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NEGOTIATING FOR RESIDENT-CENTERED CARE

Eric M. Carlson*

BENEFITS OF RESIDENT-CENTERED CARE

INTRODUCTION

If you have ever lived in a nursing home,1 or visited a family member or friend there, you have probably experienced the opposite of resident-centered care. To an excessive extent, facility operations are driven by outdated facility policies and staff convenience, rather than by resident needs and preferences.2 This type of facility has given nursing homes a bad reputation, and made the adjective "institutional" a powerful pejorative in discussions of long-term care.3

Today, the better nursing homes are adopting "culture change" to focus more on individual residents and their

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1. "Nursing home" and "nursing facility" are roughly synonymous -- this article uses the term "nursing home." The Nursing Home Reform Law sets standards for any nursing home certified to accept federal reimbursement. In the federal law, Medicare-certified and Medicaid-certified facilities are termed "skilled nursing facilities" and "nursing facilities," respectively. The standards for Medicare and Medicaid certification are virtually identical. See 42 U.S.C.A. §§1395i-3 (West, Westlaw through 2008) (Medicare certification standards), 1396r (West, Westlaw through 2008) (Medicaid).


concerns. Although these attitudes are in many ways revolutionary, it is important to recognize that such resident-centered practices have been required by federal nursing home law since 1990.

For example, a resident has a right to personalize his or her living space, as long as there is no infringement of other residents’ rights. A federal guideline explains that “[t]he right to retain and use personal possessions assures that the residents’ environment be as homelike as possible and that residents retain as much control over their lives as possible.”

Also, and more importantly, federal law establishes a resident’s right to receive care that is personalized to the resident’s health care needs and individual preferences. A nursing home must complete a full assessment of a resident’s condition within fourteen days after admission, at least once every twelve months thereafter, and promptly after a significant change in the resident’s condition. The assessment must include certain information specified by the federal Centers for Medicare and Medicaid Services (CMS); this required information is referred to as the Minimum Data Set. Federal regulations list eighteen required subject matter areas, including a resident’s customary routine, cognitive patterns,

4. See, e.g., Letter from George Grob, Assistant Inspector General for Evaluation and Inspections, Dept. of Health & Human Servs., to Dennis G. Smith, Director, Ctr. for Medicaid & State Ops. (March 2, 2005); CULTURE CHANGE IN LONG-TERM CARE (Audrey S. Weiner & Judah L. Ronch eds., 2003) (devoted to articles concerning culture change).


communication, mood and behavior patterns, psychosocial well-being, physical functioning, skin condition, and discharge potential.\textsuperscript{11}

The resident's assessment is just the first step — within seven days, it must be used to prepare the resident's comprehensive care plan.\textsuperscript{12} The care planning is done by an interdisciplinary team that includes the resident's attending physician, a registered nurse with responsibility for the resident, other appropriate staff members from the facility, and, most importantly and to the extent practicable, the resident and/or resident's family member.\textsuperscript{13}

The care plan sets forth the services that are to be furnished in order for the resident to attain or maintain his or her highest practicable well-being, and must include measurable objectives and timetables.\textsuperscript{14} Every three months, care plans must be reviewed and, if necessary, revised.\textsuperscript{15} Care plans must be implemented by "qualified persons" under "professional standards of quality."\textsuperscript{16}

In care planning, participation of the resident or family member is key.\textsuperscript{17} Care plans should be based not only on medical expertise, but also on resident preference; under federal law, a resident has the right "to reside and receive services with reasonable accommodation of individual needs and preferences, except where the health or safety of the individual or other residents would be endangered."\textsuperscript{18} The regulations expand on this right, stating that a resident has the right to "[m]ake choices

\begin{enumerate}
\item \textsuperscript{11} 42 C.F.R. § 483.315(e).
\item \textsuperscript{12} 42 U.S.C.A. §§ 1395i-3(b)(2), 1396r(b)(2); 42 C.F.R. § 483.20(k)(2)(i).
\item \textsuperscript{13} 42 U.S.C.A. §§ 1395i-3(b)(2)(B), 1396r(b)(2)(B); 42 C.F.R. § 483.20(k)(2)(ii).
\item \textsuperscript{14} 42 U.S.C.A. §§ 1395i-3(b)(2)(A), 1396r(b)(2)(A); 42 C.F.R. § 483.20(k)(1)(i).
\item \textsuperscript{15} 42 U.S.C.A. §§ 1395i-3(b)(2)(C) (requiring review of care plan after each review of assessment), 1396r(b)(2)(C) (same); 42 C.F.R. § 483.20(k)(2)(iii) (same); see 42 U.S.C.A. §§ 1395i-3(b)(3)(C)(ii) (requiring review of assessment at least quarterly), 1396r(b)(3)(C)(ii) (same); 42 C.F.R. § 483.20(c) (same).
\item \textsuperscript{16} 42 C.F.R. § 483.20(k)(3).
\item \textsuperscript{17} See 42 C.F.R. § 483.15(b)-(c).
\item \textsuperscript{18} 42 U.S.C.A. §§ 1395i-3(c)(1)(A)(v)(I), 1396r(c)(1)(A)(v)(I); see also 42 C.F.R. § 483.15(e)(1) (substantially similar language).
\end{enumerate}
about aspects of his or her life in the facility that are significant to the resident."¹⁹ More specifically, each resident has the right to "[c]hoose activities, schedules, and health care consistent with his or her interests, assessments, and plans of care."²⁰

The question is, of course, what is a "reasonable" accommodation of individual needs and preferences? Neither the law nor CMS provides much guidance.²¹ The CMS Long Term Care Facilities Surveyor's guidelines list only two examples, stating that residents who smoke should be provided with a smoking area even after a facility adopts a new non-smoking policy, and that a facility should try to schedule therapy around a resident's favorite television program.²²

Despite this lack of specificity, the savvy resident or resident's family member should not hesitate to cite the reasonable accommodation requirement to request, for example, changes in the resident's schedule or meals.²³ In most such cases, the requested change is well within the facility's capacity or, if not, it should be.²⁴ If a facility is so thinly staffed that it must keep residents on an assembly-line schedule, it would be reasonable to require the facility to increase its staffing ratios.²⁵

Put another way, it would be unreasonable for a resident to be deprived of such simple privileges as going to bed and waking up at a time of the resident's choosing.²⁶ If a reasonable accommodation requirement is to mean anything, it must give residents the ability to make such mundane but nonetheless important choices.²⁷

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¹⁹. 42 C.F.R. § 483.15(b)(3).
²⁰. 42 C.F.R. § 483.15(b)(1).
²¹. CTRS. FOR MEDICARE & MEDICAID SERVS., Appendix PP, supra note 7, at §§ 483.5-483.75.
²². Id. at § 483.15(b)(3).
²³. Id. at § 483.15(e).
²⁴. See id.
²⁵. See, e.g., SARAH GREENE BURGER ET AL., NURSING HOMES: GETTING GOOD CARE THERE 29 (1996) (short-staffing not a justification for refusing resident's request to sleep later).
²⁶. See id.
²⁷. See id.
RESIDENT-CENTERED CARE AND THE CULTURE CHANGE MOVEMENT

Of course, enactment of a law does not equate to across-the-board compliance, and nursing homes offer a glaring example of this reality.  

- The Reform Law and its reasonable accommodation requirements have been in effect since 1990.  
- Federal and state governments are authorized to enforce the Reform Law, utilizing an enforcement mechanism set forth in the Reform Law and its regulations.  
- The Inspector General of the Department of Health and Human Services, the Government Accountability Office, and other government agencies frequently have investigated and made recommendations concerning the Reform Law's enforcement.  
- Investigative reporters from across the country have

30. See 42 U.S.C.A. §§ 1395i-3(h), 1396r(h); 42 C.F.R. §§ 488.400- 488.456.  
investigated the enforcement of nursing home law.\textsuperscript{32} 
- \textit{Nonetheless,} most nursing homes routinely have provided essentially facility-centered care, with little or no concern for individual residents' preferences.\textsuperscript{33}

There are multiple explanations for the Reform Law's lack of penetration, including consumer unfamiliarity with nursing homes\textsuperscript{34} the political and legal pressures exerted by nursing homes, and the related weaknesses in government enforcement.\textsuperscript{35} Pressure from the outside – i.e., from consumers and regulators – oftentimes has not been enough to force nursing homes to comply with the law.\textsuperscript{36}

The culture change movement is one response to the current state of affairs, and is driven in large part by health care providers themselves.\textsuperscript{37} The message to facility operators: resident-centered care is, for multiple reasons, the right way to run a business.\textsuperscript{38} Consistent with the term "resident-centered," the emphasis is on the resident rather than the task.\textsuperscript{39} As human beings, residents have needs beyond the physical.\textsuperscript{40} The resident's mind and spirit should be taken into account, as should the resident's relationships with staff members and other residents.\textsuperscript{41}

In accordance with these central concepts, a culture-change


\textsuperscript{33} See THOMAS, supra note 2, at 11-13.

\textsuperscript{34} See, e.g., ERIC M. CARLSON, NAT'L SENIOR CITIZENS LAW CTR., 20 Common Nursing Home Problems - and How to Resolve Them, at 5 (2005).


\textsuperscript{36} See id.

\textsuperscript{37} See, e.g., NAT'L CITIZENS' COAL. FOR NURSING HOME REFORM, \textit{Culture Change in Nursing Homes: Consumer Fact Sheet No. 19}, 1-2 (2006).

\textsuperscript{38} Id.

\textsuperscript{39} Id.

\textsuperscript{40} Id.

\textsuperscript{41} Id.
facility gives a resident greater control in planning care and in making day-to-day decisions. The environment is more home-like; for example, a resident has greater privacy and also has opportunities for a greater sense of community within the facility.

Increasingly, implementation of culture change also has focused on the working conditions of nursing home caregivers. Under culture change principles, direct-care workers are given more control over their schedules – instead of being directed to perform particular tasks at certain times, workers have discretion to schedule tasks when most appropriate for the resident and the worker. Whenever possible, workers are assigned to the same residents, so that personal relationships can develop. Also, through work assignments and trainings, direct-care jobs are designed so that the workers have a career ladder rather than a dead-end job.

Culture-change initiatives are appearing across the country, and two prominent initiatives have close connections to Milwaukee, Wisconsin (where the Elder's Advisor Symposium was held). The Wellspring Model involved a consortium of eleven non-profit nursing homes in eastern Wisconsin. The initiative provided clinical-care training modules for each of the facilities, in order to transfer knowledge systemically to each facility and unit. In addition, the facilities' management added

42. Id.
45. See, e.g., id.; NAT'L CITIZENS' COAL. FOR NURSING HOME REFORM, supra note 37.
46. See, e.g., NAT'L CITIZENS' COAL. FOR NURSING HOME REFORM, supra note 37.
47. See, e.g., Yeatts & Cready, supra note 44, at 323.
49. STONE ET AL., supra note 48, at vii.
50. Id. at 2-4.
culture change components.\textsuperscript{51}

The results were encouraging.\textsuperscript{52} A formal evaluation found measureable improvement in several quantitative measures – fewer regulatory deficiencies and pressure sores, and better staff retention, for example.\textsuperscript{53} Also, the researchers found anecdotal evidence of residents being given more respect and privacy, and overall gave the initiative a positive review.\textsuperscript{54}

The nursing home chain Beverly Enterprises (now known as Golden Gate National Senior Care) implemented a culture change initiative in 2002.\textsuperscript{55} Beverly Enterprises contracted with Action Pact consulting of Milwaukee and, in the first stage of the initiative, pilot-tested the initiative in ten facilities.\textsuperscript{56} The second stage added eighteen facilities, and replaced some consulting services with in-house expertise.\textsuperscript{57}

The initiative focused on five culture change practices:

- Permanent staff assignments of workers to residents;
- Staff awareness of the culture change initiative;
- Leadership from staff members who did not have formal leadership positions;
- Staff members making good-faith efforts to fulfill residents' special requests; and
- Staff members going outside traditional departmental roles.\textsuperscript{58}

An academic evaluation found positive results.\textsuperscript{59} Initially, for example, 58.6\% of administrators claimed their staff were willing to meet "special" resident requests; this percentage increased to 85.6\% after six months of the initiative, and

\begin{itemize}
\item \textsuperscript{51} Id.
\item \textsuperscript{52} Id. at 27.
\item \textsuperscript{53} Id. at 12-21.
\item \textsuperscript{54} Id. at 21.
\item \textsuperscript{55} GRANT, supra note 48, at 1.
\item \textsuperscript{56} Id. at 2.
\item \textsuperscript{57} Id.
\item \textsuperscript{58} Id. at 11-12.
\item \textsuperscript{59} Id. at 12-16.
\end{itemize}
remained at 82.9% at the twelve month mark.\textsuperscript{60}

Surveys of staff members and interviews with residents painted a similar picture.\textsuperscript{61} Staff members pointed to increased resident autonomy in scheduling, meals, and activities.\textsuperscript{62} In interviews, residents similarly reported greater autonomy in day-to-day matters and cited a heightened sense of dignity.\textsuperscript{63} The residents appreciated being called by their preferred names and treated like adults rather than children.\textsuperscript{64} Staff members were complimented for respecting residents’ privacy and for taking the time to listen.\textsuperscript{65}

NEGOTIATION IN LONG-TERM CARE

\textit{NEGOTIATION IN ASSISTED LIVING MODEL}

\textit{Flexibility in Assisted Living Regulations}

In long-term care, negotiation is most often discussed in reference to assisted living.\textsuperscript{66} In its earliest conception, “assisted living” denoted individualized care provided in a person’s home.\textsuperscript{67} The living unit possibly—but not necessarily—would be part of a larger building.\textsuperscript{68} Negotiation would of course be necessary to arrange for the necessary services.\textsuperscript{69}

Today, however, assisted living care has been understood

\begin{itemize}
\item \textsuperscript{60} Id. at 15.
\item \textsuperscript{61} Id. at 16-22.
\item \textsuperscript{62} Id. at 16-19.
\item \textsuperscript{63} Id. at 21-22.
\item \textsuperscript{64} Id.
\item \textsuperscript{65} Id.
\item \textsuperscript{68} See id.
\item \textsuperscript{69} See id.
\end{itemize}
for many years as being provided in a long-term care facility.\textsuperscript{70} But an emphasis on negotiation persists, since assisted living regulations are often vague and rely explicitly or implicitly on negotiation to fill in the blanks left by regulatory frameworks.\textsuperscript{71}

Assisted living is regulated almost exclusively by state law, which tends to define "assisted living" with language that is attractive but vague.\textsuperscript{72} In Vermont, for example, the definition of "assisted living residence" claims ambitiously that "[a]ssisted living promotes resident self-direction and active participation in decision-making while emphasizing individuality, privacy and dignity."\textsuperscript{73} Similarly, New Jersey defines "assisted living" as "a coordinated array of supportive personal and health services, available twenty-four hours per day, which promote resident self-direction and participation in decisions that emphasize independence, individuality, privacy, dignity and homelike surroundings."\textsuperscript{74} Illinois' language has an even more ambitious tone, describing assisted living as "a social model that promotes the [residents'] dignity, individuality, privacy, independence, autonomy, and decision-making ability and the right to negotiated risk."\textsuperscript{75}

To be sure, some state-law definitions use less flowery language, but they can be equally vague.\textsuperscript{76} South Dakota provides an example somewhat extreme in its blandness, defining an "assisted living center" as "any institution, rest home, boarding home, place, building, or agency which is maintained and operated to provide personal care and services

\begin{thebibliography}{9}
\bibitem{70} See \textit{id}.
\bibitem{72} See, \textit{e.g.}, VT. STAT. ANN. tit. 33, \textsection 7102(11) (2001). This article's discussion of assisted living law adapted in part from ERIC M. CARLSON, \textit{Critical Issues in Assisted Living: Who's In, Who's Out, and Who's Providing the Care}, NATL. SENIOR CITIZENS LAW CTR. 13-16 (2005).
\bibitem{73} VT. STAT. ANN. tit. 33, \textsection 7102(11) (2001).
\bibitem{74} N.J. STAT. ANN. \textsection 26:2H-7.15 (West 2007).
\bibitem{75} ILL. ADMIN. CODE tit. 77, \textsection 295.100(a) (LEXIS through Aug. 2008).
\bibitem{76} See, \textit{e.g.}, S.D. CODIFIED LAWS \textsection 34-12-1.1(2) (Supp. 2008).
\end{thebibliography}
which meet some need beyond basic provision of food, shelter, and laundry.”

A more typical—but still vague—example comes from Georgia, which defines a “personal care home” (Georgia’s term for assisted living) as “any dwelling, whether operated for profit or not, which undertakes through its ownership or management to provide or arrange for the provision of housing, food service, and one or more personal services.”

All of these definitions are noteworthy for setting lowest-common-denominator minimums as to the services to be provided. Although the definition may allow or even encourage more extensive or sophisticated services, the definitions (and, typically, the state’s assisted living requirements) do not specify that such services must be made available to residents. In general, the assisted living provider is free to provide extensive, individualized services, but the provider is equally free to provide services only at the regulations’ bare minimum.

There are two principal perspectives on the flexibility in assisted living definitions and standards. From one perspective, flexibility is a positive attribute. It is assumed, explicitly or implicitly, that regulatory flexibility will allow facilities to meet resident needs. This perspective assumes a direct—and positive—relationship between flexibility and quality of care.

77. S.D. CODIFIED LAWS § 34-12-1.1(2) (Supp. 2008).
78. GA. COMP. R. & REGS. 290-5-35-.04(o) (West, Westlaw through 2007). “Personal services” are defined in turn as including but not limited to “individual assistance with or supervision of self-administered medication, assistance with ambulation and transfer, and essential activities of daily living such as eating, bathing, grooming, dressing, and toileting.” GA. COMP. R. & REGS. 290-5-35-.04(p) (West, Westlaw through 2007).
79. See CARLSON, supra note 72, at 15-16.
80. Id. at 15.
81. Id.
82. Id. at 16.
83. Id.
84. Id.
85. Id.
From the other perspective, flexibility is more weakness than benefit, owing to less confidence that assisted living facilities will use regulatory flexibility for residents’ benefit. Under flexible regulations, a facility has significant discretion over the services it will provide and the care practices that it will follow. Potential problems include consumer confusion, unexpected evictions, and substandard care.

**Negotiation as Facet of Flexible Regulatory Scheme**

Flexible regulations often are premised on an expectation that care standards will be negotiated between the facility and resident (or resident’s representative). From this premise, care standards will be set by the admissions contract rather than the state law. A good – admittedly somewhat extreme – example of a contract-focused model is found in an introductory Illinois regulation that explains the purpose of the state’s Assisted Living and Shared Housing Act:

Assisted living, which promotes resident choice, autonomy, and decision-making, should be based on a contract model designed to result in a negotiated agreement between the resident or the resident’s representative and the provider, clearly identifying the services to be provided. This model assumes that residents are able to direct services provided for them and will designate a representative to direct these services if they themselves are unable to do so. This model supports the principle that there is an acceptable balance between consumer protection and resident willingness to accept risk and that most consumers are competent to make their own judgments about the services they are obtaining.

Perhaps the purest example of a negotiation-based model is

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86. Id.
87. Id.
88. See id.
89. Id.
90. Id.
91. ILL. ADMIN. CODE tit. 77, § 295.100(a) (LEXIS through Aug. 2008).
Michigan's system for housing-with-services establishments—a license is not required, and the relevant statutes do little more than specify certain unremarkable requirements for a contract with a resident. More commonly, negotiation-based models appear in state assisted living law through disclosure requirements. The premise of these laws is that consumers will be protected if facilities are required up front to disclose certain important aspects of the care to be provided.

**Is "negotiation" realistic in long-term care?**

In long-term care policy discussions, one school of thought focuses on information and consumer decision-making. Two prominent researchers, for example, have proposed eliminating nursing home regulation:

The resources devoted to regulation could instead be allocated to a more market-based approach that emphasizes information. Such an approach would require collecting enough standardized data to provide consumers with better information on which to base better-informed LTC [long-term care] decisions. Data on various types of care could be arrayed to show measures of quality (of care and life), the nature of the services provided, staffing stability, and consumer satisfaction. The information could be disseminated through Web sites, but it could also be packaged to

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93. CARLSON, supra note 72, at 17.


95. Robert L. Kane & Rosalie A. Kane, What Older People Want from Long-Term Care, and How They Can Get It, 20 HEALTH AFF. 114, 123 (2001).
make it readily accessible to case managers.  

The less extreme view – one more common in long-term care academia – emphasizes information without positing the end of regulation. Conversations generally revolve around nursing homes, due to the astounding amount of facility-specific data available to consumers.

Other research, however, points out the limits of an information-based strategy in the real world. Nursing homes cannot be reduced accurately to a set of numbers, no matter how sophisticated the measures and, in any case, most consumers are not in a position to weigh, understand, or even consider much of the available nursing home information. One study interviewed 306 sets of nursing home residents and family members. The interviews showed that the residents and family members had made few proactive choices. Their decisions generally were not based on the facility's quality, and were made within a short period of time and with little information about the facility ultimately chosen.

This type of inquiry focuses more on how long-term care consumers actually behave. One researcher, in an essay organized around her experiences with her mother, points out the flaws of a market-focused strategy in long-term care.

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96. Id. at 122-23.
97. See, e.g., Vincent Mor, Improving the Quality of Long-Term Care with Better Information, 83 MILBANK QUARTERLY 333 (2005).
98. See id. Data about any federally-certified nursing facility is available at the federal government's Nursing Home Compare website, at www.medicare.gov/NHCompare. The data include 19 quality measures expressed in percentages, such as the percentage of residents who have pressure sores, are incontinent, have lost too much weight, or spend most of their time in bed or in a chair. The data is drawn from individual residents' Minimum Data Set assessments, as well as from data self-reported by facilities for the Online Survey, Certification, and Reporting (OSCAR) database.
99. See generally Nicholas G. Castle, Searching for and Selecting a Nursing Facility, 60 MED. CARE RES. & REV. 223 (2003).
100. Id.
101. Id. at 240.
102. Id. at 245.
103. Id.
104. See id.
From the Capital Beltway to the Ivory Tower, long-term care policy – like the larger health care landscape – is inspired by market thinking. The answers to every problem (cost, quality, loss of autonomy) are to be found in consumer sovereignty... It's fairy-tale magic, this market story with Wise Consumer as its hero, and it revolves around fairy-tale characters. I don't know any real people, especially frail elders, who are motivated or think much like homo economicus. When I read the policy literature on long-term care, I have to wonder whether the nation might envision better long-term care policy if all the analysts and politicians spent a little more time listening to their parents and a little less listening to each other.105

**HISTORY OF FACILITIES USING CONTRACTS TO TAKE ADVANTAGE OF RESIDENTS**

**NEGOTIATED RISK**

*Negotiated Risk Designed to Release Facility from Liability for Inadequate Care*

From a public policy perspective, negotiation is an appropriate strategy only if negotiation can be realistically expected to result in a fair outcome.106 If, however, facilities have excessive power – due to any combination of resources, expertise, and practical realities – then a call for negotiation puts residents at risk.107

Experience shows, in fact, that long-term care facilities have a history of taking advantage of consumers during the admissions process.108 This history counsels against an undue

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107. *Id.* at 325.
108. *Id.*
reliance on negotiation models.\textsuperscript{109} 

One example is the concept of "negotiated risk" in assisted living.\textsuperscript{110} Negotiated risk originally was envisioned as a means for an assisted living facility to avoid liability for inadequate supervision or health care.\textsuperscript{111} In a 1995 article, a provider attorney identified "negotiated risk" as "the first buzzword unique to assisted living."\textsuperscript{112} As the article described, some facilities were using negotiated risk to limit their responsibilities for resident care: "Some facilities are squeezing the concept into the blueprint of written admissions or resident contracts. Others think that if a resident can be persuaded to accept a particular service delivery plan, then the facility will be insulated from regulatory and civil liability."\textsuperscript{113}

Other provider representatives have made similar observations.\textsuperscript{114} One provider attorney explains that "[a] negotiated risk contract is where the resident agrees to accept a certain setting and they assume the risk that that setting may or may not be appropriate for their care."\textsuperscript{115} In accordance, a consulting firm’s vice president of clinical operations discusses how negotiated risk can be used to address areas in which a facility’s care might be inadequate:

\begin{itemize}
  \item \textsuperscript{109} Id. at 336-37.
  \item \textsuperscript{110} Id. at 287.
  \item \textsuperscript{111} Id. at 294-95.
  \item \textsuperscript{112} Bianculli, supra note 66, at 32; see also BIANCULLI & WILSON, supra note 66, at 1 (negotiated risk is "buzzword specific to assisted living").
  \item \textsuperscript{113} Bianculli, supra note 66, at 32.
  \item \textsuperscript{114} See John Durso, Testimony to Comm’n on Affordable Housing and Health Facility Needs for Seniors in the 21st Century (Nov. 7, 2001), http://govinfo.library.unt.edu/seniorscommission/pages/hearings/011107/durso.html.
  \item \textsuperscript{115} Id. See also N.H. Dep’t of Health & Human Servs., Final Report: H.B. 1319 – Negotiated Risk 2 (2000) ("issues sparking the debate on negotiated risk appear to focus on transferring clients who may wish to remain in a residential placement environment to which they have grown accustomed when that residence is not longer able to meet their identified care needs"); Stephanie Kissam et al., Admission and Continued-Stay Criteria for Assisted Living Facilities, 51 J. AM. GERIATRICS SOC’Y. 1651, 1652 (2003) (recommending "managed risk agreement" with liability waiver if resident remains in assisted living facility beyond point at which facility can meet care needs); Elisabeth Belmont et al., A Guide to Legal Issues in Life-Limiting Conditions, 38 J. HEALTH L. 145, 188 (2005) (in negotiated risk, “facility attempts to explain before admittance those services/responsibilities for which it intends to be responsible, as well as those for which it intends not to be responsible”).
\end{itemize}
Once residents are assessed, providers should implement shared-risk, or managed-risk, agreements for any potential risk identified for the resident, such as falls, wandering away from the community, or even the potential for skin breakdown. These vitally important agreements document that the resident and family have been advised of the inherent risks that come with choosing a long-term care model that supports quality of life, such as assisted living, as opposed to a primarily quality of care skilled nursing model. Because assisted living providers may not provide 24-7 care (and are not expected to), these agreements leave no question that the resident and the family understand this concept and accept their share of responsibility in the resident’s plan of care.\textsuperscript{116}

Consistent with these descriptions, negotiated risk agreements often are portrayed chiefly as a means for an assisted living facility to reduce its legal exposure.\textsuperscript{117} As stated in an article defending negotiated risk, “For some providers, risk consultants and lawyers, [liability waivers] are the ‘magic words’ of [a negotiated risk agreement] – the words whereby the resident essentially agrees that the provider is not liable for harm that arises from the subject risk.”\textsuperscript{118} The same article recommends negotiated risk agreements as a means of reducing a facility’s exposure to liability claims.\textsuperscript{119}

In accord, a 2004 article in Assisted Living Today (the magazine of the Assisted Living Federation of America, or ALFA) listed a “managed risk agreement” as one of ten techniques to be used by an assisted living facility to “avoid costly litigation.”\textsuperscript{120} The article’s discussion of managed risk


\textsuperscript{118.} \textit{Id.}

\textsuperscript{119.} \textit{Id.} at 4 (“the legal exposure borne by long term care providers has been anything but limited, with the long term care litigation ‘avalanche’ having crippled some operators and impacted nearly all through less liability insurance coverage at a dramatically higher cost”).

begins with the admonition to "[b]e honest with the resident and the family that there may simply be unavoidable injuries during the resident’s stay at your community. Do not promise that you can keep the resident safe." The article recommends that a facility consider using contractual clauses that waive the facility’s liability if the resident is injured after failing to wait an adequate period of time for staff assistance, and that state that the resident understands that the facility “cannot guarantee that [the resident] will not experience a fall or an injury from a fall.”

**Negotiated Risk Agreements Violate Public Policy and Are Accordingly Unenforceable**

Negotiated risk proponents have turned a blind eye to one vitally important fact – negotiated risk agreements are not enforceable. Virtually across the board, courts have invalidated liability waivers that purport to release a health care provider from liability for negligence. “In the field of medical risks,” notes one commenter, “courts have generally rejected out-of-hand attempts by physicians and hospitals to shift the risk of negligence to patients.”

In a seminal case, *Tunkl v. Regents of University of California*, the California Supreme Court refused to enforce a waiver that purportedly relieved a university hospital of liability for surgical negligence. The court listed six relevant factors: 1) a business suitable for public regulation; 2) a service of great public importance; 3) a seller willing to perform a service for any member of the public; 4) a seller with a decisive bargaining advantage; 5) an adhesion contract; and 6) a buyer under the

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121. *Id.* at 20 (emphasis in original).
122. *Id.* at 20-21.
123. See Carlson, supra note 106, at 323-34.
125. *Id.*
seller's control.\textsuperscript{127}

A finding of unenforceability does not require that all of these factors be present but, in fact, each factor is present in negotiated risk.\textsuperscript{128} Regarding the fourth and sixth factors, residents and their families are in an extremely vulnerable position, and tend to follow a facility's instructions.\textsuperscript{129}

To date, there is only one published ruling on this issue; the ruling supports this article's analysis, finding that negotiated risk agreements are unenforceable.\textsuperscript{130} A fall in an assisted living facility had caused a resident to suffer irreversible brain damage and permanent physical impairments.\textsuperscript{131} Based on the admission agreement, the facility moved for summary judgment under assumption of risk.\textsuperscript{132} The relevant admission agreement language stated:

The Resident acknowledges that these principles of independence, control, and choice will result in a higher quality of life for each resident in the community, recognizes the additional risk that results from the ability of the Resident to make such choices, and agrees to mutually accept and share this risk. Resident agrees that [the facility] shall not be liable to Resident for personal injuries or damage to property, even if resulting from the negligence of [the facility] or its employees, unless resulting from its gross negligence or willful misconduct. Resident acknowledges that the independence, control and choice afforded within [the facility] requires that the Resident assume responsibility for any loss, injury or damage resulting from Resident's personal actions and conduct.\textsuperscript{133}

The court's analysis distinguished assisted living from recreational sports, which is the context in which assumption of

\textsuperscript{127} Id. at 445-46.
\textsuperscript{128} See Carlson, supra note 106, at 328-29.
\textsuperscript{129} See id.
\textsuperscript{131} Id. at 878.
\textsuperscript{132} Id.
\textsuperscript{133} Id. at 878-79 (emphasis added).
risk has most commonly been applied.  

"[T]wo common themes" were present in the sports-related cases. First, the injured party had chosen "to engage in the activity, not out of necessity but out of a desire to satisfy a personal preference." Second, the injured party had participated in the activity knowing that participants might not act with ordinary care.

Neither of the common themes was present in the resident’s allegations against the assisted living facility. The resident had entered assisted living not out of choice but because he required care due to multiple sclerosis and an alcohol addiction. Also, a recipient of health care cannot agree to less than "ordinary care":

"[T]here is virtually no scenario in which a patient can consent to allow a healthcare provider to exercise less than "ordinary care" in the provision of services. Even if given, a patient's consent to allow a healthcare provider to exercise less than ordinary care would be specious when considered against the strict legal, ethical and professional standards that regulate the healthcare profession. Regardless of whether the patient elects to have healthcare or requires it, the patient appropriately expects that the treatment will be rendered in accordance with the applicable standard of care. This is so regardless of how risky or dangerous the procedure or treatment modality might be."

As further support for its ruling, the court cited statutory and regulatory duties of health care providers generally and assisted living providers specifically. Given the state's interest in establishing and protecting an adequate quality of care, it was improper for quality of care to be compromised by individual agreements between facility and resident.

134. Id. at 883-84.
135. Id. at 883.
136. Id.
137. Id.
138. Id. at 884.
139. Id.
140. Id.
141. Id. at 883-87.
142. Id. at 885.
Negotiated Risk Now Promoted, Unfairly, As Enhancer of Residents’ Autonomy

Negotiated risk’s core concept – a resident waiving a facility’s liability for inadequate care – has proven unappealing to consumers and policymakers.\textsuperscript{143} Also, as discussed immediately above, this core concept is likely to be found violative of public policy.\textsuperscript{144}

Nonetheless, in communications with residents and family members, assisted living facilities continue to solicit negotiated risk agreements in which a resident (or resident’s representative) waives a facility’s liability.\textsuperscript{145} But in public policy discussions, negotiated risk proponents increasingly promote the term “negotiated risk” as a mechanism allowing a resident to refuse the facility’s offer of services or advice.\textsuperscript{146} In this gambit, negotiated risk is justified by inaccurate claims about life in a nursing home.\textsuperscript{147} Allegedly, assisted living facilities follow a humanistic social model of care, as compared to the prescriptive medical model in which nursing home staff members have taken over residents’ decision-making.\textsuperscript{148} One article flatly – but incorrectly – states: “In a nursing facility, [a diabetic resident] would not be given the option of eating cake.”\textsuperscript{149}

In fact, the example of a diabetic wanting dessert is probably the most common fact pattern put forward by negotiated risk proponents.\textsuperscript{150} Other common examples are

\textsuperscript{143} See generally Carlson, supra note 106.
\textsuperscript{144} Storm, 898 A.2d 874 at 886.
\textsuperscript{146} See id.
\textsuperscript{147} See id.
\textsuperscript{148} Id.
\textsuperscript{149} Carder, supra note 145, at 12.
residents who refuse baths or medication, or insist on self-care even though staff assistance is available. In general, under this "against-facility-advice" scenario, the facility is prepared to provide adequate care, but the resident wants to act against the facility's advice in a way that increases risk to the resident. The negotiated risk agreement allegedly "describes a process by which a resident who engages in risky practices, as identified by a staff member, family member, or health care provider, signs an agreement whereby he or she indicates understanding of risks and agrees to accept responsibility for negative results." 

The end result is confusion. As conceded in a leading article advocating negotiated risk, there is "no consensus among commentators, regulators and accreditation bodies of what a negotiated risk agreement actually is – or should be." The confusion is well-illustrated by state negotiated risk laws, which, in general, are both vague and inconsistent in their treatment of negotiated risk. Depending on the state, a negotiated risk agreement purportedly is used to resolve disputes or, instead, to

preferences, such as where medical issues like diabetes are implicated): Lynch & Teachworth, supra note 117 (negotiated risk agreement used for residents not following a prescribed diet); Carder, supra note 145, at 12; Paula C. Carder & Mauro Hernandez, Consumer Discourse in Assisted Living, 59 BERK. J. GERONTOLOGY 558, S61 (2004); Janet O'Keefe et al., Using Medicaid to Cover Services for Elderly Persons in Residential Care Settings: State Policy Maker and Stakeholder Views in Six States at 27 (2003); David Peete, "Risk Management": Heeding the New Mantra, 50 NURSING HOMES: LONG TERM MGMT. 56, 56 (2001); Katherine Blanchette, NEW DIRECTIONS FOR STATE LONG-TERM CARE SYSTEMS VOL. III: SUPPORTIVE HOUSING 19 (1997).

151. Kenneth L. Burgess, supra note 145; see also Allen Lynch & Sarah Teachworth, supra note 117 (negotiated risk agreement used when resident does not want to wait for bathing assistance).

152. Carder & Hernandez, supra note 150, at S61.


154. See id.

155. Carder, supra note 145, at 12 (internal quotations omitted).

156. Lynch & Teachworth, supra note 117.

157. Id.

158. Carlson, supra note 106, at 301-17.
The agreement is allegedly designed to reduce the resident's risk or, on the other hand, to consent to inadequate care. In some states, negotiated risk law leaves open the possibility of a liability waiver, whereas in other states the law explicitly bars any liability waivers.

This confusion is a predictable result of the bait-and-switch process being followed by negotiated risk proponents. Negotiated risk was designed as a liability waiver, but the term "negotiated risk" is now promoted in public forums as an autonomy enhancement for residents.

**MISREPRESENTATIONS IN NURSING HOME ADMISSION AGREEMENTS**

**Consistent Problems**

Nursing home admission agreements provide another dramatic example of how long-term care residents often are taken advantage of in purported "negotiation." Across the board, studies of admission agreements have found that the agreements often misrepresent the relevant law and do so in a way that disadvantages residents.

This consistent level of misrepresentation is, in part, explained — but certainly not excused — by most consumers' lack of understanding. People signing admission agreements often do so in a hurried manner and without a full understanding of the contents. The agreements are often filled with legal jargon that is difficult for the average person to comprehend. Moreover, the fees associated with long-term care can be financially overwhelming, leading individuals to sign agreements quickly and without fully understanding their implications.

159. *Id.*
160. *Id.* at 301.
161. *Id.* at 301-17.
162. *Id.*
163. *Id.* at 287.
165. MARYLAND STATE BAR ASSN., supra note 164; SUBCOMMITTEE ON L. & THE ELDERLY, supra note 164; Kisor, supra note 164, at 305-06; THINK TWICE BEFORE SIGNING, supra note 164, at 9-15.
familiarity with nursing homes and by the difficult circumstances surrounding many nursing home admissions.\textsuperscript{166} A California appellate court notes "that admission of a close family member to a nursing home—usually by the child of a parent in declining mental or physical health—is often an emotionally-charged, stress-laden event."\textsuperscript{167} In the same opinion, the court found "an admissions process in which a stack of documents was hurriedly presented with little or no explanation.\textsuperscript{168} Family members were simply directed to sign by "Xs" or check marks that had "already been added by the [nursing home] employee handling the admission process."\textsuperscript{169}

\textit{Authorizing Improper Evictions}

The most recent study, published in 2007, was based on an analysis of 175 admission agreements used by federally-certified nursing homes in Missouri.\textsuperscript{170} Although the Nursing Home Reform sets just-cause requirements for eviction, seventeen percent of the agreements authorized eviction without cause.\textsuperscript{171} Furthermore, of those agreements that set forth justifications for eviction, forty-six percent misrepresented those justifications.\textsuperscript{172}

Under the Nursing Home Reform Law, eviction is allowed only for one of six limited reasons.\textsuperscript{173} Nonpayment is one reason; a second reason is the nursing home going out of business.\textsuperscript{174} The other four reasons all are based on the resident's health or behavior.\textsuperscript{175} Eviction is allowed if the resident no longer requires nursing home care (reason #3) or requires a level

\textsuperscript{167} Id.
\textsuperscript{168} Id. at 101-02.
\textsuperscript{169} Id.
\textsuperscript{170} THINK TWICE BEFORE SIGNING, supra note 164, at 1.
\textsuperscript{171} Id. at 23.
\textsuperscript{172} Id.
\textsuperscript{173} 42 U.S.C.A. §§ 1395i-3, 1396r; 42 C.F.R. § 483.12(d)(2)).
\textsuperscript{174} Id.
\textsuperscript{175} Id.
of care that cannot be provided in a nursing home (#4). The final two reasons protect others in the nursing home – a resident can be transferred or discharged involuntarily if his presence endangers others' health (#5) or safety (#6).

These six reasons translate to a general rule that eviction should almost never be justified by a resident's health care needs. While some health care conditions may be unpleasant – dementia is a good example – they rarely endanger others' health or safety. Also, while some health conditions require a resident's transfer to a hospital, those types of transfers are almost never contested by a resident.

Regardless, many of the admission agreements gave nursing homes broad authority to evict residents due to health conditions or behavior. Pursuant to one admission agreement, the nursing home's administrator had "the right to remove any Resident from [the nursing home], after appropriate notice, when in her judgment it is in the best interest of the other Residents, [and] for medical reasons as defined by [the nursing home] or [the nursing home's] physician." Similarly, another admission agreement broadly authorized transfer/discharge "due to mental [or] physical conditions." In still another agreement, eviction was authorized for a resident being "unduly disturbing, unduly noisy, objectionably untidy, noncooperative or destructive in behavior and action," even though such behaviors are common symptoms of Alzheimer's disease and other dementias, and nursing homes are designed, in large part, to care for residents with dementia.

176. Id.
177. 42 U.S.C. §§ 1395i-3(c)(2)(A), 1396r(c)(2)(A).
178. Id.
179. THINK TWICE BEFORE SIGNING, supra note 164, at 24.
180. Id.
181. Id.
182. Id.
183. Id.
184. Id. at 23-24.
Requiring or Soliciting Financial Guarantees, Despite Federal Law to the Contrary

Under the Nursing Home Reform Law, a nursing home cannot require a resident's family member or friend to become financially liable for nursing home expenses. This no-guarantee rule makes sense because it is not fair to force a family member or friend to be liable for an unspecified debt that may run into the tens of thousands of dollars. Also, a financial guarantee is usually unnecessary since the Medicaid program can step in and pay when a resident's savings have been depleted.

In an effort to evade the no-guarantee law, nursing homes have used admission agreements in which a family member or friend supposedly "volunteers" to become financially liable. Nursing homes have claimed that these guarantee agreements are legal, arguing that although the Reform Law prohibits a nursing home from requiring a financial guarantee, it does not prevent a nursing home from accepting a voluntary guarantee. These arguments fail, however, for at least three reasons. First, such admission agreements are deceptive because they are generally written to give a family member or friend the impression that a signer (often termed the "responsible party") is only a representative or contact person. Second, admission agreements with supposedly "voluntary" guarantees are often used to require guarantors, in violation of the Reform Law. Third and finally, a supposedly "voluntary" guarantee is

186. Burgess, supra note 145, at 14-15; Carder, supra note 145, at 1.
188. Burgess, supra note 145, at 14-15 (ALFA 1999); Carder, supra note 145, at 1.
189. See 42 U.S.C. §§ 1395i-3, 1396r.
190. See THINK TWICE BEFORE SIGNING, supra note 164, at 30.
191. Id.
unenforceable because it provides no benefit to either the resident or the "responsible party."\textsuperscript{192} Pursuant to the Reform Law, a guarantee cannot be \textit{quid pro quo} for the resident's admission, and the "responsible party" certainly experiences no personal benefit from taking on financial liability.\textsuperscript{193}

In the Missouri study, nineteen percent of the admission agreements \textit{required} a financial guarantee, in direct violation of the Nursing Home Reform Law.\textsuperscript{194} For example, one admission agreement had a "responsible party" agreeing "'[t]o be fully responsible for all financial obligations incurred by Resident,' without any similar promise by the resident."\textsuperscript{195} More frequently, financial liability was imposed on both a resident and a family member or friend.\textsuperscript{196}

Furthermore, another thirty percent of the agreements solicited—supposedly without requiring—a financial guarantee.\textsuperscript{197} Many of the agreements were ambiguous or confusing as to whether a resident's family member or friend was personally liable for nursing home expenses or responsible only to make payments from the resident's resources.\textsuperscript{198} As discussed above, all of these one-sided, supposedly "voluntary," agreements would be unenforceable.\textsuperscript{199}

\textit{Improperly Waiving Nursing Home's Liability for Negligent Care}

As discussed above in this article's discussion of negotiated risk, a waiver of liability is generally invalid in consumer healthcare settings.\textsuperscript{200} Courts will not enforce a liability waiver obtained from a hospital patient prior to surgery.\textsuperscript{201} For the

\begin{flushleft}
\textsuperscript{192.} \textit{Id.}
\textsuperscript{193.} \textit{Id.}
\textsuperscript{194.} \textit{Id.} at 31.
\textsuperscript{195.} \textit{Id.}
\textsuperscript{196.} \textit{Id.}
\textsuperscript{197.} \textit{Id.}
\textsuperscript{198.} \textit{Id.}
\textsuperscript{199.} \textit{Id.} at 30.
\textsuperscript{200.} \textit{Id.}
\textsuperscript{201.} See, e.g., \textit{Tunkl}, 383 P.2d 441.
\end{flushleft}
same reasons, a waiver of liability for nursing home negligence will also be deemed invalid.\textsuperscript{202}

Nonetheless, in the Missouri study, nineteen percent of the nursing homes had an incoming resident limit the nursing home's general liability.\textsuperscript{203} Another fifteen percent of the admission agreements limited the nursing home's liability to negligence or omission, and still another twenty-eight percent of the admission agreements included a liability waiver of another type.\textsuperscript{204}

Some waivers were written extremely broadly; for example, one agreement claimed that that the nursing home would "not be held responsible for accidents or injuries sustained by the Resident during residence in the Facility."\textsuperscript{205} With similar expansiveness, another agreement waived the liability of the nursing home and "its affiliates or partners, [and] the directors, officers, employees, or agents of its affiliates or partners, [and] the directors, officers, shareholders, employees, or agents thereof."\textsuperscript{206} This same agreement specified that the nursing home would "not be responsible for the criminal acts of its agents or employees, or third parties."\textsuperscript{207}

Some agreements limited the damages that could be awarded, and those limitations could be drastic.\textsuperscript{208} For example, several admission agreements waived all non-economic damages—such as damages for pain and suffering—even though the damages suffered by nursing home residents tend to


\textsuperscript{203} THINK TWICE BEFORE SIGNING, supra note 164, at 31-32.

\textsuperscript{204} Id.

\textsuperscript{205} Id.

\textsuperscript{206} Id.

\textsuperscript{207} Id. at 15.

\textsuperscript{208} Id.
be overwhelmingly comprised of non-economic damages rather than economic damages (such as lost wages).\textsuperscript{209}

\textit{Attempting to Improperly Lower Residents' Expectations}

The Nursing Home Reform Law sets high standards for nursing home quality of care.\textsuperscript{210} A central provision obligates nursing homes to provide the care that enables a resident "to attain or maintain the highest practicable physical, mental, and psychosocial well-being."\textsuperscript{211} Although certain conditions are associated with aging, the Reform Law counsels that they not be considered inevitable.\textsuperscript{212} For example, in regard to pressure ulcers and other medical conditions, the nursing home is required to provide preventive services and, if the condition nonetheless develops, to administer appropriate care and treatment.\textsuperscript{213}

Many nursing home admission agreements, however, present an opposing philosophy. Through explanations of "reasonable expectations" (or a comparable term), these agreements have the resident, or resident's representative, acknowledge that aging is a risky process and that certain conditions are essentially inevitable.\textsuperscript{214}

In the Missouri study, twenty-five percent of the admission agreements contained at least one provision designed to lower the expectations of residents or their families.\textsuperscript{215} The study identified four categories: 1) acknowledging risks of aging, 2) recognizing the unavailability of "special duty" care, 3) acknowledging adequacy of the nursing home's staffing, or 4) accepting the nursing home's occasional failure to meet

\begin{itemize}
\item \textsuperscript{209} Id.
\item \textsuperscript{210} 42 U.S.C. §§ 1395i-3(b)(2), 1396r(b)(2) (2008); see also 42 C.F.R. § 483.20(k) (2008) (corresponding requirement in Reform Law's regulations).
\item \textsuperscript{211} Id.
\item \textsuperscript{212} Id.
\item \textsuperscript{213} 42 C.F.R. § 483.25(c); see generally 42 C.F.R. § 483.25 (2008).
\item \textsuperscript{214} THINK TWICE BEFORE SIGNING, supra note 164, at 9.
\item \textsuperscript{215} Id. at 10.
\end{itemize}
standards.216

In general, the theme of the "reasonable expectations" provisions was that residents and residents' family members must reconcile themselves to facility policies rather than vice versa.217 For example, one admission agreement had a resident and representative agree "that if they believe that the Resident is not receiving the level of care which meets their expectation," they had "the right to either pay for additional care through the use of private-duty personnel or to remove the Resident from the Facility and place the Resident in another health care setting, which the Resident/Representative believes would be more suitable to the Resident's needs."218 Another illustrative provision stated:

Service Limitations: The parties hereto agree that the services provided by [the nursing home] and others within this facility are not designed to somehow protect the Resident from everyday, normal risks and responsibilities of living, including, but not limited to, such general accidents and situations such as falling, choking and weight loss and/or dehydration resulting from a Resident's failure to partake of food and drink. Additionally, the parties hereto understand that the services provided by [the nursing home] do not include 24-hour; one-on-one seven (7) days per week monitoring of its Residents.219

Of course, this theme is completely at odds with the Reform Law and its requirement that a nursing home provide the care that is needed for a resident to reach the highest practicable level of functioning.220 Also, such provisions appear designed to waive a nursing home's liability for falling, choking, and other incidents, and accordingly would run afool of the rule (discussed earlier in this article) that health care consumer contracts not absolve the health care provider from liability for

216. Id.
217. Id. at 11.
218. Id.
219. Id. at 11-12 (emphases in original).
220. See 42 U.S.C. §§ 1395i-3(b)(2), 1396r(b)(2).
negligence.221

A POSITIVE VISION FOR NEGOTIATION IN LONG-TERM CARE

Consumer negotiation can play a central role in improving the quality of long-term care. But, much will have to change, for up to this point negotiation has been largely illusory. As addressed earlier in this article, assisted living facilities have taken advantage of regulatory flexibility to push for contractual provisions that would absolve them from legal responsibility. And, nursing facilities, despite comprehensive and humane federal laws, nonetheless have pushed admission agreements that misrepresent the law to residents' detriment. Clearly, these supposed negotiations have been less than kind to residents and their families.

Consumer involvement has been a missing piece in the long-term care puzzle.222 The culture-change movement, although of course a positive development, is largely based in the community of long-term care providers.223 And within that community, its penetration is far greatest among the already-good nursing homes, with significantly less impact among below-average facilities.224

The relative lack of consumer pressure has been a significant contributing factor to nursing homes' oftentimes unsatisfactory quality of care.225 Nursing homes over the years have operated under a desultory status quo accepted by consumers as nursing home reality - just the way that things are.226 Consumer expectations are simply too low. Nursing homes' "reasonable expectations" strategy is a powerful

221. THINK TWICE BEFORE SIGNING, supra note 164, at 11-12.
222. Carlson et al., supra note 34, at 5.
223. Nat'l Citizens Coalition for Nursing Home Reform, supra note 37, at 1-2.
224. See id.
225. See Carlson et al., supra note 34, at 38; see THINK TWICE BEFORE SIGNING, supra note 164, at 2-3.
226. See Carlson et al., supra note 34, at 38; see THINK TWICE BEFORE SIGNING, supra note 164, at 2-3.
illustration of this problem. Through words and deeds, too many nursing homes have provided the minimum and, worse yet, have whittled back on what the minimum constitutes.

Theoretically, government enforcement could compensate for consumer pressure, but general consumer passivity translates also to long-term care being a relatively low priority in state and federal governments. Long-term care facilities have powerful lobbying arms compared to the consumer counterforce.

To a great extent, consumers' lack of power derives from their overly deferential or intimidated attitudes in day-to-day interactions within the facility. A resident or family member thinks: "I'm not a doctor or a nurse... I'm sure that the nursing home knows best." A common emotion is fear, and many family members decide to avoid conflict. "I don't want to say anything," they reason, "because the staff might take it out against my mom."

More education is needed. The reality of long-term care is not well-understood, particularly because information sources present such divergent views. Consumers are whipsawed between facility advertisements — full of floral patterns and expressions of concern for families' "loved ones" — and the news media's periodic exposés.

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227. See THINK TWICE BEFORE SIGNING, supra note 164, at 11.
228. Id.
229. See Carlson, supra note 34, at 5.
230. Id.; In response to the preceding paragraphs, provider representatives would be quick to cite the residents and family members who do complain, and the news media that seem to address long-term care issues only in sensationalist, overly-critical — and oftentimes unproductive — ways. This article does not deny the fact that some consumers do advocate well for their interests, that news media occasionally cover long-term care, and that government officials and employees feel some pressure to "crack down" on poorly performing long-term care facilities. The point is that this pressure is inadequate and sometimes misdirected, and that as a result the quality of long-term care is significantly lower than it should be.
231. See THOMAS, supra note 2, at 11-13.
232. Id.
233. Id.
234. Castle, supra note 99, at 245.
235. See id.
Educational materials must be honest about long-term care realities, acknowledging that the consumers' task is neither simple nor easy. In searching for a facility, it is not enough to work through a checklist and inquire about facility policies. And, even if the consumer has secured admission to a “good” facility, ongoing advocacy is essential.

Furthermore, but predictably, this advocacy is not easy, largely due to (as discussed in this article) the situation’s unfamiliarity. The resident or family member is likely to feel isolated and vulnerable. Unmoored from reference points, she does not know what to expect or demand. Accepting the inadequate becomes the path of least resistance, whether done consciously or not.

The key for consumers is to recognize the tendency to settle for too less but to resist. They must understand that although their experience may be confounding to them, it is far from unique. Over the past few decades, millions of residents and family members have confronted essentially the same circumstances and experienced similar feelings of confusion, fear, frustration, and resignation.

The elder law bar can be a significant part of the solution. Residents and family members need legal advice on a comparatively obscure area of law, and elder law attorneys are uniquely positioned to be both available and knowledgeable.

236. Helpful material includes publications written by two of the Symposium participants. This article’s author has written The Baby Boomer’s Guide to Nursing Home Care (2006) (with co-author Katharine Hsiao) and 20 Common Nursing Home Problems – and How to Resolve Them (original edition 2005). Dr. Robert Kane, along with his sister Joan West, wrote It Shouldn’t Be This Way: The Failure of Long-Term Care (Vanderbilt 2005), a revealing first-person account of their difficulties in working through the long-term care system on their mother’s behalf.
237. Kane & Kane, supra note 95, at 123.
238. THINK TWICE BEFORE SIGNING, supra note 164, at 30.
239. Stone, supra note 105, at 194.
240. Id.
241. Id.
242. Kane & Kane, supra note 95, at 123.
243. Id.
244. See id.
The attorney can advise the clients, who then negotiate for themselves, benefiting from the attorney's legal knowledge, practical experience, and emotional support.

Also, the direct involvement of an elder law attorney can be an invaluable counterweight to the facility's pressure. The attorney may participate directly in negotiations, as may a paralegal or care manager affiliated with the attorney's firm. An attorney's presence mandates more careful attention to the relevant law – the actual law, not the misapprehended law that facility staff might routinely follow. And, of course, adherence to the governing law generally is a plus for residents and their families.

There is no denying the fact that much work remains to be done. Today, too frequently, what passes for "negotiation" is a process that allows a facility to take advantage of consumers. Furthermore, the care provided is more likely to be centered on facility convenience than on residents' needs and preferences.

Nonetheless, the culture of long-term care is gradually changing, and future improvement will be greatly accelerated if consumers more consistently engage in real negotiation – before, during, and after admission. The quality of long-term care is determined, by and large, by millions of personal interactions between and among facility staff members, other health care professionals, residents, and residents' family members. Currently, residents and family members are unduly passive during a large percentage of those interactions, but an infusion of knowledge and energy promises to alter first those interactions and then the culture of long-term care generally.

245. See Podolsky, 58 Cal. Rptr. 2d at 89.
246. See 42 U.S.C. §§ 1395i-3, 1396r.
248. See generally THOMAS, supra note 2.
249. THINK TWICE BEFORE SIGNING, supra note 164, at 33.
250. Id.
251. Id.