

BIG BROTHER IS WATCHING AT COUNTRY MEADOWS: A NEW THEORY OF SURVEILLANCE TO PROTECT OUR ELDERS WITH DEMENTIA

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ABSTRACT

More than 50% of residents in nursing facilities¹ have some form of dementia² or cognitive impairment. For the past thirty years, the federal nursing home regulatory scheme has suffered from being predominantly self-regulating and self-reporting. Recommendations for reforms have focused on increased surveillance of nursing home staff and residents without addressing the need to tailor nursing home requirements or quality of care metrics to the growing population of residents with dementia. In light of the growing evidence that a “person-centered care” approach best addresses the day-to-day challenges of dementia, federal policy should blend

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1. This figure includes assisted living and nursing homes. ALZHEIMER'S ASSOCIATION, DEMENTIA CARE PRACTICE RECOMMENDATIONS FOR ASSISTED LIVING RESIDENCES AND NURSING HOMES 1 (2009), http://www.alz.org/national/documents/brochure_dcprphases1n2.pdf [hereinafter ALZHEIMER'S ASS'N, PHASES 1 & 2]. For purposes of this Note, two categories of nursing homes are considered: nursing homes that accept reimbursement from Medicaid (nursing facility [hereinafter “NF”]) and nursing homes that accept reimbursement from Medicare (skilled nursing facility [hereinafter “SNF”]). See generally *What is the Difference Between NFs and SNFs?*, PREADMISSION SCREENING AND RESIDENT REVIEW TECHNICAL ASSISTANCE CTR. (July 5, 2011), <http://www.pasrassist.org/resources/snf-nf/what-difference-between-nfs-and-snfs>. “Most facilities are certified as both NFs and SNFs. A given facility can have both ‘NF beds’ and ‘SNF beds’; they are ‘dually certified.’” *Id.* If a resident qualifies for both Medicare and Medicaid, otherwise known as “a dual-eligible,” that resident “can move from the SNF portion of a facility (which provides rehabilitative care) to the NF portion of a facility (in the event that long-term care is needed).” *Id.*

2. “Dementia is not a specific disease. It’s an overall term that describes a wide range of symptoms.” *What is Dementia?*, ALZHEIMER'S ASS'N, <http://www.alz.org/what-is-dementia.asp> (last visited Nov. 22, 2016).

person-centered care with the “surveillance quo.”³ Other recommendations for dementia reform have built upon the nursing home culture of surveillance. Some of these recommendations include decreasing the use of anti-psychotic medications in residents with dementia, installing video cameras (“granny cams”) in dementia units, and increasing reporting requirements and the frequency of survey visits. Meanwhile, federal policy has been slow to adopt a person-centered care approach because of the approach’s subjective nature and tension with a medicalized environment. Proponents of person-centered care dementia reform have failed to acknowledge that the approach must co-exist with the surveillance quo, at least during its initial acceptance and adoption by federally funded nursing facilities.

Although the Centers for Medicare and Medicaid Services (“CMS”) has acknowledged person-centered care in its initiatives and regulations, CMS should promote person-centered care as complementary to the surveillance quo. Using CMS’s Proposed Rule, Reform of Requirements for Long-Term Care Facilities (“Proposed Rule”), this Note analyzes the Proposed Rule and comments to show how CMS can advance its growing commitment to person-centered care through new metrics for the Nursing Home Compare website. These metrics would confirm the co-existence of person-centered care with the surveillance quo and, most importantly, disseminate information about nursing facilities’ dementia care to the public.

3. The term “surveillance quo” is used throughout this Note to refer to the culture of surveillance of staff and residents in nursing homes. Twentieth-century philosopher Michel Foucault wrote about institutional surveillance dating back to eighteenth-century philosopher Jeffrey Bentham’s “Panopticon” design of prison. See generally MICHEL FOUCAULT, DISCIPLINE AND PUNISH (Alan Sheridan trans., Vintage Books 2d ed. 1995) (1977) (positing that the Panopticon design, which had become popular in—among other settings—prisons, schools, and psychiatric institutions, kept a population under control through differentials of power and observation).

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INTRODUCTION

It has been a tough year for you and your family. Six months ago, your eighty-year-old grandfather fell in his apartment and was rushed to the hospital, where he was diagnosed with a subdural hematoma.⁴ Even though the doctors were able to relieve the pressure and bleeding in his brain, the injury has left Grandpa with a fractured neck and spine, incontinent, unable to swallow, confused, and angry. The surgeon tells you that his prognosis is uncertain.

4. "A subdural hematoma is a collection of blood between the covering of the brain (dura) and the surface of the brain." *Subdural Hematoma*, MEDLINEPLUS, <https://medlineplus.gov/ency/article/000713.htm> (last updated July 27, 2014).

Nearly a month after recovering in the hospital, your grandfather is discharged to a post-acute care center, where he is largely comatose on a cocktail of antipsychotic medications⁵ and left in a common room watching television for most of the day. After several falls at this facility, your family relocates your grandfather to a rehabilitation hospital. While he is making slow progress there, Grandpa develops a life-threatening case of pneumonia and is rushed to the emergency room. He is intubated and admitted to the hospital's intensive care unit. After nine days, his breathing tube is removed. He is still on antipsychotic medications, confused, and angry.

A month passes while your family desperately searches for an appropriate place for your grandfather to go following discharge from the hospital. Finally, Grandpa is accepted to the memory care (dementia) unit at a long-term nursing care center. Three weeks into his stay, you visit him and notice an incredible amount of improvement. Grandpa is no longer on antipsychotic medications. He reads the newspaper. He sings show tunes with the physical therapists. He is still on a feeding tube, but speech therapy is helping him learn to swallow again. Another three weeks later, Grandpa is moved from the dementia unit to the traditional long-term nursing care wing. Here, he does not interact as much with the staff. Your family buys Grandpa a cell phone, but he calls himself "stupid" for not knowing how to use it. He begins to exhibit signs of depression. However, he seems content participating in resident activities like bingo and trivia.

Throughout this ordeal, your family used the Centers for Medicare & Medicaid Services ("CMS") Nursing Home Compare tool⁶ to find out more about the facilities to which your grandfather was admitted. Knowing that he had brain-injury-induced dementia, it was important to your family to know how each facility treated residents with these symptoms. However, the rating system did not include dementia-specific metrics, and the overall rating was not representative of your grandfather's particular experience. For example, the facility with the dementia unit has an overall rating of two

5. For a review of the use of antipsychotic medications in nursing home residents, see *generally* OFFICE OF INSPECTOR GEN., U.S. DEP'T OF HEALTH & HUMAN SERVS., OEI-07-08-00150, MEDICARE ATYPICAL ANTIPSYCHOTIC DRUG CLAIMS FOR ELDERLY NURSING HOME RESIDENTS (2011).

6. "Nursing Home Compare [provides] detailed information about every Medicare and Medicaid-certified nursing home in the country." *Nursing Home Compare*, MEDICARE.GOV, <https://www.medicare.gov/nursinghomecompare/search.html> (search by zip code, city, state, or nursing home name) (last visited Nov. 22, 2016).

out of five stars, while the post-acute care center—where Grandpa developed pneumonia—has an overall rating of five out of five stars.

This experience highlights many problems with the current federal regulation and reporting system for nursing facilities caring for patients or residents with dementia. Dementia is becoming increasingly prevalent among nursing facility residents,⁷ but the regulatory landscape does not reflect the particular needs of these residents. Instead, the regulatory landscape is entrenched in a culture of surveillance that offers little room for dementia reform that is inconsistent with the surveillance quo.⁸

Moreover, publicly available resources do not reveal how a facility manages dementia. In 2012, CMS launched the National Partnership To Improve Dementia Care in Nursing Homes (“National Partnership”), which has reported little activity since its inception, but has expressed a commitment to person-centered care.⁹ Furthermore, in its Proposed Rule, CMS acknowledged person-centered care, but did not suggest substantial reforms to requirements of long-term care facilities consistent with the approach.¹⁰

This Note argues that the current regulatory landscape suffers from touting non-specific criteria for assessing the success of nursing homes in caring for residents with dementia. Moreover, CMS and the National Partnership can, and should, create new dementia care metrics for Nursing Home Compare that blend person-centered care and the surveillance quo. Crafting new metrics would constitute a concrete step toward incorporating person-centered care into federal policy. In addition, disseminating this information is crucial to the public’s understanding of how a nursing facility manages the day-to-day challenges of dementia. Part II of this Note provides background information on dementia and highlights federal nursing

7. ALZHEIMER’S ASS’N, DEMENTIA CARE PRACTICE RECOMMENDATIONS FOR ASSISTED LIVING RESIDENCES AND NURSING HOMES: PHASE 3 END-OF-LIFE CARE 1 (2007), https://www.alz.org/national/documents/brochure_dcprphase3.pdf [hereinafter ALZHEIMER’S ASS’N, PHASE 3].

8. See *infra* Part II.B.

9. National Partnership to Improve Dementia Care in Nursing Homes, NAT’L NURSING HOME QUALITY IMPROVEMENT CAMPAIGN, <https://www.nhqualitycampaign.org/dementiaCare.aspx> (last updated Oct. 27, 2016).

10. Medicare and Medicaid Programs; Reform of Requirements for Long-Term Care Facilities, 80 Fed. Reg. 42,168, 42,174 (proposed July 16, 2015) (to be codified at 42 C.F.R. pts. 405, 431, 447, 482, 483, 485, and 488) [hereinafter Proposed Rule]. Recently, CMS issued the Final Rule, wherein it again acknowledged person-centered care but declined to implement meaningful reforms. See Medicare and Medicaid Programs; Reform of Requirements for Long-Term Care Facilities, 81 Fed. Reg. 68,688, 68,692 (Oct. 4, 2016) (to be codified at 42 C.F.R. pts. 405, 431, 447, 482, 483, 485, 488, and 489) [hereinafter Final Rule].

home regulation.¹¹ It then considers previous dementia care reforms that have focused on increased surveillance of nursing home residents and staff.¹² Rounding out Part II is an introduction to person-centered care.¹³ Part III begins with an explanation for why person-centered care should be reconciled with the surveillance quo.¹⁴ It then analyzes several comments to CMS's Proposed Rule on Reform of Requirements for Long-Term Care Facilities to show how new regulations are still missing the mark when it comes to introducing person-centered care into federal policy.¹⁵ Finally, this Note concludes by offering several proposed metrics for the CMS Nursing Home Compare website to show how person-centered care should be adopted into the current surveillance quo.¹⁶

I. BACKGROUND

According to the Alzheimer's Association, "[d]ementia is a general term for a decline in mental ability severe enough to interfere with daily life."¹⁷ Dementia is considered symptomatic of conditions causing cognitive decline, and the term refers to "symptoms typically characterized by a loss of cognitive ability, impairment in memory, and brain changes in areas such as language, reasoning, and judgment severe enough to interfere with everyday functioning."¹⁸ Alzheimer's disease is the most common type of dementia, accounting for 60–80% of cases.¹⁹ Alzheimer's disease is the sixth leading cause of death in the United States.²⁰ The second most common type of dementia is vascular dementia, which occurs after a stroke.²¹ Other types of dementia include "dementia with Lewy bodies, Parkinson's disease, and frontotemporal lobar degeneration."²²

11. See *infra* Part II.A.

12. See *infra* Part II.B.

13. See *infra* Part II.C.

14. See *infra* Part III.A.

15. See *infra* Part III.B.

16. See *infra* Part III.C.

17. *What is Dementia?*, *supra* note 2.

18. DEMENTIA INITIATIVE, DEMENTIA CARE: THE QUALITY CHASM 4 (2013) <http://www.ahcancal.org/ncal/quality/qualityinitiative/Documents/Dementia%20CareThe%20Quality%20Chasm.pdf> [hereinafter THE QUALITY CHASM].

19. *What is Dementia?*, *supra* note 2.

20. THE QUALITY CHASM, *supra* note 18, at 9.

21. *What is Dementia?*, *supra* note 2.

22. NAT'L CTR. FOR ASSISTED LIVING, GUIDING PRINCIPLES FOR DEMENTIA CARE 2 (2014), <http://www.ahcancal.org/ncal/quality/documents/guidingprinciplesdementiacare.pdf> [hereinafter NCAL GUIDING PRINCIPLES].

“Over five million Americans—one in eight age [sixty-five] and older and one in three age [eighty-five] and older—are living with dementia”²³ “Nearly all adults with dementia . . . receive Medicare benefits,”²⁴ and those adults who are eligible for both Medicare and Medicaid (“dual eligibles”) are “three times more likely to suffer from dementia as Medicare-only patients.”²⁵ Dual eligibles pose special problems for the federally-funded bifurcated healthcare system: according to a report issued by CMS, “[a]ligning Medicare and Medicaid to streamline coverage for beneficiaries dually eligible for both programs has been more difficult and time consuming than anticipated.”²⁶ It was estimated that in 2015 alone, the United States would spend \$226 billion to care for individuals with Alzheimer’s and other types of dementia, with half of the costs borne by Medicare.²⁷

Medicare and Medicaid spending on Americans with dementia continues to climb because the population of nursing home residents with dementia has grown significantly over the years. As of 2012, more than 48% of nursing home residents were diagnosed with Alzheimer’s disease or another dementia and/or depression.²⁸ In more recent years, “[m]ore than [50%] of residents in assisted living and nursing homes have some form of dementia or cognitive impairment.”²⁹

23. Bill Frist, *Making Dementia Friendly Communities the New Normal*, FORBES (July 31, 2015, 10:47 AM), <http://www.forbes.com/sites/billfrist/2015/07/31/making-dementia-friendly-communities-the-new-normal>.

24. RACHEL GARFIELD ET AL., THE KAISER COMM’N ON MEDICAID AND THE UNINSURED, MEDICAID’S ROLE FOR PEOPLE WITH DEMENTIA 1 (2015), <http://files.kff.org/attachment/issue-brief-medicaids-role-for-people-with-dementia>.

25. Bill Myers, *Dual Eligibles Bear Brunt of Dementia’s Ravages, Study Finds*, PROVIDER (May 31, 2012), <http://www.providermagazine.com/news/Pages/Dual-Eligibles-Bear-Brunt-Of-Dementia%E2%80%99s-Ravages-Study-Finds.aspx>.

26. Mindy Yochelson, *Duals Demo Proves Challenging, CMS Report Says*, [Feb. 3, 2016] Health Ins. Rep. (BNA) (Jan. 27, 2016).

27. Frist, *supra* note 23.

28. Proposed Rule, *supra* note 10, at 42,174 (citing L. HARRIS-KOJETIN ET AL., CTRS. FOR DISEASE CONTROL & PREVENTION, U.S. DEP’T OF HEALTH & HUMAN SERVS., LONG TERM CARE SERVICES IN THE UNITED STATES: 2013 OVERVIEW 35 fig.23 (2013), http://www.cdc.gov/nchs/data/nsltcp/long_term_care_services_2013.pdf).

29. ALZHEIMER’S ASS’N, PHASE 3, *supra* note 7, at 1; *see also* L. HARRIS-KOJETIN ET AL., CTRS. FOR DISEASE CONTROL & PREVENTION, U.S. DEP’T HEALTH & HUMAN SERVS., LONG TERM CARE PROVIDERS AND SERVICES USERS IN THE UNITED STATES: DATA FROM THE NATIONAL STUDY OF LONG-TERM CARE PROVIDERS, 2013–14 40 fig.26 (2016), http://www.cdc.gov/nchs/data/series/sr_03/sr03_038.pdf.

A. Highlights of Federal Nursing Home Regulation

Because nursing homes receive federal funding through Medicare and Medicaid, federal law governs nursing home regulation.³⁰ States may also enact their own nursing home laws to supplement federal law.³¹

1. The Federal Nursing Home Reform Act of 1987

In 1986, at the request of Congress, the Institute of Medicine (“IOM”) released a study “that would ‘serve as a basis for adjusting federal (and state) policies and regulations governing the certification of nursing homes so as to make those policies and regulations as appropriate and effective as possible.’”³² IOM’s “widely respected”³³ report, *Improving the Quality of Care in Nursing Homes*,³⁴ formed the basis for the Federal Nursing Home Reform Act from the Omnibus Budget Reconciliation Act of 1987 (“OBRA”).³⁵

OBRA “requires the provision of certain services to each resident and establishes a Residents’ Bill of Rights.”³⁶ These services include periodic assessments and a comprehensive care plan for each resident; nursing, social, rehabilitation, pharmaceutical, and dietary services; and social worker services for large facilities (more than 120 beds).³⁷ In the Residents’ Bill of Rights, OBRA establishes:

The right to freedom from abuse, mistreatment, and neglect; [t]he right to freedom from physical restraints; [t]he right to privacy; [t]he right to accommodation of medical, physical, psychological, and social needs; [t]he right to participate in

30. See *Federal Nursing Home Regulations and State Laws*, NURSING HOME ALERT (2014), <http://www.nursinghomealert.com/federal-nursing-home-regulations-and-state-laws> (last visited Nov. 28, 2016).

31. See *id.*

32. TASK FORCE ON SURVEY, CERTIFICATION AND ENF’T, AM. ASS’N OF HOMES AND SERVS. FOR THE AGING, *BROKEN AND BEYOND REPAIR: RECOMMENDATIONS TO REFORM THE SURVEY AND CERTIFICATION SYSTEM 18* (2008) [hereinafter *BROKEN AND BEYOND REPAIR*].

33. *Id.*

34. See generally COMM. ON NURSING HOME REGULATION, INST. OF MED., *IMPROVING THE QUALITY OF CARE IN NURSING HOMES* (1986).

35. See Omnibus Budget Reconciliation Act (OBRA) of 1987, Pub. L. No. 100-203, 101 Stat. 1330 (codified as amended at 42 U.S.C. § 1395i-3 (2012)); *BROKEN AND BEYOND REPAIR*, *supra* note 32, at 18. “Federal Nursing Home Reform Act” and “OBRA” are used interchangeably when referring to nursing home reform. As such, this Note will use the terms synonymously.

36. Martin Klauber & Bernadette Wright, *The 1987 Nursing Home Reform Act*, AARP (Feb. 2001), http://www.aarp.org/home-garden/livable-communities/info-2001/the_1987_nursing_home_reform_act.html; see also 42 U.S.C. §§ 1395i-3(c)(1)(A), 1396r(c)(1)(A).

37. Klauber & Wright, *supra* note 36.

resident and family groups; [t]he right to be treated with dignity; [t]he right to exercise self-determination; the right to communicate freely; [t]he right to participate in the review of one's care plan, and to be fully informed in advance about any changes in care, treatment, or change of status in the facility; and [t]he right to voice grievances without discrimination or reprisal.³⁸

OBRA also created survey and certification requirements.³⁹ The law "requires states to conduct unannounced surveys, including resident interviews, at irregular intervals at least once every 15 months."⁴⁰ However, commencement of this survey process was delayed until 1995.⁴¹ If a survey reveals that a nursing home is not compliant, OBRA's enforcement scheme kicks in.⁴² As a threshold matter, the severity of the deficiency – measured by whether it "puts a resident in immediate jeopardy" – determines the harshness of the repercussions.⁴³ Nursing homes may have the opportunity to correct less severe deficiencies, while more grievous deficiencies may result in automatic sanctions.⁴⁴ Sanctions include: "[d]irected in-service training of staff; [d]irected plan of correction; [s]tate monitoring; [c]ivil monetary penalties; [d]enial of payment for all new Medicare or Medicaid admissions . . . [and] patients; [t]emporary management; and [t]ermination of the provider agreement."⁴⁵

After the enactment of OBRA, the Government Accountability Office ("GAO") issued reports "documenting serious quality of care problems in nursing homes and inadequate enforcement of federal regulations to protect residents' health, safety, and welfare."⁴⁶ Examples of these reports include *Many Shortcomings Exist in Efforts to Protect Residents from Abuse*,⁴⁷ *Despite Increased Oversight, Challenges*

38. *Id.*

39. *Id.*

40. *Id.*

41. *Id.*

42. *Id.*

43. *Id.*

44. *See id.*

45. *Id.*

46. JANET WELLS & CHARLENE HARRINGTON, KAISER COMM'N ON MEDICAID & THE UNINSURED, IMPLEMENTATION OF AFFORDABLE CARE ACT PROVISIONS TO IMPROVE NURSING HOME TRANSPARENCY, CARE QUALITY, AND ABUSE PREVENTION 1 (2013), <https://kaiserfamilyfoundation.files.wordpress.com/2013/02/8406.pdf>.

47. U.S. GEN. ACCOUNTING OFFICE, GAO-02-448T, NURSING HOMES: MANY SHORTCOMINGS EXIST IN EFFORTS TO PROTECT RESIDENTS FROM ABUSE (2002).

Remain in Ensuring High-Quality Care and Resident Safety,⁴⁸ and *Efforts to Strengthen Federal Enforcement Have Not Deterred Some Homes from Repeatedly Harming Residents*.⁴⁹ Despite over twenty GAO reports outlining shortcomings in nursing home regulation, the law remained relatively unchanged until 2010.⁵⁰

2. Nursing Home Compare

In 2008, CMS launched the Nursing Home Compare website.⁵¹ CMS promotes Nursing Home Compare as a way for consumers to gather information about long-term care and nursing facilities.⁵² Nursing Home Compare provides consumers with information on every nursing home in the country that is Medicare- or Medicaid-certified, which amounts to over 15,000 facilities.⁵³ To simplify the data, Nursing Home Compare rates each nursing home out of five stars.⁵⁴ This rating summarizes data on health inspections, staffing, and quality measures.⁵⁵

On an inspection, the government team takes a multi-dimensional approach to evaluating the nursing home's proper management of medications, protection of residents from physical and mental abuse, and storage and preparation of food.⁵⁶ In general, the inspec-

48. U.S. GEN. ACCOUNTING OFFICE, GAO-06-117, NURSING HOMES: DESPITE INCREASED OVERSIGHT, CHALLENGES REMAIN IN ENSURING HIGH-QUALITY CARE AND RESIDENT SAFETY (2005).

49. U.S. GEN. ACCOUNTING OFFICE, GAO-07-241, NURSING HOMES: EFFORTS TO STRENGTHEN FEDERAL ENFORCEMENT HAVE NOT DETERRED SOME HOMES FROM REPEATEDLY HARMING RESIDENTS (2007).

50. See WELLS & HARRINGTON, *supra* note 46, at 4 ("Between 1997 and 2010, the GAO issued more than 20 reports that found substandard care in many nursing homes; understatement of serious deficiencies by state nursing home surveyors; sanctions for harming residents that were not enforced; facilities that cycled in and out of compliance; and inconsistent and ineffective federal oversight.").

51. Press Release, Ctrs. for Medicare & Medicaid Servs., New Quality Measures on Nursing Home Compare (Apr. 27, 2016), <https://www.cms.gov/Newsroom/MediaReleaseDatabase/Fact-sheets/2016-Fact-sheets-items/2016-04-27.html>.

52. See *What Is Nursing Home Compare?*, MEDICARE.GOV, <https://www.medicare.gov/NursingHomeCompare/About/What-Is-NHC.html> (last visited Nov. 29, 2016).

53. *Id.*

54. *What Are the 5-Star Quality Ratings?*, MEDICARE.GOV, <https://www.medicare.gov/NursingHomeCompare/About/Ratings.html> (last visited Nov. 29, 2016).

55. *Id.*

56. *Health Inspections*, MEDICARE.GOV, <https://www.medicare.gov/NursingHomeCompare/About/Health-Inspections.html> (last visited Nov. 29, 2016).

tion team analyzes the care of residents and the processes used to give that care, how the staff and residents interact, and the nursing home environment.⁵⁷ In conjunction with their observations, the team reviews the residents' clinical records and conducts interviews with residents, residents' family members and caregivers, and the nursing home's administrative staff.⁵⁸

CMS reports information about the various members of the nursing home staff, including registered nurses ("RNs"), licensed practical nurses ("LPNs"), licensed vocational nurses ("LVNs"), certified nursing assistants ("CNAs"), and physical therapists.⁵⁹ CMS obtains this information from the reports that nursing homes submit to the states.⁶⁰

Nursing homes also self-report data on their residents that CMS transforms into quality of care measures.⁶¹ CMS divides the measures into long-stay resident-quality measures and short-stay resident-quality measures, with all measures reported as percentages.⁶² A user can then review a particular nursing home's measures compared to state and national averages.⁶³

Each nursing home has a profile on Nursing Home Compare where users can view information on five tabs: (1) "General information," (2) "Health & fire safety inspections," (3) "Staffing," (4) "Quality measures," and (5) "Penalties."⁶⁴ The "General information" tab provides background information on the nursing home, including its contact information, how many beds it has, its ownership status (profit or non-profit, religious affiliation, government affiliation), and its star-rating summary.⁶⁵

Under "Health & fire safety inspections," Nursing Home Compare displays the dates of the most recent health and complaint in-

57. *Id.*

58. *Id.*

59. *What Information Can I Get About Staffing?*, MEDICARE.GOV, <https://www.medicare.gov/NursingHomeCompare/About/Staffing-Info.html> (last visited Nov. 29, 2016).

60. *Id.*

61. *What Information Can I Get About Quality Measures?*, MEDICARE.GOV, <https://www.medicare.gov/NursingHomeCompare/About/Quality-Measures-Info.html> (last visited Nov 29, 2016).

62. *Id.*

63. *Nursing Home Compare*, MEDICARE.GOV, <https://www.medicare.gov/nursinghomecompare/search.html> (last visited Nov. 29, 2016).

64. *Id.* (search by zip code, city, state, or nursing home name; then follow nursing home name hyperlink).

65. *Id.* (search by zip code, city, state, or nursing home name; then follow nursing home name hyperlink; then select "General information" tab).

spections conducted at each establishment.⁶⁶ This tab also shows the nursing home's total number of health deficiencies and divides them into categories, such as mistreatment, quality care, resident assessment, resident rights, and nutrition and dietary.⁶⁷ If the nursing home has a reported deficiency, Nursing Home Compare will list the date the deficiency was revealed, the date the deficiency was corrected, the level of harm of the deficiency, and the general amount of residents affected.⁶⁸ For example, an inspection could determine that the nursing home failed to "provide care for residents in a way that keeps or builds each resident's dignity and respect of individuality."⁶⁹ Nursing Home Compare then indicates that the deficiency was discovered on June 30, 2015 ("Inspection Date"), was remedied by August 14, 2015 ("Date of Correction"), resulted in "[m]inimal harm or potential for actual harm" (a two out of four on the "Level of Harm" scale), and impacted only a few residents ("Residents Affected").⁷⁰ The "Health & fire safety inspections" tab also provides fire safety inspection information for the nursing homes.⁷¹

The "Staffing" tab shows the total number of residents and how much time per day each resident interacts with a licensed nurse (RN, LPN/LVN), CNA, and physical therapist.⁷² The "Quality measures" tab reports the percentage of long-stay residents who suffered falls, urinary tract infections, moderate to severe pain, pressure ulcers, and incontinence.⁷³ Also included are the percentage of residents who were physically restrained, needed additional help with daily activities, lost too much weight, and those who have depressive symptoms.⁷⁴ The "Quality measures" tab also reports the percentage of residents who receive influenza and pneumococcal

66. *Id.* (search by zip code, city, state, or nursing home name; then follow nursing home name hyperlink; then select "Health & fire safety inspections" tab).

67. *Id.*

68. *Id.*

69. *See, e.g., id.* (search by zip code: "08109" and nursing home name: "Cooper River West"; then select "Health & fire safety inspections" tab; then select "Resident Rights" dropdown tab). The Cooper River West facility was selected at random to facilitate this example.

70. *Id.*

71. *See id.*

72. *See, e.g., id.* (search by zip code: "08109" and nursing home name: "Cooper River West"; then select "Staffing" tab).

73. *See, e.g., id.* (search by zip code: "08109" and nursing home name: "Cooper River West"; then select "Quality measures" tab).

74. *Id.*

vaccines, and new recipients of antipsychotic medication.⁷⁵ Finally, the “Penalties” tab documents any history of federal fines or federal payment denials in the last three years.⁷⁶

Despite the breadth of information Nursing Home Compare provides, consumers have mixed reviews.⁷⁷ While some advocates say the website is one of the best resources to compare long-term care options, critics have called the website misleading and have admonished CMS for “giv[ing] a false sense of security to the public.”⁷⁸ Similarly, critics complain that “[t]he ratings . . . do not take into account entire sets of potentially negative information, including fines and other enforcement actions by state, rather than federal, authorities, as well as complaints filed by consumers with state agencies.”⁷⁹ Nursing Home Compare, however, does note on each nursing home profile that penalty information reported to state agencies may be available on the state agencies’ websites.⁸⁰ Additionally, Nursing Home Compare provides contact information for each state agency and how to file a complaint electronically with the appropriate state authority.⁸¹

Another criticism is the large reliance on nursing home’s self-reporting to generate the data:

The Medicare ratings, which have become the gold standard across the industry, are based in large part on self-reported data by the nursing homes that the government does not verify. Only one of the three criteria used to determine the star ratings—the results of annual health inspections—relies on assessments from independent reviewers. The other measures—staff levels and quality statistics—are reported by the nursing homes and accepted by Medicare, with limited exceptions, at face value.⁸²

75. *Id.*

76. *See, e.g., id.* (search by zip code: “08109” and nursing home name: “Cooper River West”; then select “Penalties” tab).

77. *See* Katie Thomas, *Medicare Star Ratings Allow Nursing Homes to Game the System*, N.Y. TIMES (Aug. 24, 2014), <http://www.nytimes.com/2014/08/25/business/medicare-star-ratings-allow-nursing-homes-to-game-the-system.html>.

78. *Id.*

79. *Id.*

80. *See, e.g., Nursing Home Compare, supra* note 6 (search by zip code: “08109” and nursing home name: “Cooper River West”; then select “Penalties” tab).

81. *See State Websites and Contact Information*, MEDICARE.GOV, <https://www.medicare.gov/NursingHomeCompare/Resources/State-Websites.html> (last visited Nov. 28, 2016).

82. Thomas, *supra* note 77.

Other accusations suggest that nursing homes are manipulating their data to increase their overall star rating.⁸³ After all, nursing homes represent a booming industry, and facilities compete to secure residents.⁸⁴

3. *Patient Protection and Affordable Care Act ("ACA")*

Without doubt, the 2010 enactment of the Patient Protection and Affordable Care Act ("ACA") imposed widespread health care reform in the United States.⁸⁵ In addition, the ACA marked "the first comprehensive legislation since [OBRA] to expand quality of care-related requirements for nursing homes that participate in Medicare and Medicaid and improve federal and state oversight and enforcement."⁸⁶ In doing so, the ACA introduced the Nursing Home Transparency and Improvement Act of 2009 as well as the Elder Justice Act and the Patient Safety and Abuse Prevention Act.⁸⁷

With respect to dementia reform, the ACA added only one specific requirement under the Nursing Home Transparency and Improvement Act.⁸⁸ The Act now requires that "nurse aides must be trained in dementia care and resident abuse prevention."⁸⁹ Under OBRA, nursing aides were required to have seventy-five hours of training, but specific training on dementia care or resident abuse prevention was not required.⁹⁰ The ACA kept the minimum number of training hours at seventy-five but required that specific training on dementia care and resident abuse prevention be added into this number.⁹¹

The Administration on Aging, which is affiliated with the U.S. Department of Health and Human Services, has noted that changes to Medicaid funding are aimed to provide new avenues for states to

83. *See id.*

84. *See id.*

85. *See generally* U.S. Dep't of Health & Human Servs., *About the Law*, HHS.GOV, <http://www.hhs.gov/healthcare/about-the-law> (last updated Aug. 13, 2015) (listing the various changes implemented through the ACA).

86. WELLS & HARRINGTON, *supra* note 46, at 1.

87. *Id.*

88. *Id.* at 2.

89. *Id.*; 42 U.S.C. § 1395i-3(f)(2)(A)(i) (2012).

90. WELLS & HARRINGTON, *supra* note 46, at 16; *see also* Omnibus Budget Reconciliation Act ("OBRA") of 1987 § 1819(f)(2)(A)(i), Pub. L. No. 100-203, 101 Stat. 1330-172 (codified as amended 42 U.S.C. § 1395i-3(f)(2)(A)(i) (2012)).

91. WELLS & HARRINGTON, *supra* note 46, at 17.

build person-centered care systems for long term facilities, but not for dementia specifically.⁹²

4. *The National Partnership to Improve Dementia Care in Nursing Homes*

On May 30, 2012, CMS announced the National Partnership to Improve Dementia Care in Nursing Homes (“National Partnership”).⁹³ The National Partnership includes “federal and state agencies, nursing homes, other providers, advocacy groups, and caregivers.”⁹⁴ Elements of the Partnership’s approach include “public reporting, state-based coalitions, research, training and revised surveyor guidance.”⁹⁵ In its press release, CMS focused squarely on a “goal of reducing the use of antipsychotic drugs in nursing home residents by [15%] by the end of 2012.”⁹⁶ CMS noted that in 2010 nearly 40% of nursing home residents with dementia were taking antipsychotic drugs without a diagnosis of psychosis.⁹⁷

In conjunction with the new requirement for training on dementia care and resident abuse prevention, the National Partnership created a training series called Hand in Hand for nursing homes to teach “person-centered care, prevention of abuse, and high-quality care for residents.”⁹⁸ The press release did not define what it meant by “person-centered care”; instead, CMS used this buzzword to con-

92. *Affordable Care Act: Opportunities for the Aging Network*, ADMIN. FOR COMMUNITY LIVING, http://aoa.acl.gov/Aging_Statistics/Health_care_reform.aspx#medicare (last modified Sept. 16, 2014) (“The law provides opportunities to states to improve access and services within Medicaid Waiver Home and Community-based Services programs, building person-centered care systems and improve outcomes and care coordination for individuals with Medicaid and those dually-eligible for Medicaid and Medicare.”).

93. Press Release, Ctrs. for Medicare & Medicaid Servs., CMS Announces Partnership to Improve Dementia Care in Nursing Homes (May 30, 2012), <https://www.cms.gov/Newsroom/MediaReleaseDatabase/Press-releases/2012-Press-releases-items/2012-05-30.html> [hereinafter CMS Partnership Announcement].

94. *National Partnership to Improve Dementia Care in Nursing Homes*, CTRS. FOR MEDICARE & MEDICAID SERVS., <https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertificationGenInfo/National-Partnership-to-Improve-Dementia-Care-in-Nursing-Homes.html> (last modified Sept. 22, 2016).

95. *Id.*

96. CMS Partnership Announcement, *supra* note 93 (calling the National Partnership “an initiative to ensure appropriate care and use of antipsychotic medications for nursing home patients”).

97. *Id.* (statement of CMS Chief Medical Officer and Director of Clinical Standards and Quality, Patrick Conway, M.D.).

98. *Id.*

note an off-hand means to the end of reducing the use of antipsychotic drugs in nursing homes through enhanced training.⁹⁹

In the years since the launch of this initiative, CMS has been relatively quiet about any progress the National Partnership has made. In 2013, CMS issued only one relevant press release about data showing that antipsychotic drug use had decreased in nursing homes.¹⁰⁰ The following year, CMS issued another press release to report that the National Partnership exceeded its goal to reduce antipsychotic drug in nursing homes.¹⁰¹ In that press release, CMS stated that its new goal was to reduce antipsychotic drug use in nursing homes “by [25%] by the end of 2015, and [30%] by the end of 2016.”¹⁰² CMS reported that “[b]etween the end of 2011 and the end of 2013, the national prevalence of antipsychotic drug use in long-stay nursing home residents was reduced by [15.1%], decreasing from [23.8%] to [20.2%] nationwide.”¹⁰³ The clear focus for the National Partnership has been on decreasing antipsychotic drug use in nursing homes, despite a public commitment to increasing a culture of person-centered care.¹⁰⁴

More recently, in January 2015, the National Partnership hosted a bi-annual state coalition call and publicly released a summary report of the call.¹⁰⁵ Many states declined to participate, but the discussion nonetheless focused on implementing a person-centered approach for residents with dementia.¹⁰⁶ Then in November 2015, the National

99. *See id.*

100. Press Release, Ctrs. for Medicare & Medicaid Servs., New Data Show Antipsychotic Drug Use is Down in Nursing Homes Nationwide (Aug. 17, 2013), <https://www.cms.gov/Newsroom/MediaReleaseDatabase/Press-Releases/2013-Press-Releases-Items/2013-08-27.html>.

101. Press Release, Ctrs. for Medicare & Medicaid Servs., National Partnership to Improve Dementia Care Exceeds Goal to Reduce Use of Antipsychotic Medications in Nursing Homes: CMS Announces New Goal (Sept. 19, 2014), <https://www.cms.gov/Newsroom/MediaReleaseDatabase/Press-releases/2014-Press-releases-items/2014-09-19.html> [hereinafter CMS Announces New Goal].

102. *Id.*

103. *Id.*

104. *See id.*

105. *See generally* NAT'L P'SHIP TO IMPROVE DEMENTIA CARE IN NURSING HOMES, BI-ANNUAL STATE COALITION CALL - SUMMARY REPORT (2015), https://www.nhqualitycampaign.org/files/Bi-Annual_State_Coalition_Call_Summary_Report_Jan_2015.pdf [hereinafter NAT'L P'SHIP COALITION CALL] (indicating the state-participants of the call and their comments about person-centered care and dementia, non-pharmacologic approaches to care, and the results of such care in their respective state).

106. *See id.*

Partnership compiled a focused dementia care survey tool for surveyors to use on their health inspections.¹⁰⁷

5. *Reform of Requirements for Long-Term Care Facilities (CMS-3260-P)*

On July 16, 2015, the Centers for Medicare & Medicaid Services issued a Proposed Rule that addressed requirements for long-term care facilities.¹⁰⁸ CMS explained, “[w]e are proposing to amend the requirements that an institution must meet in order to participate as a SNF/NF in the Medicare and Medicaid programs, by requiring that the current mandatory on-going training requirements for nurse aides (“NAs”) include dementia management and resident abuse prevention training.”¹⁰⁹

In the Proposed Rule, CMS noted the need for dementia care competency training, which is currently implemented on a state-by-state basis: “we propose to require dementia management and resident abuse prevention training to be a part of 12 hours per year in-service training for nurses aides.”¹¹⁰ The proposed rules did not change the minimum hours required for in-service training per year, so CMS advised the facilities to revise their content to incorporate the required dementia management and resident abuse prevention training.¹¹¹ The cost of implementing this training and continuing it each year after implementation was estimated to be \$3,640,312 per year for nursing homes nationwide “to review and update their current in-service training material.”¹¹²

CMS paid homage to the National Partnership and the Quality Assurance and Performance Improvement (“QAPI”)¹¹³ program by describing its “multidimensional approach” and declaring that the initiative was “targeted at enhancing person-centered care for nursing home residents, particularly those with dementia-related behav-

107. Memorandum from the Dir., Survey and Certification Grp. to State Survey Agency Dirs. (Nov. 27, 2015), <https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertificationGenInfo/Downloads/Survey-and-Cert-Letter-16-04.pdf>.

108. Proposed Rule, *supra* note 10, at 42,178; *see also* Final Rule, *supra* note 10, at 68,689.

109. Proposed Rule, *supra* note 10, at 42,178.

110. *Id.* at 42,173.

111. *Id.* at 42,223–24.

112. *Id.* at 42,240. The Final Rule increased this amount to \$3,819,332. *See* Final Rule, *supra* note 10, at 68,836.

113. QAPI Description and Background, CTMS FOR MEDICARE & MEDICAID SERVS., <https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/QAPI/qapidefinition.html> (last modified Apr. 3, 2014).

iors.”¹¹⁴ CMS explained that it was guided by a “competency-based approach” that it felt would not impede states in making their own requirements for dementia care and competency training:

We considered prescriptive approaches, such as requiring specific numbers and types of staff based on facility size and acuity of residents, but were concerned that such an approach would conflict with requirements already established in many states, and *would limit flexibility and innovation in designing new models of person-centered care delivery for residents.*¹¹⁵

With a nod toward how states and nursing homes already incorporate person-centered care into policy, law, and daily operation, CMS announced its broad objective to ensure that providers and facilities exercised competency within long-term care facilities:

Thus we are instead taking a competency-based approach that focuses on achieving the statutorily mandated outcome of ensuring that each resident is provided care that allows the resident to maintain or attain their highest practicable physical, mental, and psychosocial well-being. Under this competency-based approach, *we are proposing requirements that are compatible with existing state requirements and consistent with what we believe are already common practices by facilities.*¹¹⁶

In the Proposed Rule, CMS included an entire section on “Reduction in Inappropriate Use of Antipsychotic Medications” and described how “[t]he potential overuse of antipsychotic agents is a symptom of a much larger problem – namely, that many nursing facilities may not have a systematic plan to provide comprehensive behavioral health care to residents with diagnoses such as dementia and [behavioral and psychotic symptoms of dementia].”¹¹⁷

114. Proposed Rule, *supra* note 10, at 42,176. The Final Rule changed “nursing home residents” to “LTC facility residents.” See Final Rule, *supra* note 10, at 68,691.

115. Proposed Rule, *supra* note 10, at 42,175 (emphasis added). This section was removed from the Final Rule. See Final Rule, *supra* note 10, at 68,691.

116. Proposed Rule, *supra* note 10, at 42,175 (emphasis added). In the Final Rule, the language was changed to: “As discussed in further detail, we are requiring facilities to assess their facility capabilities and their resident population. This competency-based approach is compatible with existing state requirements and business practices, and promotes both efficiency and effectiveness in care delivery.” Final Rule, *supra* note 10, at 68,691.

117. Proposed Rule, *supra* note 10, at 42,179. This section does not appear in the Final Rule and the Final Rule changes “antipsychotic medications” to “psychotropic drugs.” Final Rule *supra* note 10, at 68,689.

Following this observation, CMS proposed requiring facilities to engage in comprehensive person-centered care planning: “We propose to require facilities to develop a baseline care plan for each resident, within 48 hours of their admission, which includes the instructions needed to provide effective and *person-centered care* that meets professional standards of quality care.”¹¹⁸

Despite incorporating person-centered care in its Proposed Rule, CMS received comments requesting that it make the Proposed Rule more harmonious with regarded aspects of person-centered care. CMS explained, “[a]nother common theme in the comments was the need to revise the regulations so that they reflect a person-centered care approach. . . . For example, commenters requested that residents be included in the care planning process and given complete control over their meal choices.”¹¹⁹ Further, CMS noted that comments regarding person-centered care applied across the board to all long-term residents, not just those with dementia.¹²⁰

In response to the comments, CMS specified that under the new requirements, “the resident has the right to participate in the care planning process, including the right to identify individuals or roles to be included in the planning process, the right to request meetings, and the right to request revisions to the person-centered plan of care. . . . Further, the facility must recognize each resident’s individuality and provide services in a person-centered manner.”¹²¹

CMS concluded its discussion of person-centered care by noting that “[t]he Department of Health and Human Services has issued guidance for implementing person-centered planning and self-direction in home and community-based services programs, as set forth in . . . the Affordable Care Act. The principles in that guidance regarding dignity and self-direction apply equally to individuals who reside in a nursing facility.”¹²²

118. Proposed Rule, *supra* note 10, at 42,170 (emphasis added).

119. *Id.* at 42,174. This discussion was not included in the Final Rule. Final Rule, *supra* note 10, at 68,858.

120. See Proposed Rule, *supra* note 10, at 42,182; see also Final Rule, *supra* note 10, at 68,740 (“We believe that a comprehensive person-centered care plan should be developed for all residents regardless of length of stay.”).

121. Proposed Rule, *supra* note 10, at 42,182–84. The Final Rule states: “[T]he facility would be required to recognize each resident’s individuality and provide services in a person-centered manner.” Final Rule, *supra* note 10, at 68,704.

122. Proposed Rule, *supra* note 10, at 42,184–85. CMS upheld this notion in the Final Rule stating:

As we noted in the preamble to the proposed rule, our proposals support the guidance issued by HHS for implementing person-centered planning and self-direction in home and community-based services

*B. Prior Recommendations for Increased Surveillance in
Dementia Care*

Over the years, nursing homes have transformed into places of surveillance. Not only do staff members watch residents, but now, staff members are watched by the regulatory system and entities concerned with preventing abuse.¹²³ As nursing home practices have come to public attention, advocates for nursing home reform and dementia care have recommended practices in line with the nursing home culture of surveillance, or the surveillance quo.¹²⁴ Some examples of these recommendations include: (1) decreased use of anti-psychotic medication and chemical restraint;¹²⁵ (2) increased reporting and surveying requirements;¹²⁶ and (3) increased use of video surveillance.¹²⁷

In particular, the dialogue regarding anti-psychotic medication use in dementia patients has been considerable.¹²⁸ In fact, the prescribing of this class of medications to nursing home residents with dementia was at the forefront of recent litigation and subsequent settlement, showing that this is a very real problem with dire consequences for those residents who have suffered abuse at the hands of

programs, as set forth in section 2402(a) of the Affordable Care Act. We agree that the principles in that guidance regarding dignity and self-direction apply equally to individuals who reside in a nursing facility.

Final Rule, *supra* note 10, at 68,713.

123. See, e.g., CENTERS FOR MEDICARE & MEDICAID SERVICES, CMS SURVEY AND CERTIFICATION GROUP 2016/2017 NURSING HOME ACTION PLAN 1, 3-10 (2015), <https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/CertificationandCompliance/Downloads/2016-2017-Nursing-Home-Action-Plan.pdf> (detailing CMS's action plan for promoting quality nursing home care through oversight, enforcement, and intra-agency cooperation).

124. See, e.g., Selket Nicole Cottle, "Big Brother" and Grandma: An Argument for Video Surveillance in Nursing Homes, 12 ELDER L.J. 119, 124 (2004) (noting that "granny cams ensure that abuse does not continue by discouraging those potentially abusive caregivers who do not want to work under constant observation from working in nursing homes"). But see, e.g., Lisa Minuk, *Why Privacy Still Matters: The Case Against Prophylactic Video Surveillance in For-Profit Long-Term Care Homes*, 32 QUEEN'S L.J. 224, 227-28 (2006) (Can.) (arguing that "granny cams" should not be used by nursing homes in light of residents' privacy interests).

125. See CMS Announces New Goal, *supra* note 101.

126. See U.S. GOV'T ACCOUNTABILITY OFFICE, GAO-16-33, NURSING HOME QUALITY: CMS SHOULD CONTINUE TO IMPROVE DATA AND OVERSIGHT 1-2 (2015) (noting that consumer complaints have increased in recent years, and that CMS should take various steps to improve its oversight functions and reporting requirements) [hereinafter CMS SHOULD CONTINUE TO IMPROVE OVERSIGHT].

127. See Cottle, *supra* note 124, at 124.

128. See, e.g., CMS Announces New Goal, *supra* note 101; Michael D. Williamson, *Antipsychotic Drug Use Declines in Nursing Homes, Data Show*, [Aug. 24, 2015] HEALTH CARE POLICY REPORT ("BNA") (Aug. 11, 2015).

both administrators and pharmaceutical companies. For example, the United States government recently alleged that Omnicare, Inc., “the nation’s largest provider of pharmacy services to nursing homes” received kickbacks from a drug manufacturer, Abbott Laboratories, Inc., “to promote the use of the prescription drug Depakote to control the behavior of elderly nursing home residents with dementia.”¹²⁹

Through its consultant pharmacists, Omnicare wielded enormous influence over the drugs administered to the residents of Omnicare-serviced nursing homes. In exchange for millions of dollars in kickbacks disguised as rebates, educational grants, and other corporate financial support, Omnicare used its consultant pharmacists to tout Depakote as a tool to control agitation, aggression, and other behavioral disturbances and to avoid federal regulations designed to prevent the use of chemical restraints on the elderly. By knowingly and actively soliciting kickbacks to promote Depakote, Omnicare enhanced its profits at the expense of the elderly nursing home residents it purported to protect and caused the Medicaid and Medicare programs to pay hundreds of millions of dollars for claims that should not have been paid.¹³⁰

Ultimately, the United States and Abbott Laboratories settled the case for \$1.5 billion.¹³¹

However, CMS has indicated its success in reducing the prevalence of anti-psychotic medication use among nursing home residents since the inception of the National Partnership.¹³² In August 2015, the American Health Care Association reported a 21.7% decrease in anti-psychotic drug use from 2011 to 2015.¹³³ Despite this tide change, the Center for Medicare Advocacy estimates that over

129. Complaint at 1, *United States v. Abbott Laboratories*, No. 1:07-CV-00081 (W.D. Va. Dec. 22, 2014).

130. *Id.* at 1-2.

131. See Press Release, U.S. Dep’t of Justice, *Abbott Labs to Pay \$1.5 Billion to Resolve Criminal & Civil Investigations of Off-label Promotion of Depakote* (May 7, 2012), <https://www.justice.gov/opa/pr/abbott-labs-pay-15-billion-resolve-criminal-civil-investigations-label-promotion-depakote>.

132. See Williamson, *supra* note 128.

133. *Id.*

200,000 residents are still inappropriately prescribed these medications, which put them at risk of death or serious harm.¹³⁴

This focus on anti-psychotic drug use demonstrates how the surveillance quo has shifted, yet remained intact. While long-term nursing facilities have used medications as a primary way to control resident behavior and oversee resident activity, the tables have turned. Increased reporting on the prevalence of anti-psychotic drug use—particularly among residents with dementia—probing examinations of resident records, and the threat of lawsuits against prescribing providers and facilities have transformed the former observers into the observed.¹³⁵

In addition to proposing reforms on anti-psychotic drug use, other scholars, government officials, and advocates have pushed for increased reporting and surveying requirements, as well as increased surveillance.¹³⁶ With respect to many suggested reforms for dementia care, the influence of the surveillance quo is alive and well.

Litigation, legal scholarship, Government Accountability Office reporting, and CMS initiatives and regulations have favored these dementia care reforms because they fit within the surveillance quo by increasing observation of either residents, staff, or both. Also, the implementation and success of these recommendations is relatively easily quantifiable.

C. *Person-Centered Care*

A main theme of non-legal scholarship on dementia care practices and recommendations is the focus on person-centered care to increase quality of life for those suffering from dementia.¹³⁷ Person-centered care diverges from the bio-medical nature of the nursing home.¹³⁸ CMS describes person-centered care as “an aspect of culture change that focuses on the resident as the locus of control, sup-

134. *Id.*

135. See, e.g., U.S. GOV'T ACCOUNTABILITY OFFICE, GAO-15-211, ANTIPSYCHOTIC DRUG USE: HHS HAS INITIATIVES TO REDUCE USE AMONG OLDER ADULTS IN NURSING HOMES, BUT SHOULD EXPAND EFFORTS TO OTHER SETTINGS 26-30 (2015) [hereinafter HHS INITIATIVES ON ANTIPSYCHOTIC DRUG USE].

136. See *supra* note 124 and accompanying text.

137. See generally Sonya Brownie & Susan Nancarrow, *Effects of Person-centered Care on Residents and Staff in Aged-care Facilities: A Systematic Review*, 8 CLINICAL INTERVENTIONS IN AGING 1 (2013) (evaluating the effects of person-centered care on residents of aged-care facilities by surveying and summarizing numerous relevant articles); Jane Stein-Parbury et al., *Implementing Person-Centered Care in Residential Dementia Care*, 35 CLINICAL GERONTOLOGIST 404 (2012) (detailing the strengths and successes of a person-centered care approach in improving quality of life for people with dementia).

138. THE QUALITY CHASM, *supra* note 18, at 5.

ported in making their own choices and having control over their daily lives.”¹³⁹ Advocates for this approach emphasize the importance of trained staff and an appropriate environment to implement person-centered care practices.¹⁴⁰ Person-centered care in the nursing home context will change depending on the residents’ needs.

According to the Dementia Initiative:

The current bio-medical approach to healthcare focuses almost exclusively on the *physical* condition of a person. Health and well-being, however, are contingent upon more than the physical condition and also includes the psychosocial-spiritual dimensions. The separation or disregard of interconnected components of healthcare created the impersonal and fragmented healthcare culture.¹⁴¹

This approach is based on the work of psychologists Carl Rogers and Abraham Maslow, who recognized that “people are multi-dimensional beings and the psychosocial context of health and well-being is as important as the physical/medical aspects.”¹⁴²

Person-centered care is also associated with “culture change.”¹⁴³ Under the person-centered approach, the nursing home environment mimics the residents’ homes.¹⁴⁴ As much as possible, the staff acknowledges and follows through on residents’ “express preferences for the majority of daily decisions.”¹⁴⁵ Staff members facilitate this process by observing residents’ behavior patterns and recognizing preferences and habits that form the basis of the residents’ daily routines.¹⁴⁶

Person-centered care is a cornerstone of many dementia care advocates’ recommendations for best practices in nursing homes. For example, person-centered care is the first guiding principle outlined by the National Center for Assisted Living (“NCAL”) in their Guiding Principles for Dementia Care. According to the NCAL, “[p]erson-centered care focuses on meeting the individual resident’s

139. Proposed Rule, *supra* note 10, at 42,177.

140. *See id.* at 42,220–23.

141. *See* THE QUALITY CHASM, *supra* note 18, at 10.

142. *Id.* at 11.

143. NAT’L DEMONSTRATION PROJECT ON CULTURE CHANGE, CULTURE CHANGE AND RESIDENT CENTERED CARE IN NURSING HOMES, HEALTH CARE REFORM ACT (HR 3590) 2, <http://www.pioneer-network.net/Data/Documents/NationalDemonstration%20.pdf>.

144. *See id.*

145. *Id.* at 5.

146. *Id.* at 5–6.

needs."¹⁴⁷ In this context, the resident makes decisions on his own or with the assistance of his family or a surrogated decision maker.¹⁴⁸ Instead of "task-oriented" staff assistance, person-centered care focuses on relationship building such that the staff knows "each resident as an individual, his/her life story, strengths, weaknesses, needs, preferences and expectations."¹⁴⁹

Person-centered care impacts how a facility uses its physical space. There are competing theories on how to best organize a facility's layout to accomplish person-centered care.¹⁵⁰ In a traditional dementia care unit setting, the "[u]nique physical arrangements have been designed to both insure [sic] the safety and security of residents and to reduce undue stimulation."¹⁵¹ Typically the units are locked so visitors and staff are required to use a keypad for exit and entry to and from the units.¹⁵²

As described by the NCAL, person-centered care is a holistic model designed to help a person with dementia maintain his or her individuality or autonomy through various techniques.¹⁵³ For example, NCAL has outlined ambiguous ways to accomplish person-centered care, including "[e]ncouraging personal development of residents, on an individual basis," "[m]aximizing the resident's dignity, autonomy, privacy, socialization, independence, choice, and safety," "[d]eveloping positive relationships among residents, staff, families, and the community," and "[s]upporting lifestyles that promote health and fitness."¹⁵⁴

II. ANALYSIS

In light of the growing evidence that a person-centered care approach best addresses the day-to-day challenges of dementia, federal policy should blend person-centered care with the surveillance quo. As described previously, other recommendations for dementia

147. NCAL GUIDING PRINCIPLES, *supra* note 22, at 2.

148. *Id.*

149. *Id.*

150. See THE LONG TERM CARE OMBUDSMAN PROGRAM, SPECIAL CARE UNITS FOR DEMENTIA: A SURVEY OF CONNECTICUT NURSING HOMES 20-21 (2004), <http://www.ct.gov/lscop/lib/lscop/pdf/dementiaunitstudyreport.pdf> (comparing characteristics among long-term care facilities that have dementia programs).

151. *Id.* at 33.

152. *Id.*

153. NCAL GUIDING PRINCIPLES, *supra* note 22, at 2-5.

154. *Id.* at 2. NCAL's other guiding principles are "Staff Education," "Physical Environment," and "Safety." See *id.* at 5-8.

reform have built upon the nursing home culture of surveillance.¹⁵⁵ Meanwhile, despite using the buzzword in its initiatives and regulations, CMS and its policies have been slow to adopt a person-centered care approach into its regulations and requirements because of its subjective nature and tension with a medicalized environment.¹⁵⁶ Proponents of person-centered care dementia reform have failed to recognize that the approach must co-exist with the surveillance quo, at least during its initial acceptance and adoption by federally funded nursing facilities.¹⁵⁷

Although CMS has acknowledged person-centered care in its initiatives and regulations,¹⁵⁸ CMS should promote person-centered care as complementary to the surveillance quo. The Proposed Rule and comments show how CMS and the National Partnership can advance their growing commitment¹⁵⁹ to person-centered care through new metrics for the Nursing Home Compare website. These metrics would confirm the co-existence of person-centered care with the surveillance quo and, most importantly, disseminate information about nursing facilities' dementia care to the public.¹⁶⁰

A. *The Case for Person-Centered Care Amidst the Surveillance Quo*

Since nursing home regulation came under fire in the 1980s, and was addressed in part through the enactment of OBRA, there has been an intense focus on reducing anti-psychotic medications as a hallmark of dementia reform.¹⁶¹ This goal is echoed in a plethora of CMS policies, including Nursing Home Compare and CMS regulations.¹⁶² Reducing anti-psychotic medication has also become a primary metric for determining whether nursing care facilities are doing an adequate job in caring for residents with dementia care.

While it has become virtually inarguable that this metric serves an important purpose in determining quality of care, organizations have set forth other criteria that should be used to evaluate care for those living with dementia, including, primarily, person-centered

155. *See supra* Part II.B.

156. *See infra* Part III.A.

157. *See infra* Part III.B.

158. *See supra* Part II.A.4-5.

159. *See infra* Part III.B.

160. *See infra* Part III.C.

161. *See supra* Part II.A.

162. *See supra* Part II.A.

care.¹⁶³ As such, CMS should focus on adding new person-centered care dementia requirements to its Proposed Rule and Nursing Home Compare.

Foreign healthcare systems set the precedent for incorporating person-centered care as a central tenet of long-term care.¹⁶⁴ For example, in England, a long-term care facility must be licensed as a “Person-Centered Care Provider.”¹⁶⁵ In Canada, “Psycho-geriatric Resource Consultants” (“PRCs”) enter nursing homes to teach and promote a culture of person-centered care.¹⁶⁶ Primarily, a PRC educates and works with facilities to develop person-centered care solutions, particularly for those residents who exhibit anger, depression, or other common emotions.¹⁶⁷ These professionals bridge the gap between facilities, community agencies, and other services and organizations.¹⁶⁸

However, there is a lot of pushback on adopting something as fast and loose as “person-centered care” into national policy. Unlike striving to reduce antipsychotic medication use among residents by 21.7%,¹⁶⁹ the goal of adopting person-centered care does not suggest objectivity. In addition, “[p]erson-centered care . . . represents a shift in focus away from a traditional, biomedical approach . . . in elder care.”¹⁷⁰

According to some states, nursing homes are resistant to change, comfortable with the status quo, and familiar with the “medical model of nursing home care.”¹⁷¹ In January 2015, the National Partnership sponsored a telephone call among representatives of twenty-five states to discuss person-centered care.¹⁷² When asked to de-

163. See, e.g., ALZHEIMER’S ASS’N & PLANNING COUNCIL FOR HEALTH AND HUMAN SERVS., HANDCUFFED: A REPORT OF THE ALZHEIMER’S CHALLENGING BEHAVIORS TASK FORCE 8–11 (2010), [http://www.alz.org/sewi/documents/alzheimers_report_handcuffed\(3\).pdf](http://www.alz.org/sewi/documents/alzheimers_report_handcuffed(3).pdf) [hereinafter ALZHEIMER’S TASK FORCE REPORT]; THE QUALITY CHASM, *supra* note 18, at 19–34.

164. See ALZHEIMER’S TASK FORCE REPORT, *supra* note 163, at 9–11.

165. *Id.* at 9.

166. *Id.* at 10–11.

167. *Id.* at 11. It should be noted, however, that Canada’s healthcare system “utilizes a single-payer system, requires full support of the facility[,] and requires ongoing training regarding the model and use of PRCs.” *Id.*

168. *Id.*

169. See Williamson, *supra* note 128.

170. Patrick J. Doyle & Robert L. Rubinstein, *Person-Centered Dementia Care and the Cultural Matrix of Othering*, 54(6) THE GERONTOLOGIST 952, 952 (2013) (noting that the emphasis on “mental pathology” undermines the “personhood of people with dementia” by failing to consider the “psychological, social, and cultural complexities” present in individual cases of dementia).

171. NAT’L P’SHP COALITION CALL, *supra* note 105, at 1, 5, 6, 9, 15.

172. *Id.* at 1.

scribe challenges in “transition[ing] to a more person-centered, non-pharmacologic approach,” some coalition representatives commented: “[n]ot everyone understands nor believes in person-centered care; some prefer to stick with the old medical model of nursing home care” (Alabama);¹⁷³ “[r]eliance on old methods” (Idaho);¹⁷⁴ “[m]edicating first culture” (Illinois);¹⁷⁵ “[b]reaking the mentality that medications are the answer” (Maine);¹⁷⁶ and “[d]ifficult to step out and try new approaches; [t]he unknown is scary” (Montana).¹⁷⁷

Aside from provider resistance and deference to the biomedical surveillance quo of the current dementia care treatment regime, metrics are enforced through self-regulation, which has been deemed an ineffective way to identify problems and enforce rules and regulations.¹⁷⁸ If nursing home staff and administration are so cultured to this surveillance quo, incorporating a person-centered approach into national policy must co-exist with the surveillance quo. The surveillance quo is perpetuated by the culture of self-reporting and self-regulation inherent in the day-to-day operation of nursing homes.¹⁷⁹ As such, dementia care measures should conform to this culture during their initial acceptance and adoption.

B. Review of Comments on CMS’s Proposed Rule

1. Center for Medicare Advocacy (“CMA”)

In its request for comments following the release of the Proposed Rule to the public, CMS received input from the Center for Medicare Advocacy (“CMA”).¹⁸⁰ The CMA expressed its dismay that CMS “has not added any requirements for dementia care, despite its ongoing CMS Partnership to Improve Dementia Care.”¹⁸¹ The CMA

173. *Id.*

174. *Id.* at 5.

175. *Id.* at 6.

176. *Id.* at 10.

177. *Id.* at 15.

178. *See, e.g.,* DEP’T OF HEALTH & HUMAN SERVS., NURSING FACILITIES’ COMPLIANCE WITH FEDERAL REGULATIONS FOR REPORTING ALLEGATIONS OF ABUSE OR NEGLECT 12 (2014) (“In 2012, [53%] of allegations of abuse or neglect and the subsequent investigation results . . . were reported, as [f]ederally required.”).

179. *See, e.g.,* Thomas, *supra* note 77.

180. Center for Medicare Advocacy (“CMA”), Comment Letter on Proposed Rule to Reform Requirements for Long-Term Care Facilities (Oct. 14, 2015), <https://www.regulations.gov/contentStreamer?documentId=CMS-2015-0083-8377&attachmentNumber=1&disposition=attachment&contentType=pdf>.

181. *Id.* at 28.

proposed adding language to the comprehensive person-centered care planning section specific to dementia care:

- (1) For a resident with dementia, the facility must include in the assessment
 - (a) How the resident typically communicates physical needs such as pain, discomfort, hunger or thirst, as well as emotional and psychological needs such as frustration or boredom; or a desire to do or express something that he/she cannot articulate;
 - (b) The resident's usual and current cognitive patterns, mood and behavior, and whether these present a risk to the resident or others;
 - (c) How the resident typically displays personal distress such as anxiety or fatigue;
 - (d) The physical, functional, psychosocial, environmental, and other potential causes of behavior and related symptoms, including how they interact with each other.
- (2) If the behaviors observed represent a change or worsening from the baseline, the attending physician/practitioner and staff are expected to consider potential underlying medical, physical, psychosocial, or environmental causes of the behaviors.
- (3) If medical causes are ruled out, the facility should attempt to establish other root causes of behavior using individualized, holistic knowledge about the person and when possible, information from the resident, family or previous caregivers, and direct care staff. The facility must conduct a systematic analysis and consider possible causes, including but not limited to:
 - (a) Boredom
 - (b) Anxiety related to changes in routines such as shift changes, unfamiliar or different caregivers, change of (or relationship with) roommate, inability to communicate;
 - (c) Care routines (such as bathing) that are inconsistent with a person's preferences;
 - (d) Personal needs not being met appropriately or sufficiently, such as hunger, thirst, constipation;
 - (e) Fatigue, lack of sleep or change in sleep patterns which may make the person more likely to misinterpret envi-

ronmental cues resulting in anxiety, aggression or confusion.

- (f) Environmental factors, for example, noise levels that could be causing or contributing to discomfort or misinterpretation of noises such as over-head pages, alarms, etc. causing delusions and/or hallucinations.
- (g) Mismatch between the activities or routines selected and the resident's cognitive and other abilities to participate in those activities/routines. For example, a resident who has progressed from mid to later stages of dementia may become frustrated and upset if he/she is trying but unable to do things that she previously enjoyed, or unable to perform tasks such as dressing or grooming.
- (h) The comprehensive person-centered care planning must consider individualized person-centered approaches, utilizing a consistent process to address behaviors that focuses on the resident's individual needs and tries to understand their behaviors as a form of communication and that uses non-pharmacological interventions.¹⁸²

As this comment demonstrates, the Center for Medicare Advocacy wants CMS to push its commitment to person-centered care even further. This added language fleshes out the assessment to encompass many facets of person-centered care. While the language is specific, it does not provide much guidance about how the facility should elicit this kind of information from the resident. Left to their own devices, it is not expected that many facilities would have the time or resources to develop this kind of assessment for each resident.

2. *California Advocates for Nursing Home Reform*

Another robust set of dementia-related recommendations on the Proposed Rule comes from California Advocates for Nursing Home Reform ("CANHR").¹⁸³ In contrast to other comments on the Proposed Rule, praising CMS's commitment to person-centered care, CANHR levied a well-founded criticism: "requiring care to be per-

182. *Id.* at 30-31.

183. California Advocates for Nursing Home Reform ("CANHR"), Comment Letter on Reform of Requirements for Long-Term Care Facilities (Sept. 9, 2015), <https://www.regulations.gov/contentStreamer?documentId=CMS-2015-0083-9111&attachmentNumber=1&disposition=attachment&contentType=pdf> [hereinafter CANHR Comments].

son-centered is not a substitute for establishing dementia care standards within the regulations.”¹⁸⁴ The comments note that CMS’s endorsement of person-centered care, without developing specific regulations with respect to dementia care, goes no further than OBRA’s endorsement of “individualized care” as its cornerstone.¹⁸⁵ CANHR encouraged CMS to establish a standard of care for residents who have dementia.¹⁸⁶

CANHR went on to explain that, “person-centered care is little more than a slogan *without informed consent*.”¹⁸⁷ The group ultimately recommended that the proposed, “regulations provide the right to written informed consent prior to the use of a psychotropic drug.”¹⁸⁸

3. *The Society for Post-Acute and Long-Term Care Medicine*

The Society for Post-Acute and Long-Term Care Medicine (“AMDA”) proposed a revised definition of person-centered care for the Proposed Rule.¹⁸⁹ Their recommendation for a new definition is “individualized and appropriate care and services of any kind that directly and indirectly accommodate and support resident quality of life, input, and choice, to the extent practicable.”¹⁹⁰ Driving this suggestion was AMDA’s concern that the CMS definition is too narrow.¹⁹¹ AMDA also suggested adding “consultant pharmacist[s], psychologist[s], podiatrists, dentists, [and] respiratory therapists” to the definition of “licensed health professional.”¹⁹²

4. *Long Term Care Community Coalition*

The Long Term Care Community Coalition (“LTCCC”), “a non-profit organization wholly dedicated to improving quality of life and quality of care for elderly and disabled individuals who rely on

184. *Id.* at 4.

185. *See id.*

186. *Id.* at 3–6.

187. *Id.* at 21 (emphasis added).

188. *Id.* (reasoning that “[t]he use of mind-altering drugs without consent violates perhaps our most precious and fundamental human right: the right to control what goes into our bodies and the freedom to make our own decisions”).

189. Society for Post-Acute and Long-Term Care Medicine (“AMDA”), Comment Letter on Reform of Requirements for Long-Term Care Facilities app. at 304–05 (Oct. 14, 2015), <https://www.regulations.gov/contentStreamer?documentId=CMS-2015-00838458&attachmentNumber=1&disposition=attachment&contentType=pdf>.

190. *Id.*

191. *See id.*

192. *Id.* app. at 303.

long term care services, particularly those who reside in nursing homes or other residential care settings,” focused their comments on systemic change.¹⁹³ The organization identified four main areas of concern—dementia care, quality of life, arbitration, and staffing, and dementia care.¹⁹⁴

Notably, however, LTCCC applauded CMS for its renewed focus on person-centered care:

In general, we appreciate and support the overall focus on person-centered care that is found throughout the proposed regulations. With meaningful enforcement, we believe this focus will enhance residents’ quality of care and quality of life. There are other aspects of the proposed requirements that we support as well, including its greater focus on resident choice and preferences; more robust protections against abuse and neglect; and enhancements to the care planning process, such as a greater emphasis on resident participation. We are also pleased that residents’ rights have been strengthened in certain provisions.¹⁹⁵

Nevertheless, LTCCC underscored the importance of addressing insufficient staffing in order to successfully implement person-centered care in long-term nursing facilities, stating that “[g]ood staffing practices are necessary for facilities to deliver quality person-centered care.”¹⁹⁶ Adequate numbers of staff form the foundation of person-centered care, together with competent training, the

193. Long Term Care Community Coalition (“LTCCC”), Comment Letter on Reform of Requirements for Long-Term Care Facilities 1 (Oct. 14, 2015), <https://www.regulations.gov/contentStreamer?documentId=CMS-2015-0083-8882&attachmentNumber=1&disposition=attachment&contentType=pdf> [hereinafter LTCCC Comments].

194. *Id.* at 3–6.

195. *Id.* at 3.

196. *Id.* at 4. In addition to LTCCC, other groups—including CANHR, which issued separate comments on the topic—have noted the importance of sufficient staffing. See California Advocates for Nursing Home Reform (“CANHR”), Comment Letter on Reform of Requirements for Long-Term Care Facilities 4 (Oct. 13, 2015) <http://www.ltccc.org/news/documents/CANHRCommentsonProposedRequirementsofParticipationFinalOctober132015.pdf> (highlighting the importance of “strong staffing requirements” to implementing person-centered care as “involving nursing assistants in [person-centered] care planning meetings is a great idea if it does not come at the expense of having enough staff on a unit at all times to meet other residents’ needs.”); Justice in Aging, Comment Letter on Proposed Medicaid Managed Care Regulations 16 (July 27, 2015), <https://www.regulations.gov/contentStreamer?documentId=CMS-2015-0068-0720&attachmentNumber=1&disposition=attachment&contentType=pdf> (recommending that family caregivers be permitted to participate in the “long term services and supports” planning process in order to ensure that family members may participate in person-centered care).

promotion of individualized care, and consistent assignment.¹⁹⁷ On this basis, LTCCC challenged CMS to expand upon its requirement for “sufficient nursing staff with the appropriate competencies and skill sets” in order to develop “concrete standards” and prevent harm to nursing home residents.¹⁹⁸

C. Proposed Nursing Home Compare Measures

As CANHR noted in their comments to the Proposed Rule, tossing around the person-centered care “slogan” in regulations neither increases the quality of life for residents with dementia nor promotes autonomy and dignity. This apt observation highlights that if CMS truly endorses person-centered care in long-term facilities with care plans tailored to residents with dementia, the agency must incorporate dementia-specific criteria into its measures and evaluations.

For person-centered care, recommended practices “include a comprehensive assessment and care planning as well as understanding behavior and effective communication. Strategies for implementing person-centered care rely on having effective staff approaches and an environment conducive to carrying out recommended care practices.”¹⁹⁹

Keeping the central tenets of person-centered care in mind, the CMS health inspections and Nursing Home Compare reports should incorporate the following measures:

- Percentage of staff members (RNs, LPNs/LVNs, CNAs, physical therapists, speech therapists) who complete yearly dementia competency training;
- Number of days per week each staff member (RN, LPN/LVN, CNAs, physical therapist, speech therapist) engages resident with dementia in 15 minutes of conversation per day;
- Percentage of time awake resident with dementia spends outside his or her private room per day; and
- Family member participation in care planning assessment, including providing staff with a detailed report of resident’s likes, dislikes, personality, and interests.

These metrics would demonstrate whether, and to what extent, a facility adopted person-centered care into its daily routine and in-

197. See LTCCC Comments, *supra* note 193, at 4.

198. *Id.* at 4–5.

199. ALZHEIMER’S ASS’N, PHASES 1 & 2, *supra* note 1, at 3.

teractions with residents. Additionally, these metrics would promote three key objectives: (1) documenting staff competency; (2) highlighting staff interest in learning residents' preferences, interests, and habits; and (3) engaging residents in social interaction with staff members and fellow residents. Finally, by publishing information based on these metrics, public awareness of dementia and person-centered care would increase and consumers would be able to recognize the capacity of facilities to fully engage residents with dementia in autonomous, dignified, and social lives.

CONCLUSION

As the number of nursing home residents with dementia continues to increase, dementia care best practices and policies must be incorporated into the existing federal regulations and requirements. However, recognizing that the regulatory landscape will not change overnight, recommendations for reform must co-exist with the current nursing home surveillance quo. CMS and the National Partnership can and should create new dementia care metrics for Nursing Home Compare that blend person-centered care and the surveillance quo. This would constitute a concrete step toward incorporating person-centered care into federal policy. In addition, disseminating this information would educate the public about how various nursing facilities manage the day-to-day challenges of dementia.