

TRENDS AND TIPS IN LONG-TERM CARE: WHO BENEFITS — OR LOSES — FROM EXPANDED CHOICES?

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Over the past decade, the range of choices for consumers of long-term care has expanded. However, with greater choice comes greater responsibility to choose wisely. This essay examines three aspects of the trend to increase consumer choice in long-term care: 1) increased long-term care options for consumers, 2) an emphasis on providing information and statistics to consumers, and 3) increased reliance on negotiation and admission agreements to establish the standards of care and allocate risk in long-term care (especially assisted living) facilities. The author notes, however, that the positive of increased choice in each context is accompanied by the negative of diminished consumer protections and offers advice to help consumers navigate each trend.

Introduction

The last decade has seen significant changes in the long-term care landscape. A unifying theme is “choice.” An inability to live safely at home no longer leads inevitably to the door

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of the local nursing home. Options include assisted living facilities and, increasingly, long-term care provided at home.

Along with choice comes responsibility, and, indeed, consumers must shoulder more decision-making responsibility than they have in the past. Consumers and their families must consider the pros and cons of the various long-term care settings (nursing home, assisted living facility, or at-home care) and determine which is likely to be the best fit.

Also—and this is a less positive development—consumers through their choices are increasingly expected to maintain systemic quality of care. Government enforcement of standards has been deemphasized, with the implicit (and occasionally explicit) explanation that market forces will reward high-quality facilities while punishing those facilities with a record of lower quality. To support consumers in their decision making, the federal government has undertaken a substantial initiative to publish an increasing amount of information and statistics about nursing homes.

Furthermore, consumers to a certain extent—particularly in assisted living—are expected to set the standard of care through the negotiation of admission agreements. State assisted living regulations often are silent or vague on such important issues as the level of care that a facility must provide or the legal justifications for a resident's eviction. Under a common understanding of the assisted living model, these types of issues are resolved in negotiation between the resident and the facility, as memorialized in the admission agreement. Alternatively, the admission agreement simply discloses to the resident the standards followed by the facility. Under either framework, consumers must be vigilant to assure that facilities are obligated to provide a sufficient level and quality of care.

This essay will discuss three aspects of choice in long-term care: 1) increased options for consumers, 2) the emphasis on providing information and statistics to consumers, and 3) the reliance on negotiation and admission agreements to set standards of care, focusing on negotiated risk in assisted living. The increase in options is a significant positive for consumers. The availability of information and statistics also is a positive, but this positive is tempered by the concomitant de-emphasis of regulatory enforcement. Finally, the reliance on negotiation and admission agreements is a troubling negative for consumers. As a practical matter, long-term care facilities prepare pre-

printed admission agreements that are presented to consumers within a take-it-or-leave-it environment. Unfortunately, but not surprisingly, consumers routinely sign such agreements with little or no negotiation. Under these circumstances, relying on purported “negotiation” is equivalent to delegating regulatory standards to the individual long-term care facilities, which is not appropriate for or fair to consumers.

Trend #1: Consumers Increasingly Have Options for Long-Term Care.

A. Home and Community-Based Services Waivers

The increase in long-term care options is primarily attributable to increased options within the Medicaid program. The most common option is a Home and Community-Based Services waiver (HCBS waiver), also referred to as a “1915(c) waiver” due to its statutory authorization in section 1915(c) of the Social Security Act.¹ Under the waiver, Medicaid reimbursement is available only for persons whose long-term care needs would qualify them for nursing home admission, and only for those services that enable them to remain at home or (in most of the states) at an assisted living facility.² A broad package of services may be provided under the waiver, including but not limited to home health aide services, personal care services, adult day health care, home modifications, and home-delivered meals.³ Generally, the Medicaid program does not pay for room and board expenses, with the primary exception of hospitals and nursing homes.⁴

An HCBS waiver can be approved only if the waiver is deemed cost-neutral, i.e., if the overall Medicaid expenses for waiver recipients is less than what it would be for those same persons if the waiver did not exist.⁵ Cost-neutrality may or may not apply to individual beneficiaries, at the option of the state. In other words, as long as the pro-

1. 42 U.S.C. § 1396n(c) (2006).

2. §§ 1396a(a)(10)(A)(ii)(VI), 1396n(c)(1); 42 C.F.R. § 435.217 (2009).

3. 42 U.S.C. § 1396n(c)(4)(B); 42 C.F.R. § 440.180(b)(3)-(4); *CTRS. FOR MEDICARE & MEDICAID SERVS., APPLICATION FOR A §1915(C) HOME AND COMMUNITY-BASED SERVICES WAIVER* app. C (2009). Home modifications and home-delivered meals are examples of the services that are not explicitly listed in statute but are allowed under the statutory authorization of payment for “such other services requested by the State as the Secretary may approve.” § 1396n(c)(4)(B).

4. *See* 42 U.S.C. § 1396n(c)(1); 42 C.F.R. § 441.310(a)(2).

5. *See* 42 U.S.C. § 1396n(c)(2)(D); 42 C.F.R. §§ 441.203(e), 441.303(f)(1).

gram overall is cost-neutral, the state may choose to grant eligibility to individual beneficiaries even though the approval will increase Medicaid expenses for that particular beneficiary.⁶

A waiver may limit eligibility to particular areas of the state or, more commonly, to a set number of beneficiaries annually. This ability to limit eligibility is an attractive feature to state fiscal officers worried about a waiver's potential "woodwork effect": that if Medicaid were to fund an attractive variety of long-term care (as opposed to nursing home care only), people might come out of the woodwork (so to speak) seeking Medicaid assistance.⁷

Because HCBS waiver services are offered as an alternative to nursing home care, financial eligibility can be obtained not only through the state's broadly applicable standards (categorical Medicaid eligibility based on Supplemental Security Income (SSI) eligibility, for example), but also through any eligibility method specific to long-term care. The long-term-care-specific eligibility generally is based on the person having monthly income less than the state's special income limit, which can be no more than 300% of the federal SSI benefit rate.⁸ Most states in fact set their income limit at this maximum, which is \$2,022 (\$674 X 3) for 2010.

Currently, every state offers at least one Medicaid HCBS waiver, and most states offer several.⁹ Overall, approximately 300 waiver programs are in operation across the country.¹⁰

B. State-Plan Personal Care Services

State Medicaid programs also may make personal care services available as an entitlement under the Medicaid state plan. The statutory authority establishes that these services may be "furnished in a home or other location."¹¹ The federal government has explained that "other locations" in the statutory language "may be any location, as specified by the State, except for the statutorily excluded locations set

6. See, e.g., CTRS. FOR MEDICARE & MEDICAID SERVS., *supra* note 3, at app. B-2 (explaining the effects of the statute).

7. 42 U.S.C. § 1396n(c)(3); 42 C.F.R. § 441.301(a)(2).

8. 42 U.S.C. §§ 1396a(a)(10)(A)(ii)(V), 1396b(f)(4)(C).

9. ENID KASSNER ET AL., AARP PUBLIC POLICY INST., A BALANCING ACT: STATE LONG-TERM CARE REFORM 3 (2008), <http://www.ok.gov/osbeltca/documents/AARP%20Public%20Policy.pdf>.

10. *Id.*

11. 42 U.S.C. § 1396d(a)(24)(C).

forth in [the statute] (hospital, nursing facility, or [intermediate care facility for the mentally retarded]).”¹²

To be eligible for Medicaid reimbursement, the services must be either “authorized for the individual by a physician in accordance with a plan of treatment or (at the option of the State) otherwise authorized for the individual in accordance with a service plan approved by the State.”¹³ As is the case for services provided under an HCBS waiver, qualifying “personal care services” are defined in an expansive manner so the program is prepared to address the broad long-term care needs of Medicaid beneficiaries.¹⁴

State-plan personal care services are provided in thirty-four states (including the District of Columbia).¹⁵ These services are particularly prominent in states such as California, New York, and North Carolina, where the entitlement of personal care services is much more extensive than the more limited services made available through HCBS waivers.¹⁶

C. Progress in “Re-Balancing” Long-Term Care Away from Nursing Homes

The expanded use of HCBS waivers and state-plan personal care services has had an impact. Overall, state Medicaid programs have made significant progress in “re-balancing” themselves away from a nursing-home-only orientation. In 1995, for example, 17% of Medicaid funding for long-term care service was spent for services outside of a nursing home.¹⁷ By 2006, that percentage had more than doubled to 37%.¹⁸ Results are similar when the focus is limited to Medicaid funding for older adults and persons with physical disabilities: a doubling from 12% to 25% from 1995 to 2006.¹⁹

The same momentum is apparent when looking at the number of Medicaid beneficiaries receiving certain long-term care services rather

12. Medicaid Program; Coverage of Personal Care Services, 62 Fed. Reg. 47,896, 47,898 (Sept. 11, 1997); see 42 C.F.R. § 440.167(a) (2009).

13. 42 U.S.C. § 1396d(a)(24)(A); see 42 C.F.R. § 440.167(a)(1).

14. See § 440.167(a); Medicaid Program; Coverage of Personal Care Services, 62 Fed. Reg. at 47,898 (definition of “personal care services”).

15. KASSNER ET AL., *supra* note 9, at 3.

16. *Id.* at 3, 29–30, 85–88.

17. *Id.* at 4.

18. *Id.*

19. *Id.* at 5. This narrower focus excludes Medicaid beneficiaries with developmental disabilities or mental retardation.

than at dollars spent for those services. From 1999 to 2004, for older adults and persons with physical disabilities, the number of Medicaid beneficiaries receiving HCBS services or personal care services increased by approximately 43%, from approximately 935,000 to 1.3 million persons.²⁰ During the same five years, the use of nursing home services by the same population showed an increase of only approximately 6%, from approximately 1.6 to 1.7 million persons.²¹ And these numbers may actually underestimate the relative movement away from nursing homes, as the average daily nursing home census showed a 4% *decrease* during that same time period. The reason for this discrepancy is the increasing use of nursing home beds for short-term rehabilitation, which explains how the number of nursing home residents can still be increasing while the number of total nursing home days is decreasing.²²

D. Recently Authorized Programs

1. STATE-PLAN HOME AND COMMUNITY-BASED SERVICES

The Deficit Reduction Act of 2005 has introduced a new mechanism for Medicaid coverage of home and community-based services. Referred to as the “state-plan HCBS benefit,” or the “1915(i) benefit” (referring to statutory authorization in section 1915(i) of the Social Security Act), this new mechanism combines features of the HCBS waiver and state-plan personal care services.²³

Like the HCBS waiver, the state-plan HCBS benefit allows a state to offer a package of services to support persons who need long-term care. Also, as is the case with the waiver, the state has authority to cap enrollment. In other ways, however, the benefit resembles other state-plan benefits. Specifically, the state does not need to show cost-neutrality or to seek a formal waiver from the Centers for Medicare and Medicaid Services (CMS).²⁴

The state-plan HCBS benefit presents several novel twists in regard to individual eligibility. By statute, the clinical eligibility standard for the HCBS state-plan benefit must be less stringent than the clinical eligibility standard used by the state for nursing home services

20. *Id.* at vii, tbl.I.

21. *Id.* at 9.

22. *Id.*

23. See 42 U.S.C. § 1396n(i) (2006); Deficit Reduction Act of 2005, Pub. L. No. 109-171, § 6086, 120 Stat. 4, 121 (2006).

24. § 1396n(i).

or for HCBS waiver services.²⁵ Theoretically, this requirement could lead either to stricter or more lenient clinical eligibility standards depending on whether the state chooses to make its HCBS state-plan benefit standard more lenient than existing standards for long-term care eligibility or, alternatively, sets eligibility for its new state-plan benefit at the standard used until now by nursing homes and HCBS waivers and compensates by stiffening the standard that will be used by nursing homes and waivers in the future. According to CMS, the former strategy should be used, as the “purpose of the [HCBS state-plan benefit] appears to be to expand access to HCBS to individuals who are not at an institutional level of care, rather than to reduce access to institutional and waiver services.”²⁶ CMS counsels that states can avoid “complications” by “preserving existing level of care requirements, and defining the State plan HCBS benefit needs-based criteria as less stringent than the existing institutional criteria.”²⁷

On the other hand, although clinical eligibility standards for the HCBS state-plan benefit may be relatively more accommodating, the financial eligibility standards are less generous. By statute, eligibility cannot be granted to any person whose income is greater than 150% of the federal poverty line.²⁸ For 2010, accordingly, a state cannot offer state-plan HCBS eligibility to any person with a monthly income exceeding \$1,353.75 ($\$902.50 \times 150\%$), even though the maximum special income limit for long-term care services generally is \$2,022, as discussed above.

The state-plan HCBS benefit is still in a nascent stage. Thus far, only four states have received approval from CMS to offer the benefit: Colorado, Iowa, Nevada, and Washington.²⁹

2. MONEY FOLLOWS THE PERSON GRANTS

Like the HCBS state-plan benefit, the Money Follows the Person program (MFP) also was enacted as part of the Deficit Reduction Act

25. § 1396n(i)(1)(A), (B).

26. Medicaid Program: Home and Community-Based State Plan Services, 73 Fed. Reg. 18,676, 18,678 (Apr. 4, 2008) (to be codified at 42 C.F.R. pts. 431, 440, 441).

27. Medicaid Program: Home and Community-Based State Plan Services, 73 Fed. Reg. at 18,684.

28. § 1396n(i)(1).

29. GENE COFFEY, NAT'L SENIOR CITIZENS LAW CTR., THE MEDICAID LONG-TERM SERVICES AND SUPPORTS PROVISIONS IN THE SENATE'S PATIENT PROTECTION AND AFFORDABLE CARE ACT 6 (2010), http://www.nslc.org/areas/medicaid/the-medicaid-long-term-services-and-supports-provisions-in-the-senate2019s-patient-protection-and-affordable-care-act/at_download/attachment.

of 2005. Under MFP, the federal government has made grants to thirty-one selected states for five-year demonstration projects.³⁰ The goal of these projects is to enable nursing home residents to move out of their facilities into home or community-based settings. As the program name suggests, projects are to be designed so that Medicaid reimbursement can “follow” a nursing home resident who chooses to leave a nursing home for a home or community-based alternative. As stated in the legislation, the project should “[e]liminate barriers or mechanisms, whether in the State law, the State Medicaid plan, the State budget, or otherwise, that prevent or restrict the flexible use of Medicaid funds to enable Medicaid-eligible individuals to receive support for appropriate and necessary long-term services in the settings of their choice.”³¹ CMS has allocated approximately \$1.5 billion to the thirty-one states, with the expectation (based on the states’ estimates) that approximately 34,000 persons will be transitioned out of nursing homes.³²

The MFP program is limited to persons who have lived in an “inpatient facility” for six months to two years and who move into a “qualified residence.”³³ The MFP law specifies that a “qualified residence” can be the person’s home (owned or leased), a community-based residence with no more than four unrelated residents, or—and this is disqualifying language for many assisted living facilities—“an apartment with an individual lease, with lockable access and egress, and which includes living, sleeping, bathing, and cooking areas over which the individual or the individual’s family has domain and control.”³⁴

30. See DEBRA LIPSON ET AL., MATHEMATICA POLICY RESEARCH, INC., MONEY FOLLOWS THE PERSON, DEMONSTRATION GRANTS: SUMMARY OF STATE MFP PROGRAM APPLICATIONS 1, 3 (2007), <http://www.cms.hhs.gov/CommunityServices/Downloads/StateMFPGrantSummaries-All.pdf>.

31. Deficit Reduction Act of 2005, Pub. L. No. 109-171, § 6071(a)(2), 120 Stat. 4, 102 (2006).

32. Centers for Medicare & Medicaid Services, Money Follows the Person, www.cms.gov/CommunityServices/20_MFP.asp (last visited Apr. 3, 2010).

33. Deficit Reduction Act §§ 6071(b)(2)(A)–(B).

34. § 6071(b)(6).

Tip #1: Consumers Should Be Vigilant to Assure that the Increase in Consumer Options Is Not Used to Justify Reductions in Eligibility or Quality of Care Standards.

Without question, the development of long-term care options is generally a positive development for consumers. Admission to a nursing home should be a last resort, and the country's long-term care system has gone a long way in recent years to make home and community-based services a reality for Medicaid beneficiaries. But the attractiveness of this development should not obscure a risk—that the move away from nursing homes will weaken the Medicaid safety net and devalue quality of care standards. Already, examples exist where the development of non-nursing-home options has done exactly that.

A. Eligibility Cutbacks

Nursing home care under Medicaid is a mandatory service: it must be provided to every qualified beneficiary.³⁵ Vermont, however, recently restricted nursing home eligibility through a Medicaid demonstration waiver entitled Choices for Care that allowed the state to whittle back on this entitlement.³⁶ Under the waiver, the persons previously eligible for either nursing home services or home and community-based services were reclassified into two groups: highest need and high need. In this reclassification, the "high need" group lost its entitlement to long-term care services, and thereafter would receive services only as funds were available. On the other hand, a limited package of services was extended to a "moderate need" group, with the intent that those services would prevent deterioration and allow the moderate-need persons to remain at home longer.³⁷

Although Choices for Care was promoted as an expansion of home and community-based services, the flexibility granted by the waiver has allowed the state to cut back on both nursing home services and home and community-based services. At the beginning of 2008, enrollment in the high-need group was open, with beneficiaries having access to either nursing home services, assisted living care

35. 42 U.S.C. §§ 1396a(a)(10)(A), 1396d(a)(4) (2006).

36. See KAISER FAMILY FOUND., THE VERMONT CHOICES FOR CARE LONG-TERM CARE PLAN: KEY PROGRAM CHANGES AND QUESTIONS (2006), <http://www.kff.org/medicaid/upload/7540.pdf>.

37. CTRS. FOR MEDICARE & MEDICAID SERVS., STATE OF VERMONT "CHOICES FOR CARE" DEMONSTRATION WAIVER OPERATIONAL PROTOCOL 3 (2005).

(called enhanced residential care), or home and community-based services. In March 2008, however, enrollment in the high-need group was frozen, leading to an enrollment drop of almost 27% (from 745 to 545) from May 2008 to October 2009.³⁸ This 200-person drop was comprised of 161 recipients of home and community-based services, thirty-eight assisted living residents, and one nursing home resident.

Only in late 2009 and early 2010 did the Vermont Medicaid program make some effort to reverse the decline by adding approximately 100 enrollment slots back into the high-need program. Meanwhile, however, in November 2009 Vermont froze enrollment for the moderate-need program.³⁹

B. Lesser Quality-of-Care Standards

The quality-of-care issue arises from the fact that federal law contains strong protections for nursing home residents but generally defers to state law for Medicaid-funded home and community-based services, whether those services are provided in an assisted living facility or at the beneficiary's home. This state law likely is relatively loose (in the case of assisted living facilities) or nonexistent (for in-home care).

The federal Nursing Home Reform Law is extensive, and it is not this essay's intent to argue that all nursing home regulations be extended to assisted living facilities and at-home services.⁴⁰ But the inappropriateness of equivalent regulations certainly does not justify the very minimal quality-of-care standards that currently apply to Medicaid HCBS-funded assisted living services and at-home care—particularly considering that Medicaid HCBS waiver funding is only available to persons with care needs that would qualify them for nursing home admission.

One good example is how Medicaid-certified assisted living facilities often have the freedom to discriminate against Medicaid beneficiaries. Some assisted living facilities refuse to accept Medicaid

38. Memorandum from Joan Senecal, DAIL Comm'r, and Joshua Slen, Office of Vt. Health Access, to Rep. Martha Heath and Rep. Mark Larson, LTC Choices for Care FY09 Appropriation (Mar. 7, 2008).

39. Memorandum from Lorraine Wargo, Div. Director, Div. of Disability & Aging Servs., to Choices for Care Moderate Needs Providers, Moderate Needs Program Enrollment Freeze (Nov. 3, 2009).

40. See 42 U.S.C. §§ 1395i-3, 1396r (2006) (Nursing Home Reform Law); 42 C.F.R. §§ 483.1-483.75 (2009) (regulations implementing Nursing Home Reform Law).

reimbursement from a resident unless the resident already has paid privately for a specified period of months. The routineness of such requirements is illustrated by disclosure statements used by New Jersey assisted living facilities at the state's direction. Among the topics required by the state to be disclosed is "Spend-down (private pay) requirements before you accept the person on the Medicaid Waiver, e.g.: none, one year, two years, other."⁴¹

Such a requirement, although evidently routine in New Jersey, is obviously unfair to Medicaid beneficiaries because by definition a Medicaid-eligible resident is indigent and will not be able to pay for assisted living care if the facility refuses Medicaid coverage. Notably, the federal Nursing Home Reform Law prohibits a nursing home from imposing such a requirement by barring any waiver of a beneficiary's Medicaid coverage.⁴²

Trend #2: Consumers Have Access to Extensive Information About Individual Nursing Homes.

Consumer information and especially ratings systems are becoming more and more common, in part driven by Internet technology. A 2009 *Atlantic* article predicts the future:

[R]ating is about to spread like a pandemic. Everything—everyone—will get rated by Web users. You. Me. The dentist. All the hairstylists in town. The sermons in every place of worship. Youth soccer coaches. Lunch meats. Wine. The fact is, on tomorrow's Internet, everyone will know if you're a dog.⁴³

To a certain extent, the future is already here for nursing homes. The federal government, as discussed in detail below, has developed a Web site that contains voluminous statistical information on nursing homes across the country. Furthermore, the federal site has hastened the development of a plethora of private Internet sites. Even a casual Google search uncovers multiple private sites that repackage portions of the federal information for consumers.⁴⁴

41. N.J. Dep't of Health & Senior Servs., Div. of Aging & Cmty. Servs., Policy Memorandum # 2004-5, VIII-1, Disclosure of Assisted Living Facilities' Medicaid Policies (July 30, 2004).

42. 42 U.S.C. §§ 1395i-3(c)(5)(A)(i), 1396r(c)(5)(A)(i); 42 C.F.R. § 483.12(d)(1).

43. Kevin Maney, *The Rating Game*, ATLANTIC, July/Aug. 2009, at 38, 38.

44. See, e.g., HealthInsight, National Rankings for Nursing Homes, http://www.healthinsight.org/performance/nh_rankings/rankings.html (last visited Apr. 3, 2010); U.S. News & World Report, America's Best Nursing Homes, <http://health.usnews.com/health/best-nursing-homes> (last visited Apr. 3, 2010).

A. Resident Assessment Information Used for Quality Measures

The federal government's information includes data regarding individual nursing home residents. This data is drawn from the assessments that by law must be performed by a nursing home within fourteen days after a resident's admission, at least once every twelve months thereafter, and "promptly after a significant change in the resident's physical or mental condition."⁴⁵ The assessment must include certain information specified by CMS, called the Minimum Data Set (MDS).⁴⁶ Federal regulations list eighteen topics that must be included in the Minimum Data Set, including a resident's customary routine, cognitive patterns, communication, mood and behavior patterns, psychosocial well-being, physical functioning, skin condition, and discharge potential.⁴⁷

There are years of development, testing, and debate behind the documents used to gather and report the required information. A document entitled MDS 2.0 has been in use in recent years, but it will be replaced by MDS 3.0 beginning on October 1, 2010.⁴⁸

The data from assessments first is used, naturally, in care planning for the individual resident.⁴⁹ In addition, at the end of each month, the nursing home electronically transmits all of that month's assessment data to the state, which in turn sends the data to CMS.⁵⁰ CMS and the states use this data in the enforcement of the Nursing Home Reform Law by, for example, identifying outlier nursing homes and, for particular nursing homes, identifying areas in which the nursing home may be having quality-of-care problems.⁵¹

Also, CMS publishes this data on its Nursing Home Compare Web site as "quality measures."⁵² There are fourteen quality measures that pertain to long-stay residents; these include the percentages of residents who have pressure sores, have moderate to severe pain, are

45. 42 U.S.C. §§ 1395i-3(b)(3)(C)(i), 1396r(b)(3)(C)(i); 42 C.F.R. § 483.20(b).

46. 42 U.S.C. §§ 1395i-3(b)(3)(A)(ii), (f)(6)(A), 1396r(b)(3)(A)(ii), (f)(6)(A).

47. 42 C.F.R. § 483.315(e).

48. Centers for Medicare & Medicaid Services, MDS 3.0 for Nursing Homes and Swing Bed Providers, http://www.cms.gov/Nursinghomequalityinits/25_NHQIMDS30.asp (last visited Apr. 3, 2010).

49. 42 U.S.C. §§ 1395i-3(b)(2), 1396r(b)(2); 42 C.F.R. § 483.20(k)(2)(ii).

50. 42 C.F.R. § 483.315(h)(1).

51. Medicare and Medicaid: Resident Assessment in Long Term Care Facilities, 62 Fed. Reg. 67,174, 67,178-81 (Dec. 23, 1997) (to be codified at 42 C.F.R. pt. 483).

52. Medicare.gov, Nursing Home Compare, <http://www.medicare.gov/NHCompare> (last visited Apr. 3, 2010).

incontinent, have become more depressed or anxious in the nursing home, or spend more of their time in a bed or chair. Five quality measures are used for short-stay residents; these include the percentages of residents who have delirium, moderate to severe pain, or pressure sores. For all of these percentages, the Nursing Home Compare Web site shows the relevant percentage for the facility, along with corresponding national percentage and the percentage for all facilities from the same state.

B. Inspection Information

The Nursing Home Compare Web site also contains information about a facility's inspection results. The inspection information includes the date of the most recent inspection, along with the total number of health deficiencies. To put this number in context, the site also includes the average numbers of deficiencies for nursing homes in the nation and for nursing homes in the same state.

This summary information is followed by more specific information about each of the recorded deficiencies, listing the date, scope, and severity of the deficiency. The scope of a deficiency is characterized within CMS as isolated, constituting a pattern, or widespread.⁵³ For the Nursing Home Compare Web site, these categories are translated for a consumer audience into "few," "some," or "many" residents affected by the deficiency.

For severity, CMS uses four categories: 1) no actual harm with a potential for minimal harm, 2) no actual harm with a potential for more than minimal harm, but not immediate jeopardy, 3) actual harm that is not immediate jeopardy, and 4) immediate jeopardy to resident health or safety.⁵⁴ For the Nursing Home Compare Web site, these categories are translated for consumers as 1) potential for minimal harm, 2) minimal harm or potential for actual harm, 3) actual harm, and 4) immediate jeopardy.

C. Staffing Information

The Nursing Home Compare Web site lists staffing information for three separate categories: licensed nurses, registered nurses, and certified nursing assistants. The staffing is listed in terms of hours per

53. 42 C.F.R. § 488.404(b)(2).

54. § 488.404(b)(1).

resident day. For example, if a nursing home had 100 residents and employed 10 nursing assistants on every shift, the nursing home daily would be providing 240 hours of nursing assistant services, or 2.4 hours per resident per day (240 hours ÷ 100 residents = 2.4 hours per resident per day). As is the case with both quality measures and inspection information, the Web site includes the staffing information from the individual nursing home along with the comparable information from nursing homes nationwide and in the same state.

D. Five-Star Rating System

1. INITIAL RATING BASED ON INSPECTION RESULTS

Since late 2008, the Nursing Home Compare Web site has included a five-star rating system to synthesize the site's information on quality measures, inspection results, and staffing. The calculations start with the inspection results. Each deficiency is assigned a point value based on the recorded scope and severity. The highest point value of 175 points is assigned for a deficiency that has caused immediate jeopardy to resident health or safety, is widespread in scope, and has led to a finding of substandard quality of care. If, however, a deficiency is linked to actual harm that is not immediate jeopardy and has a scope of "pattern" rather than widespread, then only thirty-five points are assessed. At an even lower rung, only four points are assessed for a deficiency that causes "no actual harm with potential for more than minimal harm that is not immediate" and has an "isolated" scope. These are only examples; CMS has developed a matrix that lists point values for the various combinations of scope and severity.⁵⁵

Additional points are assessed if surveyors need to do revisits to verify compliance. The first revisit is "free," but the second, third, and fourth revisits are assessed 50%, 70%, and 85% of the original inspection score, respectively.⁵⁶

All of these points are weighed depending on recency: one-half value for inspections from the past year (roughly), one-third value for deficiencies from the prior year, and one-sixth value for the year before that. Then stars are assigned based on a curve.⁵⁷ In each state, the top 10% of facilities receive an initial rating of five stars, and the

55. CTRS. FOR MEDICARE & MEDICAID SERVS., DESIGN FOR NURSING HOME COMPARE FIVE-STAR QUALITY RATING SYSTEM: TECHNICAL USERS' GUIDE 5 (2010).

56. *Id.* at 4-5.

57. *Id.* at 4-6.

bottom 25% receive one star. The 70% in the middle receive four, three, or two stars, with essentially even distribution (i.e., approximately a range of 23.33% of the facilities for each star rating).⁵⁸

2. RATING INCORPORATING STAFFING AND QUALITY MEASURES

This initial star rating is only the starting point. CMS calculates separate star ratings based on staffing and quality measures and uses the staffing and quality-measure star ratings to convert the inspection star rating into the final rating.

The staffing rating is based on the ratio of employees to residents for all direct-care employees (nurses and nursing assistants) and only for registered nurses; these two measures are weighted equally in determining the staffing rating. The ratios are adjusted to account for the severity of residents' care needs.

A one-star staffing rating is assessed if either the direct-care ratio or the registered nurse ratio falls within the bottom 25% compared to other facilities in the state and the other ratio falls below the median. On the other end of the spectrum, a five-star staffing rating is assessed if the facility exceeds CMS aspirational standards for both direct-care staffing and registered nurse staffing (at least 4.08 hours per resident per day of direct-care staffing, and 0.55 hours per resident per day of registered nurse staffing). Ratings of two, three, or four stars are assigned depending on the quartiles in which the facility's staffing ratios fall.⁵⁹

The calculations related to quality measures are even more complicated, and can only be summarized here. CMS considers ten quality measures, seven of which pertain to long-stay residents. After these measures are tallied, weighed, and combined, stars are assessed in the same way that they are assessed for quality measures—five stars for the top 10%, one star for the bottom 20%, and two, three, or four stars given with an equal distribution within the remaining 70%.⁶⁰

3. CALCULATING THE OVERALL RATING

For the overall rating, the starting point is the star rating from the inspection reports. Then, based on the staffing ratios, one star is

58. *Id.* at 6.

59. *Id.* at 10-11.

60. *Id.* at 11-15 tbl.5.

added if the facility received a four- or five-star staffing rating and the staffing rating is higher than the facility's inspection rating. One star is subtracted if the facility received a one-star staffing rating. The resulting rating cannot be more than five stars or less than one star.

The quality measures then are factored in. One star is added if the facility received a five-star rating on quality measures, and one star is subtracted if the facility received only one star on quality measures. Again, the overall rating cannot be more than five stars or less than one star.⁶¹

Tip #2: Rankings Are Not Gospel, and Statistical Information Is Helpful but Not Sufficient.

Consumers generally are unfamiliar with nursing homes and do not think about nursing homes until the need is immediate and undeniable. One study involving 306 sets of nursing home residents and family members 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.⁶²

Furthermore, statistical information may not be as helpful as Nursing Home Compare and the other long-term care Web sites would suggest. One researcher, in an essay organized around her experiences with her mother, points out the weakness of a model that depends upon long-term care consumers making information-driven decisions.

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.⁶³

61. *Id.* at 16.

62. Nicholas G. Castle, *Searching for and Selecting a Nursing Facility*, 60 *MED. CARE RES. & REV.* 223, 223 (2003).

63. Deborah Stone, *Shopping for Long-Term Care*, *HEALTH AFF.*, July-Aug. 2004, at 191, 192.

For better or for worse, nursing homes cannot be reduced accurately to a set of numbers, no matter how sophisticated the measures. In any case, most consumers are not in a position to weigh, understand, or even consider much of the available nursing home information.

This is not to say that nursing home statistics should not be compiled or published. The point rather is that statistics are useful but not sufficient, both for the federal government and for consumers. The federal government, for example, should put additional resources into enforcement, recognizing that the Five-Star System specifically and Nursing Home Compare more generally are not adequate to maintain nursing home quality.

For their part, consumers cannot assume that star ratings and other numerical measures are determinative. As much as a potential resident might want to rely mechanically on such measures, decision making about long-term care cannot be so simple.

In large part, the quality of a nursing home depends upon the character and culture of its management and staff, and the best way to judge that is for a potential resident (or family member) to speak personally with the facility administrator and other staff members. For example, better facilities will make accommodations for a resident's preferences, and a question regarding accommodations and preferences can lead to very revealing responses from facility representatives. Also, potential residents and family members are well-advised to speak with current residents and their families because the current residents and family members are the best persons to comment on the facility's pluses and minuses.

Trend #3: The Assisted Living Model Relies on Negotiation, and Some Facility Representatives Claim that a Resident May Negotiate to Waive the Facility's Liability.

In long-term care, negotiation is most often discussed in reference to assisted living. Assisted living regulations often are vague, relying explicitly or implicitly on negotiation to fill in the gaps in the regulations. Illinois law is particularly articulate on this topic, describing assisted living as "a social model that promotes [residents'] dignity, individuality, privacy, independence, autonomy, and deci-

sion-making ability and the right to negotiated risk,” and emphasizing that a consumer may even negotiate away consumer protection:

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.⁶⁴

Most commonly, negotiation-based models appear in state assisted living law through disclosure requirements. These laws’ premise is that consumers will be protected if facilities are required to disclose up front certain important aspects of the care to be provided.⁶⁵

An extreme example of negotiation in assisted living is the concept of negotiated risk, which originally was envisioned as a means for an assisted living facility to avoid liability for inadequate supervision or health care.⁶⁶ As explained by a provider attorney in a 1995 article, some assisted living 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.”⁶⁷

Another provider attorney explained 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

64. ILL. ADMIN. CODE tit. 77, § 295.100(a) (2010).

65. See, e.g., 40 TEX. ADMIN. CODE § 92.51 (2010); TEX. HEALTH & SAFETY CODE ANN. § 247.026(b)(4)(B) (Vernon 2009) (state-developed standardized disclosure form); 13-110-007 VT. CODE R. § 6.11 (2010) (required disclosure of services, rates, and admission/discharge criteria); see also Patrick A. Bruce, Note, *The Ascendancy of Assisted Living: The Case for Federal Regulation*, 14 *ELDER L.J.* 61, 73-74 (2006) (disclosure requirements in state law).

66. This essay’s discussion of negotiated risk is adapted in part from Eric Carlson, *Protecting Rights or Waiving Them? Why ‘Negotiated Risk’ Should Be Removed from Assisted Living Law*, 10 *J. HEALTH CARE L. & POL’Y* 287 (2007).

67. Joseph Bianculli, *Negotiated Risk—An Operational Issue*, *PROVIDER*, Nov. 1995, at 32, 32.

for their care.”⁶⁸ In accord, a 2004 article in *Assisted Living Today* (the magazine of the Assisted Living Federation of America) listed a “managed risk agreement” as one of ten techniques to be used by an assisted living facility to “avoid costly litigation.”⁶⁹ The article’s discussion of managed risk 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.”⁷⁰ 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.”⁷¹

Tip #3: Negotiated Risk Agreements Are Inappropriate and Unenforceable, as an Admission Agreement Cannot Include Liability Waivers.

Negotiated risk proponents ignore a fundamental issue—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. As one commenter notes, “[i]n the field of medical risks, courts have generally rejected out-of-hand attempts by physicians and hospitals to shift the risk of negligence to patients.”⁷²

68. COMM’N ON AFFORDABLE HOUSING & HEALTH FACILITY NEEDS FOR SENIORS IN THE 21ST CENTURY (Nov. 7, 2001) (testimony of John Durso); *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 no longer able to meet their identified 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, “the 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”); 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).

69. Donna Fudge, *Staying Out of Court: Use These 10 Tips to Avoid Costly Litigation*, ASSISTED LIVING TODAY, Jan.–Feb. 2004, at 18.

70. *Id.* at 20.

71. *Id.* at 20–21.

72. Glen O. Robinson, *Rethinking the Allocation of Medical Malpractice Risks Between Patients and Providers*, 49 LAW & CONTEMP. PROBS. 173, 184 (1986).

In the seminal case of *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 seller's control.⁷³ The *Tunkl* test is to a certain extent a balancing test, not requiring that all six factors be present. In the case of negotiated risk, however, each of the six factors is present.

In the only published case on these issues, the Delaware Superior Court refused to enforce a liability waiver in an assisted living admission agreement.⁷⁴ A fall in an assisted living facility had caused a resident to suffer irreversible brain damage and permanent physical impairments. 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.*⁷⁵

The court rejected the facility's assumption of risk defense, distinguishing assisted living from recreational sports, which is the context in which assumption of risk most commonly has 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 with knowledge that participants might not act with ordinary care.⁷⁶

Neither of the common themes, however, 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

73. 383 P.2d 441, 445-47 (Cal. 1963).

74. *Storm v. NSL Rockland Place, LLC*, 898 A.2d 874, 887 (Del. 2005).

75. *Id.* at 878-79 (emphasis added).

76. *Id.* at 883.

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.⁷⁷

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.⁷⁸

The message for residents and family members is simple: they should not sign negotiated risk agreements or any other types of liability waivers. A similar message should be communicated to facility operators, as negotiated risk or similar concepts are ultimately counterproductive. Any provider of long-term care services should be prepared to provide adequate care, whether or not the resident signs a liability waiver. One way or another, a system based on inadequate care is not sustainable.

Conclusion

Expanded choice is the most conspicuous and important development in long-term care policy over the past fifteen years. Prior to that time, nursing home care was virtually synonymous with long-term care, and consumers felt consigned to nursing homes when they could no longer live independently. Now, however, at-home care is much more available, and assisted living facilities are full of residents who in the past would have been living in nursing homes.

The movement away from nursing homes, however, should not be made at the expense of consumer protections. Those protections are just as essential for at-home care and assisted living care as they

77. *Id.* at 884.

78. *Id.* at 885.

have proven to be for nursing home care. Within Medicaid programs, entitlements to necessary long-term care services should be maintained. Also, standards of care should be maintained or developed via regulation and should not be left to be negotiated between the consumer and the long-term care provider. In practice, "negotiation" is a misnomer for what actually occurs. Admission agreements and service agreements in fact are generally developed by the provider and presented to the consumer on what is, or will appear to the consumer to be, a take-it-or-leave-it basis. Thus, because consumers realistically cannot negotiate for standards of care, regulatory standards are necessary to protect consumers adequately.

The concept of consumer choice has become prominent also for nursing home policy, as shown by the extensive resources devoted by CMS to Nursing Home Compare and the Five-Star Rating System. Here again, the emphasis on choice should not detract from consumer protections. While consumers benefit from the extensive on-line information on individual nursing homes, the availability of that information cannot substitute for regulatory standards and enforcement.