA, 1987). At that time, in 1986, the Institute of Medicine (IOM, 1986) cast a spotlight on many shortcomings in providing care to SNF residents across the United States. SNF increasingly were providing care to persons with dementia and other psychiatric disorders. SNF environments were considered hazardous, staffing was insufficient in number and poorly trained, and inappropriate antipsychotic medication prescribing was a common component of care. More than 10% of SNF residents experienced some form of documented abuse. In 1987, with a blueprint created by the IOM, a bi-partisan Congress moved beyond “politics as usual” and passed the federal NHRA. This legislation requires each and every licensed nursing facility provide a physical environment, a staff culture, and care processes that contribute to the highest practicable level of a resident’s medical and psychosocial well-being (Lin & Kramer, 2013).

To reach this goal, the NHRA assigned the Center for Medicare and Medicaid Services (CMS) administrative responsibility and, for the past 25 years, CMS has implemented a regulatory structure consisting of more than 200 standards, addressing issues such as the safety of the physical plant, identification of psychiatric conditions, and antipsychotic prescribing practices (Hughes & Lapane, 2005; Lin & Kramer, 2013). In addition, CMS has developed a surveillance system to assess how well the standards are being met (Harrington et al., 2004). This system relies on contracted state-level inspectors to identify deficient nursing home practices during annual or complaint-driven inspections, assessing the scope and severity of any deficiencies. Sanctions can range from notices of violation, requirements

to correct deficient practices, civil monetary penalties, or facility closure.

While the implementation of care standards and the corresponding surveillance system has been characterized as burdensome by many providers, these efforts have been linked to numerous process and outcome improvements as well as increased health of facility residents. For example, initial implementation of the NHRA care standards and surveillance system was tied to the decade-long (1989–1998) reduction in inappropriate prescribing of antipsychotic medications and related decreases in care complications and other harmful resident outcomes (Briesacher et al., 2013; Chen et al., 2010; Hughes & Lapane, 2005).

Beyond addressing a major public health concern involving the health and welfare of older persons with dementia living in AL and upholding the federal ADA and FHA, the federal government has a duty to uphold and enforce Section 504 of the Rehabilitation Act of 1973, which requires states to enforce specific environmental and service standards for persons with disabilities in programs that receive any federal funding (U.S. Department of Justice, Civil Rights Division, 2009). As of 2009, 35 state Medicaid programs reimbursed nearly 12,000 AL facilities for services provided to more than 54,000 beneficiaries, at a total annual cost of \$1.7 billion (Levinson, 2012). As such, the federal government has become a primary stakeholder in purchasing services provided to AL residents across the United States (Bruce, 2006), and now has assumed a de facto obligation to ensure that the facilities which receive Medicaid support adhere to federal standards.

Perhaps our federal leaders will move to consider improving the protection of nearly 700,000 AL residents with dementia not only because they are concerned with their health and welfare but because they have a multifaceted legal obligation to do so. Perhaps our federal leaders will follow the approach taken by the NHRA and assign CMS responsibility for: (a) creating a set of national standards concerning the condition of facilities, staffing, care processes, and resident outcomes and (b) designing a surveillance system to ensure that every licensed facility across the United States meets a minimum set of national standards (Cox et al., 2011). While such a far-ranging national effort will rely extensively on states to uphold and enforce any federal regulation and such a model is not likely to remove all failures in care, it is likely to improve the overall protection of the growing number residents with dementia living in AL across the United States. It's déjà vu all over again, or is it?

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