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# ANNALS OF HEALTH LAW

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*Advance Directive*

**THE STUDENT HEALTH POLICY AND LAW REVIEW OF  
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ANNALS OF HEALTH LAW  
*Advance Directive*

Editor's Note

The *Annals of Health Law* is proud to present the Tenth Issue of our online, student-written publication, *Advance Directive*. *Advance Directive* aims to support and encourage student scholarship in the area of health law and policy. In this vein, this issue explores the challenges and opportunities facing the long-term care industry and consumers of long-term care. The authors examine a variety of issues related to long-term care, ranging from the viability of long-term care insurance to the use of electronic health records (EHR) in long-term care facilities.

The Issue begins by exploring issues related to caring for individuals with terminal illnesses. First, our authors examine the effect of the Patient Protection and Affordable Care Act's (PPACA) elimination of lifetime limits on cancer patients and the ability to pay for necessary healthcare. Second, we explore the legal issues associated with using tracking devices when caring for patients with Alzheimer's who have a propensity for wandering.

The Issue then addresses the role that advance directives play in end-of-life care planning and how the current legal landscape, at times, falls short of adequately serving patients. First, we examine the legal and policy implications of physician-assisted suicide. Then, our authors address the role that culture plays in a patient's willingness to execute advance directive documents. Specifically, our authors explore how advance directives may be devised to address various cultural norms. Finally, we examine how mental health advance directive forms may better communicate a patient's wishes than the current forms do.

Our authors next explore the opportunities and challenges currently facing nursing homes and their residents. First, we address ethnic disparities in the quality of nursing homes and provisions in the PPACA that may be available to help address this issue. Next, the authors explore the benefits of EHR use in nursing homes, while also examining whether the PPACA goes far enough in incentivizing nursing homes to implement EHRs. Finally, we address the ways in which nursing homes in Illinois can be exposed to liability and whether the Illinois legal framework is specific enough, such that nursing homes can adequately protect themselves from liability.

The Issue then addresses the ongoing debate between community-based and institutional care, including the ability of institutional care to adequately serve specific populations. First, we examine the effects of moving to community-based care on the lesbian, gay, bisexual, transgender, and queer (LGBTQ) community. Specifically, we examine whether community-based care is the best option for the LGBTQ community, or whether this population's needs are better served by institutional care. Second, our authors explore the benefits of moving intellectually and developmentally disabled individuals into community-based care. Third, we explore whether Illinois' movement toward deinstitutionalization for the mentally ill will succeed in properly caring for the State's mentally ill population. Finally, on a similar note, the authors analyze whether the Illinois Nursing Home Care Act adequately addresses the challenges of caring for mentally ill patients in nursing homes.

Finally, the Issue concludes by examining potential solutions for addressing the problem of costs associated with long-term care in the United States. First, we address the possibility of repealing the spousal anti-impaoverishment provision as a means for reducing costs to Medicaid for long-term care. Second, we explore the possibility of expanding Medicare to cover the costs of long-term care. Third, our authors examine long-term care insurance and the ways in which it fails to adequately fund long-term care for consumers. Finally, we take a broader view and explore the ways in which improving primary care will serve to lessen the cost burden on the long-term care industry.

We would like to thank Timothy Loveland, our *Advance Directive* Senior Editor, and Brian Troutman, our Technical Editor, because without their knowledge and commitment this issue would not have been possible. We would like to give special thanks to our *Annals* Editor-in-Chief, Ashley Leonard, for her unwavering leadership and support. The *Annals* Executive Board Members, Logan Parker, Karim Hussein, Alissa Bugh, and Kristin Peterson, provided invaluable editorial assistance with this Issue. The *Annals* members deserve special recognition for their thoughtful and topical articles and for editing the work of their peers. Lastly, we must thank the Beazley Institute for Health Law & Policy and our faculty advisors, Professor Lawrence Singer, Professor John Blum, and Megan Bess for their guidance and support.

We hope you enjoy your Tenth Issue of *Advance Directive*.

Sincerely,

Carrie S. Gilbert  
Advance Directive Editor  
*Annals of Health Law*  
Loyola University Chicago School of Law

Coverage Capped when You Need it Most: The  
Effect of Lifetime Insurance Limits on Cancer  
Patients

*Christopher MacDonald\**

I. INTRODUCTION

Cancer is a deadly, all-consuming disease. In 2009, it trailed only heart disease in the number of people it killed, at over 500,000 deaths in the United States alone.<sup>1</sup> Those who survive are faced with medical care that is exceedingly expensive.<sup>2</sup> As medical science improves, and new cancer treatments create a better survival rate, more and more people will be living with cancer. Currently, there are approximately 12.5 million people in the United States living with cancer<sup>3</sup> and more than 1.6 million are expected to be diagnosed in 2013 alone.<sup>4</sup> While many people view cancer as a death sentence, the five-year survival rate is now at sixty-eight percent up from forty-nine percent between 1975-1977.<sup>5</sup> This improved survival rate can be

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1. Melonie Heron, *Deaths: Leading Causes for 2009*, 61(7) NAT'L VITAL STATISTICS REP. 1, 9 (2012).

2. In the United States, cancer care is among the most expensive treatment plans. See Marilyn Marchione, *Cancer's Growing Burden: The High Cost of Care*, USA TODAY (Feb. 27, 2012), available at <http://usatoday30.usatoday.com/news/health/story/health/story/2012-02-27/Cancers-growing-burden-the-high-cost-of-care/53271430/1>.

3. Nat'l Cancer Inst, *SEER Stat Fact Sheets: All Sites*, WWW.CANCER.GOV, <http://seer.cancer.gov/statfacts/html/all.html> (last visited Feb. 18, 2013). These statistics include any living person as of January 1, 2009, who had been diagnosed with cancer at any site prior to January 1, 2009. *Id.* This also includes any persons with active disease and those who have been cured. *Id.*

4. AM. CANCER SOC'Y, *CANCER FACTS & FIGURES 2013* 1 (2013), <http://www.cancer.org/acs/groups/content/@epidemiologysurveillance/documents/document/acspc-036845.pdf>.

5. *Id.* at 2. This rate does not distinguish between cancer in remission and those still in treatment and cancer deaths can still occur more than five years after diagnosis. *Id.*

attributed to a number of factors, including early detection and improved treatment techniques.<sup>6</sup> While this progress is encouraging, it is causing increased financial hardships on families faced with paying for long-term care.

In 2008, the overall medical costs of cancer in the U.S. totaled \$77.4 billion.<sup>7</sup> That collective number, while staggering, does little to paint a picture of the costs for the average patient. From patient to patient, costs vary dramatically. Factors such as the patient's type of cancer, the patient's complications, and the doctor's treatment decisions all contribute to the costs.<sup>8</sup>

Faced with such high costs, even insured individuals have difficulty paying their medical bills and medical bankruptcies have become prevalent in the U.S.<sup>9</sup> Many of these individuals find themselves facing a "double disaster:" being sick and dealing with a bankruptcy.<sup>10</sup> A 2009 clinical research study found strong connections between high medical bills and bankruptcy.<sup>11</sup> Before the financial crisis, in 2007, using the most conservative definitions, sixty-two percent of all bankruptcies were medical.<sup>12</sup> It is not just the patient that is affected by high medical costs, the

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6. *Id.*

7. *Id.* at 3.

8. *See* Marchione, *supra* note 2.

9. *See* Elizabeth Warren, *Sick and Broke*, WASH. POST, (Feb. 9, 2005), available at <http://www.washingtonpost.com/wp-dyn/articles/A9447-2005Feb8.html>.

10. *Id.*

11. *See* David U. Himmelstein, et al., *Medical Bankruptcy in the United States, 2007: Results of a National Study*, AM. J. MED. 1, 2 (2009).

12. *Id.*; but *see* Erika Gonzalez, *Patients Go Bankrupt As Medical Costs Soar*, COLO. PUB. NEWS, (May 21, 2012), <http://www.pnhp.org/news/2012/may/patients-go-bankrupt-as-medical-costs-soar>. Other studies have found lesser connections between medical bills and bankruptcies. A Northwestern University study found that just 17% of bankruptcies were medical related and a U.S. Department of Justice study between 2000 and 2002 found just 13% of bankruptcies to be medical. *Id.* Of a sample of bankrupt individuals, 57.1% had high medical bills, 5.7% of homeowners had mortgaged their homes to pay medical bills, and 40.3% had lost income due to illness. Himmelstein, et al., *supra* note 11, at 3.

whole family suffers.<sup>13</sup> Nearly seventy-five percent of the bankrupt individuals were insured and most were middle class and educated.<sup>14</sup> Despite this relative affluence, the average out of pocket medical expense for those with insurance was \$17,749.<sup>15</sup>

Compounding the financial strain on families coping with cancer, many insurance plans have both a yearly and lifetime limit for the amount of coverage they will expend.<sup>16</sup> With a high-cost disease such as cancer, many patients routinely exceed those limits, and are quickly faced with high out of pocket costs.<sup>17</sup> This causes families to face tough financial decisions, including rationing what type of care they can afford.<sup>18</sup> However, by 2014, as part of the Patient Protection and Affordable Care Act (PPACA), insurers will no longer be able to include these yearly and lifetime caps on coverage.<sup>19</sup>

Unfortunately, the elimination of lifetime limits on healthcare coverage will do little to reduce medical costs for the average cancer patient. Only rare, outlier patients with exceedingly high medical costs and low lifetime limits will really benefit financially from this provision. On the other hand, the emotional freedom afforded by no longer having to take into account lifetime limits is important and immeasurable.

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13. *Id.* In the same study, 77.9% of the patients were either the debtor or the spouse, a child caused 14.6% of cases, and 7.5% of the cases were a parent, sibling, or other adult patient. *Id.* at 4.

14. *Id.* at 3.

15. *Id.* at 4.

16. Lifetime limits are caps placed on coverage in many insurance plans that stipulate a maximum total dollar in benefits that the insurer will pay over a patient's lifetime. PRICEWATERHOUSECOOPERS, THE IMPACT OF LIFETIME LIMITS, 2 (2009), <http://www.hemophilia.org/docs/LifetimeLimitsReport.pdf>. Once a patient reaches their lifetime limit, they no longer receive any coverage from their insurer and are essentially "uninsured." *See id.*; *see also* discussion *infra* Section II.

17. *See* Reed Abelson, *Awaiting Health Law's Prognosis*, N.Y. TIMES, (Feb. 1, 2011), <http://www.nytimes.com/2011/02/02/business/02insure.html?pagewanted=all>.

18. *See id.*

19. Patient Protection and Affordable Care Act, 42 U.S.C. § 2711 (2010) [hereinafter PPACA].

This article will begin with a detailed explanation of lifetime limits in Section II. Section III will discuss the costs of cancer and the effect of lifetime limits on average cancer patient, and Section IV will discuss the elimination of caps under the PPACA.

## II. LIFETIME LIMITS

A lifetime limit, in the health insurance context, is a stipulation in an insurance plan that puts a dollar limit on the amount of benefits patients can receive in their lifetime.<sup>20</sup> After patients reach their lifetime limit, their health insurance will no longer pay them benefits.<sup>21</sup> Insurers implement these provisions as a cost cutting move<sup>22</sup> in order to limit the amount paid for their most expensive clients. In a typical insurance plan, lifetime limits are assessed on an individual, “per-person” basis;<sup>23</sup> thus if one member of a family exceeds his or her lifetime limit, and lost his or her coverage, the rest of the family would be unaffected and still be covered. In a typical insurance plan, these provisions can be hard to find, but they are often listed as the “Maximum Lifetime Plan Benefit”<sup>24</sup> or “Lifetime Maximum.”<sup>25</sup>

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20. PRICEWATERHOUSECOOPERS, *supra* note 16. These figures were based on a PriceWaterhouseCooper survey of health insurance lifetime limits. *Id.* In this study, “PwC researched the public domain for survey and reports on lifetime maximum distributions and cost. The overall estimates were based on the 2007 Kaiser Foundation Annual Survey Report on Employer Health Benefits.” *Id.*

21. *Id.*

22. *See* Requirements for Group Health Plans and Health Insurance Issuers Under the Patient Protection and Affordable Care Act Relating to Preexisting Condition Exclusions, Lifetime and Annual Limits, Recessions, and Patient Protections, 75 Fed. Reg. 37, 187, 37,206 (June 28, 2010) (to be codified at 26 C.F.R. pt. 54) [hereinafter Requirements for Group Health Plans]. Eliminating these caps will lead to higher costs for the insurer, so naturally they were put in place to keep costs lower. *Id.*

23. *See* BLUE CROSS BLUE SHIELD, BCBS HIGH DEDUCTIBLE HEALTH PLAN (2009), available at [http://www.bcbsnc.com/assets/members/public/pdf/progressenergy/2009BCBSNC\\_High\\_Deductible\\_Health\\_Plan.pdf](http://www.bcbsnc.com/assets/members/public/pdf/progressenergy/2009BCBSNC_High_Deductible_Health_Plan.pdf).

24. *See id.*

25. *See* CIGNA HEALTHCARE, SUMMARY OF BENEFITS: YOUR HEALTH SAVINGS ACCOUNT QUALIFIED-OPEN ACCESS PLUS PLAN (2010), available at [http://www.cigna.com/assets/docs/information-for-small-group-brokers/HDHP\\_1-90.pdf](http://www.cigna.com/assets/docs/information-for-small-group-brokers/HDHP_1-90.pdf).

Generally, all medical, mental health, substance abuse services, and prescription drugs benefits count towards the patient's lifetime limit.<sup>26</sup>

Not all insurance plans contain a lifetime limit provision and the dollar amount of the cap varies from plan to plan.<sup>27</sup> Approximately ninety-one million people are covered by an employer health insurance plan subject to a lifetime limit,<sup>28</sup> which is about fifty-five percent of people with employer-provided insurance.<sup>29</sup> In 2009, it was estimated that 20,000-25,000 people reached their lifetime limit.<sup>30</sup>

When patients reach their lifetime limit, they are no longer covered by their insurance plan, and are "essentially uninsured."<sup>31</sup> Once they reach their lifetime limit they have a variety of options; they can pay out of pocket<sup>32</sup> or limit their future healthcare costs, often by changing their treatment plan to one that is cheaper or experimental.<sup>33</sup> In addition, a patient may switch insurance plans to reset his cap.<sup>34</sup> This can be accomplished either by switching employers, buying into a new plan, or if he works for an employer with multiple plan options, switching plans.<sup>35</sup> Potentially, a patient could also "spend down" his assets and qualify for federal medical assistance through Medicaid.<sup>36</sup> While these options may be viable for certain individuals, many patients do not have the flexibility to

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26. See BLUE CROSS BLUE SHIELD, *supra* note 23.

27. PRICEWATERHOUSECOOPERS, *supra* note 16, at 3. About 1% of insurance plans have a lifetime limit of less than \$1 million; 22% of plans have a cap of \$1 million, but less than \$2 million; 32% of plans have a limit of \$2 million or greater; while 45% of plans have no lifetime limit (unlimited). *Id.*

28. *Id.*

29. *Id.* at 1.

30. *Id.* at 3.

31. Requirements for Group Health Plans, *supra* note 22, at 37,205.

32. PRICEWATERHOUSECOOPERS, *supra* note 16, at 2.

33. See Abelson, *supra* note 17, at 2.

34. Requirements for Group Health Plans, *supra* note 22, at 37,220.

35. *Id.*

36. PRICEWATERHOUSECOOPERS, *supra* note 16, at 2.

switch jobs at will or do not have an employer that offers multiple plans.<sup>37</sup> It can take several months or even years to spend down their assets in an effort to qualify for Medicaid.<sup>38</sup> Thus, even if a patient had the option to switch insurers or qualify for Medicaid, he could still experience a gap in coverage<sup>39</sup> and potentially miss treatments.<sup>40</sup> Furthermore, the care beneficiaries do receive may be of a lower quality, and they may have to switch to an unfamiliar doctor or hospital when they switch insurers.<sup>41</sup>

However, patients cannot wait until they reach the limit to begin planning; they need to decide early on in their treatment how to ration their care to ensure they do not lose treatment when they need it most.<sup>42</sup> In addition, many health insurance plans do not inform patients until they have reached their lifetime limit.<sup>43</sup> Thus, cancer patients are often required to track expenses on their own to predict when they will reach their lifetime limit. All of these factors place not just a significant financial burden, but also a severe emotional burden on a patient. A cancer patient is already facing an all-consuming disease, and must also make decisions through the lens of lifetime limits. These lifetime limits put an additional strain on care decisions, and require patients to focus not simply on getting well, but also take into consideration costs based on how long they will be treated, or more practically, how long they will live.

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37. JEANNE M. LAMBREW, "CHOICE" IN HEALTH CARE: WHAT DO PEOPLE REALLY WANT? 3 (2005), available at [http://www.commonwealthfund.org/usr\\_doc/lambrew\\_853\\_choice\\_ib.pdf](http://www.commonwealthfund.org/usr_doc/lambrew_853_choice_ib.pdf). Only 53% of working-aged adults with employer provided healthcare have a choice between two or more health plans. *Id.*

38. PRICEWATERHOUSECOOPERS, *supra* note 16, at 2.

39. Requirements for Group Health Plans, *supra* note 22, at 37,207.

40. *See id.* at 37,205.

41. *See* Abelson, *supra* note 17, at 3.

42. *Id.*

43. *See* KARYN SCHWARTZ, ET AL. SPENDING TO SURVIVE: CANCER PATIENTS CONFRONT HOLES IN THE HEALTH INSURANCE SYSTEM 32 (2009), available at <http://www.kff.org/insurance/upload/7851.pdf>.

## III. THE COSTS OF CANCER

Despite the high financial costs of cancer, it is unlikely that the average patient will ever reach his or her lifetime limit. While there has been no formal study conducted, a recent survey indicated that only ten percent of cancer patients had reached their lifetime limit.<sup>44</sup>

Using average cancer costs, one can better grasp this issue's prevalence. The average annual cost of cancer for an insured patient varies widely based on type of cancer.<sup>45</sup> For patients over the age of sixty-five, this can range from about \$5,000 per year for melanoma to \$110,000 per year for brain cancer.<sup>46</sup> Overall, brain, pancreas, esophagus, ovary, and stomach cancers have the largest annualized initial cost, while melanoma, breast, and prostate cancers have the lowest annualized initial cost.<sup>47</sup> In addition, costs tend to be higher in the first year of treatment and in the patient's final years,<sup>48</sup> and vary by gender.<sup>49</sup> For patients under the age of sixty-five, annual costs for the first year's treatment range from around \$6,000 for melanoma to nearly \$140,000 for brain cancer.<sup>50</sup> The average annual co-pay for cancer patients under the age of sixty-five tends to lower in the interim years, and then rise in the final year of treatment.<sup>51</sup> Older patients

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44. Susan Jaffe, *The New Health Care Law and Annual and Lifetime Coverage Limits*, AARP.ORG (Aug. 23, 2010), [http://www.aarp.org/health/health-care-reform/info-08-2010/hcr\\_explained.html](http://www.aarp.org/health/health-care-reform/info-08-2010/hcr_explained.html).

45. See Angela B. Mariotto et al., *Projections of the Cost of Cancer Care in the United States: 2010-2020*, 103 J. N. CANCER INS. 117 (2010), <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3107566/pdf/djq495.pdf>. For this study, cancer costs were estimated using Medicare claims SEER data. *Id.* at 118.

46. *Id.* at 125.

47. *Id.*

48. *Id.*

49. *Id.*

50. *Id.*

51. The average annual co-pay cost for the first year of treatment is \$62,238. *Id.* In the intervening years, this lowers to \$5,891, but in the last year of life, the costs are again much higher, with an average cost of \$138,538. *Id.*

face slightly lower costs, overall.<sup>52</sup>

Using these figures, it seems unlikely that most cancer patients would reach their lifetime limits. Under average figures it would take an individual who started treatment at age sixty-five or older approximately 161 years to reach his or her lifetime limit of \$1 million.<sup>53</sup> A patient who was under the age of sixty-five in his or her first year of treatment would take 159 years to reach his or her lifetime limit of \$1 million.<sup>54</sup> Even using the most generous figures, it would take a male brain cancer patient, who began treatment under the age of sixty-five, over ninety-one years to reach his lifetime limit of \$1 million.<sup>55</sup> Thus, the average cancer patient is unlikely to have to grapple with lifetime limits.

Despite this, outlier costs can be significantly higher. Drug costs can be a major factor in someone exceeding his or her lifetime limit, and may significantly raise their out of pocket costs. For example, Zytiga, a prostate cancer medicine approved last year, costs \$6,100 a month.<sup>56</sup> Insured patients have reported paying as little as \$1.50 per month and as much as \$5,943 copayment.<sup>57</sup> Meanwhile, Neulesta, a shot that boosts white blood cells to help patients better tolerate chemotherapy, can cost as much as \$14,865.<sup>58</sup> Some insured patients have reported paying as much as \$12,000 for the shot, while others have reported paying less than \$7,000 in copayments.<sup>59</sup> Neither of these cost nearly as much as the most expensive

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52. For the first year of treatment, the average annual cost for a patient over the age of sixty-five is \$52,303. *Id.* This levels out to a more reasonable average annual cost of \$5,891 in subsequent years. *Id.* In the last year of life, the costs rise significantly again, with an average cost of \$94,473. *Id.*

53. This assumes they do not pay the higher “final year” costs. *Id.*

54. This assumes they do not pay the higher “final year” costs. *Id.*

55. This assumes they do not pay the higher “final year” costs. *Id.*

56. Marchione, *supra* note 2.

57. *Id.*

58. *Id.*

59. *Id.*

cancer drugs—Bexxar and Zevalin, used to treat rare forms of Non-Hodgkins Lymphoma – which cost nearly \$25,000 per treatment.<sup>60</sup>

With drug costs at this level, an individual could quickly surpass their lifetime limit. For instance, the American Cancer Society interviewed several cancer patients coping with high medical bills, including ten-year-old Taylor Whilhite.<sup>61</sup> Taylor was diagnosed with Acute Myeloid Leukemia and doctors prescribed an aggressive treatment program.<sup>62</sup> Subsequently, “[s]he received three rounds of chemotherapy and a bone marrow transplant; at one point she was taking twenty-three pills a day in addition to IV medications.”<sup>63</sup> In addition, the cancer caused numerous side effects including heart problems, hip problems, diabetes, and a compromised immune system,<sup>64</sup> which required further treatment. Even at the young age of ten, Taylor reached her lifetime limit of \$1 million.<sup>65</sup> Her parents were able to secure an increase of their lifetime limit to \$1.5 million, but that was not enough to cover the surgeries and treatment she needs.<sup>66</sup> Her family has decided to rely on HIPAA<sup>67</sup> coverage upon exhausting their lifetime limit, at a great expense to them.<sup>68</sup>

Furthermore, patients that have not reached their lifetime limit still worry about rationing their care for fear of reaching their lifetime limit. For

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60. Alex Berenson, *Market Forces Cited in Lymphoma Drugs' Disuse*, N.Y. TIMES (Jul. 14, 2007).

61. See Schwartz et al., *supra* note 43, at 32.

62. *Id.*

63. *Id.*

64. *Id.*

65. *Id.*

66. See *id.*

67. HIPAA is the Health Insurance Portability and Accountability Act which offers insurance individuals who have exhausted their normal coverage. See CTR. FOR MEDICARE AND MEDICAID SERVICES, HIPAA ELIGIBILITY CRITERIA FOR INDIVIDUAL COVERAGE 1, available at [http://www.cms.gov/Regulations-and-Guidance/Health-Insurance-Reform/HealthInsReformforConsume/downloads/HIPAA\\_Eligibility\\_Criteria.pdf](http://www.cms.gov/Regulations-and-Guidance/Health-Insurance-Reform/HealthInsReformforConsume/downloads/HIPAA_Eligibility_Criteria.pdf).

68. Schwartz et al., *supra* note 43, at 32.

example, Judy Lamb, who was interviewed during an HHS article series on the PPACA, had breast cancer that spread to her liver and bones.<sup>69</sup> She had a lifetime limit of \$2 million, while her care cost between \$250,000-\$500,000 a year.<sup>70</sup> At that rate, she knew that she would soon exceed her lifetime limit, and needed to ration her care.<sup>71</sup>

Patients may also alter their care decisions for fear of reaching their lifetime limits. For example, Hillary St. Pierre, who was interviewed by the New York Times about the effect of the PPACA on her health care choices, had Hodgkin's lymphoma, and was close to reaching her lifetime limit of \$2 million.<sup>72</sup> She received a bone marrow transplant, which failed, but her insurance was going to run out before she could receive a second.<sup>73</sup> To receive further chemotherapy, she was forced to enroll in a clinical trial for an experimental treatment.<sup>74</sup> She was also forced to consider a variety of options for her medical care including divorcing her husband, so she could qualify for Medicaid, or moving to Massachusetts, where there is universal healthcare.<sup>75</sup>

While most patients will likely never have to deal with their coverage being capped, all three of these patients were faced with changing their care plan or risking the loss of insurance coverage. The elimination of these caps will allow patients like them to focus more on getting well and on the best treatment plan for their health, rather than on what will contribute the least to their lifetime limit. Nonetheless, the elimination of lifetime limits

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69. *Dori Salcido, Judy-Care: Focusing on Fighting Cancer, Without Fear of Lifetime Insurance Caps, HEALTHCARE.GOV (May 22, 2012), [http://www.healthcare.gov/blog/2012/05/mycare\\_judy.html](http://www.healthcare.gov/blog/2012/05/mycare_judy.html).*

70. *Id.*

71. *See id.*

72. Abelson, *supra* note 17.

73. *Id.*

74. *Id.*

75. *Id.*

will have little effect on the average cancer patient.

#### IV. THE PPACA AND LIFETIME LIMITS

By 2014, the PPACA eliminates annual and lifetime limits on health insurance.<sup>76</sup> Specifically, any healthcare plan started or renewed after September 23, 2010 may not put any lifetime limit on coverage.<sup>77</sup> Furthermore, annual limits will be slowly phased out, and any insurance plan purchased or renewed by January 1, 2014 will have no annual limit.<sup>78</sup>

In addition, it is likely that eliminating lifetime limits will have only a modest effect on individual insurance premiums, adding about one percent to the cost.<sup>79</sup> On the group market, the percentage will be even less, at just 0.5%.<sup>80</sup> Furthermore, because there will be fewer people losing their insurance due to lifetime limits, there will be fewer people joining Medicare and Medicaid, which should alleviate some of the stress on those programs.<sup>81</sup> Thus, for most insured individuals, the cost increases in their insurance should be slight.

When drafting this law, Congress aimed to ensure that people had health insurance when they needed it most. Government regulations note that: “prohibiting lifetime limits and restricting annual limits assures that insurance will perform the function for which it was designed—namely, protecting health and financial well-being for those most in need of care.”<sup>82</sup> Congress offered that banning lifetime limits was a basic safeguard to

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76. PPACA, *supra* note 19.

77. U.S. Dep’t of Health and Human Servs., *Lifetime & Annual Limits*, HEALTHCARE.GOV, <http://www.healthcare.gov/law/features/costs/limits/index.html> (last updated Jan. 24, 2012).

78. *Id.*

79. Abelson, *supra* note 17. If a plan has a \$1 million limit, eliminating that cap would cause a rise of 1% to the premium. *Id.*

80. Requirements for Group Health Plans, *supra* note 22, at 37,216.

81. *Id.* at 37,206.

82. *Id.* at 37,205.

ensure that families were not arbitrarily denied healthcare coverage,<sup>83</sup> and believed that the ban would save families money.<sup>84</sup> In addition, Congress stated they believed it to be only fair that citizens have the same benefits afforded to members of Congress, who do not have a lifetime limit on their insurance plan.<sup>85</sup>

Taking all of these goals into account, it seems that eliminating lifetime limits is an easy choice to make. This program does not cost the average insured person much, and it helps eliminate what has been a source of anxiety and worry for many patients with chronic illnesses. However, few cancer patients actually reach their lifetime limit, and therefore, removing the lifetime cap does not go far enough to significantly help families facing medical bills. A more comprehensive package needs to be put into place that brings costs down in every aspect of healthcare. It is the high cost of medications, doctors, treatments, prescriptions, and everything in between that is leading to the financial strain on the average cancer patient. If Congress truly wants to save families coping with cancer money, it must do more than simply eliminate lifetime limits. While banning lifetime limits is a good start that will help those with the highest medical bills, it does little to alleviate the financial strain on the average cancer patient.

## V. CONCLUSION

While it seems unlikely that the average cancer patient would need to worry about reaching their lifetime limit, health insurance coverage caps still affect many individuals. Aggressive treatment plans and expensive cancer drugs, coupled with earlier detection, have led to rising costs. But

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83. 111 CONG. REC. S7407-09 (daily ed. Sept. 23, 2010) (statement of Sen. Robert Casey).

84. 111 CONG. REC. S9697 (daily ed. Sept. 23, 2010) (statement of Sen. Jeff Merkley).

85. 111 CONG. REC. H1459 (daily ed. Mar. 16, 2010) (statement of Sen. Robert Andrews).

for the new PPACA provisions, many more individuals would likely have reached their limit in the next decade. The elimination of lifetime and annual limits does not necessarily eliminate a cancer patient's need to worry about the costs of treatments. On the contrary, co-pays can still be very high and vary widely from person to person and treatment to treatment. What the prohibition of these caps does guarantee is that cancer patients will never have to fear their coverage will run out just because they are pursuing an aggressive treatment plan or have complications with their treatment. They will no longer have to budget their treatment based on how long they think they may live. It may just be one less thing they have to worry about, but for many patients, it is key.

Private Use of Electronic Tracking Devices  
on Individuals with Dementia:  
Balancing Possible Ethical and Legal Issues with  
Potential Safety Benefits

*Sarah Jin\**

I. INTRODUCTION

*It was early evening when Lee Ferrero got in his car to make the trip home from a meeting for work. He'd done the trip many times over the years, and he looked forward to the drive. Several hours later he found himself in open farmland in unfamiliar territory. He pulled over, brought out a book of maps, and realized he had driven two hours past the turnoff to this home in Los Osos, California. "It was terrifying," he remembers now. "I thought, I didn't mean to come here. How did this happen? I just zoned out." But he wasn't just zoning out. A visit to the Mayo Clinic in Scottsdale, Arizona, showed Ferrero was in the beginning stages of Alzheimer's disease, a form of dementia.<sup>1</sup>*

In 2012, an estimated 5.4 million Americans had Alzheimer's disease, including 5.2 million individuals age 65 or older and 200,000 individuals under age 65.<sup>2</sup> Alzheimer's disease is a form of "dementia," a term that describes various diseases and conditions resulting from the death or malfunction of nerve cells, or neurons, in the brain.<sup>3</sup> This deterioration of nerve functions in the brain leads to changes in behavior and cognitive ability.<sup>4</sup> Alzheimer's disease,<sup>5</sup> in particular, eventually interferes with the

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1. Elizabeth Cohen, *How to Limit Alzheimer's Wandering*, CNN (Nov. 10, 2011), <http://www.cnn.com/2011/11/10/health/alzheimers-lost-empowered-patient>.

2. ALZHEIMER'S ASS'N, 2012 Alzheimer's Disease Facts and Figures, in 8 ALZHEIMER'S & DEMENTIA 1, 14 (2012).

3. *Id.* at 4.

4. The changes in cognitive ability can include memory loss or ability to think clearly.

individual's ability to perform basic daily functions, like walking or swallowing.<sup>6</sup>

Those suffering from dementia generally face impaired judgment, difficulties with visual and spatial perception, and physical disorientation.<sup>7</sup> These issues also often lead to an increased risk of wandering.<sup>8</sup> Due to cognitive, environmental and psychosocial factors, wandering is a frequent behavioral symptom of dementia.<sup>9</sup> This behavior includes aimless walking, walking with an inappropriate purpose, nighttime walking, or walking out of the home and getting lost.<sup>10</sup> Wandering is a serious concern for caretakers. It presents substantial risks for individuals with dementia, including falls, injuries, dehydration, hypothermia, and even death.<sup>11</sup>

Of the over fifteen million Americans who provide unpaid care for a person with dementia, about eighty percent of them are family members.<sup>12</sup> These private caretakers (as opposed to professional caretakers), however, cannot devote all their time to keep watch over the individuals with dementia.<sup>13</sup> As a result, they are now turning to various types of assistive technology, particularly electronic tracking devices that utilize Global

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*Id.*

5. This article will refer only to dementia without explicitly discussing Alzheimer's disease, as it is covered by the term "dementia." For specific distinctions between dementia and Alzheimer's disease, *see id.* at 5.

6. *Id.* at 4.

7. *Id.* at 55.

8. *Id.*

9. Eleanor Bantry White & Paul Montgomery, *Electronic Tracking for People with Dementia: An Exploratory Study of the Ethical Issues Experienced By Carers in Making Decisions About Usage*, *DEMENTIA* 2 (Oct. 3, 2012), <http://dem.sagepub.com/content/early/2012/09/24/1471301212460445.full.pdf+html>.

10. Ruth Landau et al., *Families' and Professional Caregivers' Views of Using Advanced Technology to Track People with Dementia*, 20 *QUALITATIVE HEALTH RES.* 409, 409 (2010).

11. White & Montgomery, *supra* note 9, at 2.

12. *ALZHEIMER'S ASS'N*, *supra* note 2, at 27.

13. Katina Michael et al., *The Emerging Ethics of Human-centric GPS Tracking and Monitoring* 1, 4 (2006), available at <http://ro.uow.edu.au/cgi/viewcontent.cgi?article=1384&context=infopapers>.

Positioning System (“GPS”)<sup>14</sup> technology.<sup>15</sup>

This use of GPS technology, as well as other electronic tracking technologies, to track individuals with dementia presents a myriad of issues that requires balancing the ethical concerns and legal issues of such use with the safety benefits. On one hand, electronic tracking can create a more secure environment for individuals with dementia,<sup>16</sup> helping to immediately locate those who get lost, thereby reducing the risk of harm or injury.<sup>17</sup> But on the other hand, electronic tracking can be dehumanizing to individuals with dementia, interfering with their personal autonomy and right to privacy.<sup>18</sup>

Part II.A of this article provides a brief overview of the different types of tracking devices that are available and may be employed to prevent wandering.<sup>19</sup> Part II.B discusses the safety benefits of electronic tracking devices on individuals with dementia,<sup>20</sup> whereas Part II.C outlines the treatment of this issue in the United States through applicable federal and state legislation.<sup>21</sup> Part III then discusses legal issues presented by this particular use of electronic tracking devices.<sup>22</sup> This article focuses on legal issues exclusive to the common law tort of invasion of privacy, as outlined by the Second Restatement of Torts and various related case law, rather

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14. Waseem Karim, *The Privacy Implications of Personal Locators: Why You Should Think Twice Before Voluntarily Availing Yourself to GPS Monitoring*, 14 WASH. U. J. L. & POL’Y 485, 485 (2004). In the early 1970s, the United States Department of Defense first designed GPS to track the locations of military troops and equipment. GPS is a network of satellites that transmit radio signals, which are used by a radio receiver on Earth to triangulate its own position. GPS became available for civilian use in the 1980s. *Id.*

15. Michael et al., *supra* note 13, at 4.

16. *See id.* at 7.

17. *See id.*

18. Ruth Landau et al., *Who Should Make the Decision on the Use of GPS for People with Dementia*, 15 AGING & MENTAL HEALTH 78, 78 (2011).

19. *See infra* Part II.A.

20. *See infra* Part II.B.

21. *See infra* Part II.C

22. *See infra* Part III.

than the constitutional violations of the Fourth Amendment.<sup>23</sup> Part III.A, therefore, describes the four “invasion of privacy” tort claims under the Second Restatement of Torts, and how they may be applied to this context of using electronic tracking devices on individuals with dementia.<sup>24</sup> Part III.B then presents an overview of the issues that arise with obtaining consent to use the tracking device.<sup>25</sup> Part III.C looks to the possible violations of personal autonomy that these devices may prompt.<sup>26</sup> Finally, Part IV outlines a brief discussion of these conflicting interests, and the importance of weighing practical safety concerns with the previously discussed ethical and legal issues that may arise in each particular situation.<sup>27</sup>

## II. BENEFITS OF AND MOTIVATIONS FOR USING TRACKING DEVICES

### A. *Types of Tracking Devices*

With advancements in technology, personal tracking devices are now available in various forms, utilizing radio frequency (“RF”) range finding or

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23. For information on the constitutional issues implicated by electronic or GPS tracking, particularly by the government on criminal defendants, *see generally* Marc McAllister, *The Fourth Amendment and New Technologies: The Misapplication of Analogical Reasoning*, 36 S. ILL. U. L.J. 475 (2012); *see also* Elizabeth G. Currid, *More Bite Than Bark: The Legal and Social Consequences of Microchipping Individuals with Alzheimer’s Disease*, 6 IND. HEALTH L. REV. 357, 372-73 (2009) (outlining the Fourth Amendment’s protection of citizens from unreasonable search and seizure by the government); William A. Herbert, *No Direction Home: Will the Law Keep Pace with Human Tracking Technology to Protect Individual Privacy and Stop Geoslavery?*, 2 J.L. & POL’Y 409, 417-25 (2006); *see generally* David Myers, *The Warrantless Use of GPS Tracking Devices: Fourth Amendment Protection Restored Through Application of an Analytical Framework*, 3 CASE W. RESERVE J.L. TECH. & INTERNET 101 (2012); *U.S. v. Jones*, 132 S. Ct. 945, 946 (2012) (holding that the government’s installation of a GPS device on the defendant’s vehicle and using it to monitor its movements constituted a “search” in violation of the Fourth Amendment).

24. *See infra* Part III.A.

25. *See infra* Part III.B.

26. *See infra* Part III.C.

27. *See infra* Part IV.

global positioning systems (“GPS”).<sup>28</sup> The companies Wherify Wireless, Inc. and Applied Digital Solutions have both produced GPS tracking devices in the form of wristwatches, using GPS technology as well as mobile networks.<sup>29</sup> Individuals can also wear a transmitter in the form of a pager, an ankle bracelet, or a box-like device carried in a small bag.<sup>30</sup> This transmitter allows caretakers to locate the tracked individuals with a computer, mobile phone, or other mobile device.<sup>31</sup> GTX Corp., a company that specializes in creating GPS tracking personal location based services,<sup>32</sup> markets the patented GPS Smart Shoe.<sup>33</sup> This shoe is fitted with built-in GPS technology designed to track individuals with dementia who may wander.<sup>34</sup> The most invasive tracking device available, however, is the VeriChip, a miniature radio frequency identification device (“RFID”) surgically imbedded underneath the skin, stored with the individual’s verification number that can provide personal information.<sup>35</sup>

*B. Potential Safety Benefits of Tracking Individuals with Dementia*

Thirty-seven to sixty percent of individuals diagnosed with dementia develop wandering behaviors at some point.<sup>36</sup> Wandering is often classified

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28. William D. Kearns et al., *Attitudes and Expectations of Technologies to Manage Wandering Behavior in Persons with Dementia*, 6 GERONTECHNOLOGY J. 89, 91 (2007).

29. Karim, *supra* note 14, at 488-89.

30. For information on the specific benefits of various assistive technology and the requirements to make them effective, *see generally* F.J.M. MEILAND ET AL., *FUNCTIONAL REQUIREMENTS FOR ASSISTIVE TECHNOLOGY FOR PEOPLE WITH COGNITIVE IMPAIRMENTS AND DEMENTIA* (R. Wichert et al., eds. 2012).

31. *See* Karim, *supra* note 14, at 488-89.

32. GTX CORP., *About GTX Corp.*, <http://www.gtxcorp.com/about> (last visited Feb. 17, 2013).

33. GPS CORP., *GPS Smart Shoe 1*, [http://www.gtxcorp.com/sites/default/files/GPS\\_Shoe\\_Brochure\\_2011b.pdf](http://www.gtxcorp.com/sites/default/files/GPS_Shoe_Brochure_2011b.pdf) (last visited Feb. 17, 2013).

34. *Id.*

35. Karim, *supra* note 14, at 490.

36. Ruth Landau & Shirli Werner, *Ethical Aspects of Using GPS for Tracking People with Dementia: Recommendations for Practice*, 24 INT’L PSYCHOGERIATRICS 358, 358 (2011).

as a medical behavior.<sup>37</sup> This classification has caused some scholars to legitimize social control, defining and controlling risky behaviors like wandering.<sup>38</sup> Many individuals with dementia who wander and go missing are later found seriously injured, subjected to exposure from harsh weather conditions, or even dead.<sup>39</sup> Wandering and getting lost has also led caretakers to reduce the wandering individuals' freedom, as they are likely to keep wanderers confined in the home after a wandering incident.<sup>40</sup>

Even individuals who have not been diagnosed with dementia may still experience wandering behavior.<sup>41</sup> Fifty percent of individuals who meet the requirements to be diagnosed with dementia never receive that diagnosis.<sup>42</sup> As such, delayed or missed diagnoses can lead to lost opportunities to treat symptoms or missed opportunities to prevent injuries.<sup>43</sup> Even with a delayed or missed diagnosis, electronic tracking can effectively prevent possible injuries.<sup>44</sup> A tracking device can locate wandering individuals at any time by positioning the device through satellite technology and providing information through a mobile phone network.<sup>45</sup>

Furthermore, professional legal opinion has commanded much of the discourse regarding the ethical issues behind the use of electronic tracking devices for those with dementia.<sup>46</sup> However, studies that have explored the effects on actual individuals with dementia may provide more accurate and

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37. Johanna M. Wigg, *Liberating the Wanderers: Using technology to Unlock Doors for Those Living with Dementia*, 32 *SOC'Y HEALTH & ILLNESS* 288, 290 (2010).

38. *Id.*

39. Landau et al., *supra* note 10, at 409.

40. White & Montgomery, *supra* note 9 at 2. Wandering and getting lost has also been associated to higher rates of admission to care-homes and higher levels of caretakers' subjective burden. *Id.*

41. ALZHEIMER'S ASS'N, *supra* note 2, at 54.

42. *Id.*

43. *Id.*

44. White & Montgomery, *supra* note 9, at 2.

45. *Id.*

46. *See id.*

practical contribution to this discourse.<sup>47</sup> One scholar, in particular, has suggested that professional opinion is overrepresented and worth noting, as a recent survey found that professionals have greater reservations about electronic tracking than caretakers do.<sup>48</sup> Thus, many of the reservations expressed in the media may reflect hesitations of a cautious legal population rather than unbiased opinions of the general population, which includes individuals who actually take care of a family member with dementia.

### *C. Applicable Federal and State Legislation in the United States*

Federal legislation recognizes that individuals with dementia are people who retain the right to their personal autonomy, despite any mental or physical disabilities. Section 701 of the United States Code<sup>49</sup> asserts that while millions of Americans live with at least one physical or mental disability, these individuals still retain certain rights.<sup>50</sup> These rights include the freedom to live independently, enjoy self-determination and make

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47. *See id.*

48. *Id.*

49. Outside the U.S., other jurisdictions have performed studies or made attempts to pass legislation regarding this issue. *See* White & Montgomery, *supra* note 9, at 3 (explaining that Article Eight of the European Convention for the Protection of Human Rights and Fundamental Freedoms outlines the right to private life, which has been adopted into law in many jurisdictions, because electronic tracking inherently infringes on the privacy of individuals with dementia by enabling others to check their whereabouts); *see generally* Beate Thorsen et al., *GPS for Demented, an Analysis of Success Criteria and of Health and Care Workers' Attitudes to Using Tracking Technology*, SCANDINAVIAN CONFERENCE ON HEALTH INFORMATICS 1 (2012) (discussing studies conducted in Norway); *see also* Noam Shoval et al., *The Use of Advanced Tracking Technologies for the Analysis of Mobility in Alzheimer's Disease and Related Cognitive Diseases*, 8 BMC GERIATRICS 1 (2008). Despite the studies and attempts at legislation, however, few countries have developed policies specifically tailored to individuals with dementia, as most of the existing policies only focus on patients or the elderly. *See* Landau & Werner, *supra* note 36, at 360. The more advanced policy may be the Mental Capacity Act (Eng. and Wales). *See generally* DEP'T FOR CONSTITUTIONAL AFFAIRS, THE MENTAL CAPACITY ACT, 2005, cm. 6121 (U.K.), available at <http://webarchive.nationalarchives.gov.uk/+http://www.justice.gov.uk/docs/mca-cp.pdf>. The Act presumes that (1) every individual has decision-making ability until it is established otherwise and (2) where an individual cannot make a decision, any decision made on their behalf must be in their best interest. Landau & Werner, *supra* note 36, at 360.

50. 29 U.S.C. § 701(a)(1) (1998).

choices.<sup>51</sup> Furthermore, it states that the country's goals include giving individuals with disabilities the tools to make informed choices and decisions to live independently, and to achieve "economic and social self-sufficiency."<sup>52</sup> These sections of the Code demonstrate that all individuals with disabilities, including those with dementia, should retain the right to their personal autonomy. Additionally, some states, like California, more stringently restrict the use of tracking devices. For example, Section 637.7 of the California Penal Code prohibits any use of an electronic tracking device, unless the individual uses it on his or her own vehicle, or obtains consent from the individual being tracked.<sup>53</sup>

### III. CONCERNS WITH USING TRACKING DEVICES

Though numerous safety benefits provide justification and impetus for using electronic tracking devices on individuals with dementia, many legal and ethical issues also arise within this context. One organization<sup>54</sup> that helps locate and return wanderers to their homes has said that GPS tracking is not suitable for locating individuals with dementia because the information may be inaccurate and unreliable.<sup>55</sup> Beyond concerns about the

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51. 29 USC. §§ (3)(A)-(C), (F) (1998).

52. 29 U.S.C. §§ 701(6)(A)-(B) (1998).

53. CAL. PENAL CODE §§ 637.7(a)-(b) (2011). However, Part III.A of this article cites case law where courts have permitted the use of tracking devices though the use was alleged to have violated the privacy rights of the individuals whose vehicles were tracked. *See infra* Part III.A. Nonetheless, no such precedent exists in the context of using tracking devices on individuals with dementia.

54. PROJECT LIFESAVER, *About Us*, <http://www.projectlifesaver.org/about-us/> (stating that its primary mission is to provide timely response to save individuals who wander or reduce their potential injury). For information on Project Lifesaver's methods, *see also* PROJECT LIFESAVER, *About Us*, <http://www.projectlifesaver.org/how-it-works/>. Individuals enrolled in Project Lifesaver wear a small personal transmitter around the wrist or ankle, and if an individual wanders, his or her caretaker contacts a trained emergency team who can then track the transmitter's individualized tracking signal. *Id.*

55. Michael et al., *supra* note 13, at 6. The organization explained that GPS lacks four fundamental qualities of effective assistive technology: (1) reliability; (2) responsiveness; (3) practicality; and (4) affordability. *Id.*

functionality of GPS tracking, this use also creates a number of legal and ethical issues, namely invasions of privacy, problems with establishing consent, and violations of personal autonomy.

*A. Invasion of Privacy Torts*

Advances in technology continue to provide additional means to intrude on another individual's privacy.<sup>56</sup> The increasing number of human tracking technology constricts privacy interests, which may result in a societal demand for more options for legal recourse when privacy rights have been violated.<sup>57</sup> The Second Restatement of Torts recognizes four invasion of privacy torts: (1) unreasonable intrusion upon the seclusion of another individual; (2) appropriation of another individual's name or likeness; (3) unreasonable publicity given to another individual's private life; and (4) publicity that unreasonably places another individual in a false light before the public.<sup>58</sup> Only the torts of unreasonable intrusion upon the seclusion of another individual<sup>59</sup> and unreasonable publicity of an individual's private life<sup>60</sup> may be applicable in the context of using electronic tracking devices.<sup>61</sup>

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56. Herbert, *supra* note 23, at 409.

57. *Id.*

58. RESTATEMENT (SECOND) OF TORTS § 652A (1977).

59. RESTATEMENT (SECOND) OF TORTS § 652B (1977). Anyone who intentionally intrudes upon the solitude, private affairs, or concerns of another individual in a way that would be highly offensive to a reasonable person is subject to liability for invading that individual's privacy. *Id.*

60. RESTATEMENT (SECOND) OF TORTS § 652D (1977). Anyone who publicizes a matter concerning another individual's private life is subject to liability for invading that individual's privacy if the matter would be highly offensive to a reasonable person and it is not of legitimate concern to the public. *Id.*

61. Karen Eltis, *Society's Most Vulnerable Under Surveillance: The Ethics of Tagging and Tracking Dementia Patients with GPS Technology: A Comparative View*, OXFORD U. COMPARATIVE L. FORUM 6 (2005), available at <http://ouclf.iuscomp.org/articles/eltis.shtml>. Section 652B of the Restatement, defining the tort of intrusion upon seclusion, is applicable in the context of using electronic tracking devices because the intrusion does not need to be physical and can include eavesdropping. *Id.* Furthermore, solitude depends upon the expectation of privacy and the type of invasion, not whether the location is considered

Where employers attach tracking devices on their employees' cars, the factors of productivity, security, and impact on third parties have largely supported employer interest in using these devices.<sup>62</sup> And though issues of privacy and informed consent may arise from employer use of tracking devices,<sup>63</sup> employees have generally been unsuccessful in their invasion of privacy claims.<sup>64</sup> In *Alexandre v. New York City Taxi & Limousine Com'n*, for instance, New York taxi drivers protested against the New York City Taxi and Limousine Commission's ("TLC") installation of GPS tracking devices on their taxis.<sup>65</sup> The taxi drivers asserted that the tracking devices would continue to track their movements even when they were off duty, and that this unduly invaded their right to privacy.<sup>66</sup>

The *Alexandre* court upheld the use of the devices reasoning that adequate safeguards existed to protect personal information.<sup>67</sup> It further reasoned that the taxi drivers did not have "a legitimate expectation of privacy,"<sup>68</sup> and the City of New York, acting through TLC, had a strong interest in tracking and protecting the vehicles.<sup>69</sup> Similarly, the court in *Elgin v. St. Louis Coca-Cola Bottling Co.* found that the employer's use of GPS tracking devices on its employees' vehicles did not violate the

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private. *Id.*

62. See Michael et al., *supra* note 13, at 3.

63. Andrew McNamee, *Ethical Issues Arising from the Real Time Tracking and Monitoring of People Using GPS-based Location Services* 1, 27 (2005) (unpublished B.S. thesis, University of Wollongong) (on file with Research Online through the University of Wollongong Library) (identifying privacy, accuracy, inconsistency, right to examine records, and informed consent as ethical issues in using tracking devices on employees).

64. See, e.g., *Alexandre v. New York City Taxi and Limousine Com'n*, No. 07 Civ. 8175, 2007 WL 2826952 at \*1, (S.D.N.Y. 2007); see also, e.g., *Elgin v. St. Louis Coca-Cola Bottling Co.*, No. 4:05CV970-DJS, 2005 WL 3050633 at \*3 (E.D.Mo. 2005).

65. *Alexandre*, 2007 WL 2826952 at \*1.

66. *Id.* at \*2.

67. *Id.* at \*7.

68. *Id.* (quotations omitted).

69. *Id.* at \*8.

employees' privacy interests.<sup>70</sup> The court found that this use was reasonable because the vehicles were in public view and the employer actually owned those tracked vehicles.<sup>71</sup>

Beyond the context of employer use of tracking devices on employees' vehicles, a rental car customer alleged that the rental car service invaded his privacy when it installed a GPS tracking device on his rental car.<sup>72</sup> However, the court in *Turner v. Am. Car Rental, Inc.* held that the car rental service did not invade the customer's privacy when it installed the GPS device and deducted certain amounts of money from the customer's bank account each time he exceeded the posted speed limit.<sup>73</sup> The customer alleged that the rental service knew or should have known that the use of the GPS would be "offensive to persons of ordinary sensibilities and that its use constituted an intrusion on his privacy," but the court found that the use was reasonable.<sup>74</sup>

Section 652D's disclosure of personal information tort also often fails because an individual's movements in public places is observable to the public.<sup>75</sup> A New Jersey appellate court recently upheld a wife's use of a tracking device on her husband's car during their divorce proceedings.<sup>76</sup> In *Villanova v. Innovative Investigations, Inc.*, the wife hired the defendant, a private investigation agency, to investigate her husband's suspected infidelities.<sup>77</sup> The agency suggested that she place a GPS tracking device

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70. *Elgin v. St. Louis Coca-Cola Bottling Co.*, No. 4:05CV970-DJS, 2005 WL 3050633 at \*3, (E.D. Mo. 2005).

71. *Elgin*, 2005 WL 3050633 at \*3.

72. *Turner v. Am. Car Rental, Inc.*, 884 A.2d 7, 9 (Conn. App. 2005).

73. *Id.*

74. *Id.*

75. *Eltis*, *supra* note 61, at 6.

76. *Villanova v. Innovative Investigations, Inc.*, 21 A.3d 650 (N.J. Super. App. Div. 2011).

77. *Id.* at 652.

on his car.<sup>78</sup> The husband then brought suit, alleging that she invaded his privacy.<sup>79</sup> The court found in favor of the investigation agency because the husband had failed to produce evidence that he had driven the GPS-tracked vehicle “into a private or secluded location that was out of public view and in which he had a legitimate expectation of privacy.”<sup>80</sup> As such, the question of whether a tracking device violates the tracked individual’s legitimate expectation of privacy seems to hinge upon whether the individual was in public view or whether the individual was in a private or secluded place.<sup>81</sup> Therefore, the success of an invasion of privacy claim may depend on where the individual with dementia travels while being tracked.

### *B. Issues with Consent*

In one psychological study conducted by a professor of social work and social welfare, the majority of participants stated that electronic tracking devices should only be used on individuals with dementia with their consent and cooperation.<sup>82</sup> If an individual consents to be tracked, invasion of

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78. *Id.*

79. *Id.* at 651.

80. *Id.* at 651-52.

81. *Id.* The court found that no invasion of privacy occurred because the husband had been out in public view, where he lacked a legitimate expectation of privacy. *Id.* However, even if a private caretaker did commit an invasion of privacy by using a tracking device on an individual with dementia, that individual may lack the cognitive or physical capacity to bring an action against the caretaker. See H. Richard Beresford, *Ethical Issues in Dementia*, AM. ACAD. OF NEUROLOGY 1, 5 (2009), available at <http://www.aan.com/globals/axon/assets/6113.pdf>. In such a case, particularly if the individual’s legal guardian is the caretaker, the individual is left without recourse. If the individual lacks the facilities to manage his or her legal affairs, a court may appoint a guardian to act on behalf of the individual, which is discussed in Part III.B. See *infra* Part III.B. This situation then raises the question of whether the courts or states should intervene to act in the best interests of these individuals with dementia whose rights have been violated but who lack the ability and resources to seek redress. This article will not discuss this policy issue, however, as it largely focuses on the concerns arising from the use of tracking devices, rather than methods whereby individuals may seek legal redress resulting from the use.

82. Landau & Werner, *supra* note 36, at 362.

privacy issues no longer apply. However, the question then becomes whether an individual with dementia is capable of giving informed consent. In 1996, the American Bar Association issued a Formal Opinion that answered various questions regarding lawyers' conduct when representing individuals with dementia.<sup>83</sup> It stated that a lawyer may consult with others and take protective action or support the application of a guardian if the lawyer believes that the individual is no longer mentally capable of handling her or her legal affairs.<sup>84</sup>

In the context of will contests, courts determining testamentary capacity have relied on evidence such as observations of the individual's behavior by neighbors and friends, and the individual's medical history.<sup>85</sup> In cases where experts assessed an individual's testamentary capacity to establish the validity of a will, the court's finding was consistent with expert assessments.<sup>86</sup> However, "the medical profession has historically done a terrible job of diagnosing dementia in patients in a timely and accurate fashion."<sup>87</sup> One study found that less than twenty-five percent of individuals with moderate to severe dementia were actually diagnosed with dementia by their primary care physicians.<sup>88</sup> Though case law has supported findings of expert testimony regarding an individual's testamentary capacity, a physician's testimony cannot be the only factor considered when determining mental capacity because medical diagnoses

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83. Robert B. Fleming & Rebecca C. Morgan, *Lawyers' Ethical Dilemmas: A "Normal" Relationship When Representing Demented Clients and Their Families*, 35 GA. L. REV. 735, 747 (2001).

84. *Id.*

85. Pamela Champine, *Expertise and Instinct in the Assessment of Testamentary Capacity*, 51 VILL. L. REV. 25, 27 (2006).

86. *Id.* at 35.

87. Marshall B. Kapp, *Legal Standards for the Medical Diagnosis and Treatment of Dementia*, 23 J. LEGAL MED., 359, 368 (2002).

88. *Id.*

have not always been accurate or timely.<sup>89</sup>

If an individual with dementia is, in fact, declared unfit to give consent to a caretaker's use of tracking device, that individual may then be appointed a guardian.<sup>90</sup> A guardian may be necessary if the individual lacks the mental capacity to handle his or her legal affairs, but how it should be done then becomes the critical question.<sup>91</sup> This question has been answered in the context of will contests,<sup>92</sup> but no legal standard or precedent exists in this specific situation of private caretakers of individuals with dementia using electronic tracking devices.<sup>93</sup> Consequently, this type of case must take into account all relevant factors, weighing the potential benefits with possible consequences.

### *C. Preserving Personal Autonomy*

Beyond issues of privacy and consent, individuals with dementia are often anxious that their dementia will deprive them of their independence and control over their lives.<sup>94</sup> This concern for personal autonomy intertwines with invasions of privacy, as the tort of invasion of privacy involves intrusions into an individual's personal and private life.<sup>95</sup> However, it is also linked with rational and independent decision-making.<sup>96</sup>

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89. *Id.*

90. *See* Beresford, *supra* note 81, at 2.

91. *See id.*

92. For more information on testamentary capacity, *see generally* Champine, *supra* note 85.

93. For more information on issues of consent, *see, e.g.*, White & Montgomery, *supra* note 9, at 4-5; *see also* Landau & Werner, *supra* note 36, at 362. The majority of participants in a study of tracking individuals with dementia agreed that the devices should not be used without the cooperation and consent of the individuals with dementia, but that some of the family caregivers were willing to force their relatives to use a GPS tracking device while still a few were willing to implant a chip in their bodies. *Id.*

94. Landau & Werner, *supra* note 36, at 362.

95. Alistair R. Niemeijer et al., *Ethical and Practical Concerns of Surveillance Technologies in Residential Care for People with Dementia*, 22 INT'L PSYCHOGERIATRICS 1129, 1135 (2010).

96. *Id.*

Society tends to infantilize individuals with dementia.<sup>97</sup> But in spite of this treatment, these individuals are still adults who have retained some skills, even if those skills are limited.<sup>98</sup> Individuals with mild dementia can still express their thoughts,<sup>99</sup> and their caretakers – to the extent that they can determine the individual’s desires – should respect those wishes.<sup>100</sup>

In one psychological study, family caretakers of individuals with dementia supported the use of electronic tracking devices to help them locate wanderers.<sup>101</sup> However, these family members had reservations as to the effect of those devices on the individuals’ privacy and personal autonomy, as well as the stigmas associated with the electronic tagging of criminal offenders.<sup>102</sup> The idea of using a tracking device to keep a family member with dementia safe is a reasonable one. Yet, applying that idea to specific situations can create reservations in caretakers, particularly if such use attaches negative stigmas or demoralizes the tracked family member. Just as legal and ethical issues relating to private use of electronic tracking devices on individuals with dementia conflict with the potential safety benefits of that use, family caretakers are often conflicted by both their desire to keep their loved one safe and their reluctance to force an unwilling family member to submit to electronic tracking. Therefore, balancing the safety benefits of tracking devices against the legal and ethical concerns is the threshold issue for these caretakers.

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97. *Id.*

98. *Id.*

99. Landau & Werner, *supra* note 36, at 362.

100. Beresford, *supra* note 81, at 1 (arguing that the principle of autonomy obligates neurologists or other caregivers to take the preferences of the dementia patient into account).

101. Landau & Werner, *supra* note 36, at 359.

102. *Id.*

#### IV. BALANCING INTERESTS: SAFETY BENEFITS VERSUS LEGAL AND ETHICAL CONCERNS

The key to this discourse is balancing the potential safety benefits with ethical and legal concerns, particularly the infringement on civil liberties, of using electronic tracking devices.<sup>103</sup> The use of these devices may be justified if such use prevented the institutionalization of individuals with dementia, thereby allowing them to live at home.<sup>104</sup> Particularly in circumstances where family members or close friends are taking care of individuals with dementia, the existing emotional connection eliminates any question of malicious intent to violate their rights or infringe upon their personal liberties. In fact, their use of electronic tracking devices is motivated, and may be justified, by the desire to keep their loved ones safe. However, a survey of forty-three caretakers found that only two of the caretakers who were planning on using electronic tracking devices intended to give the individual with dementia more freedom.<sup>105</sup> None of the thirteen caretakers who actually used the devices gave the individuals more freedom.<sup>106</sup>

Case law where employers installed tracking devices on its employees' cars has demonstrated that this installation generally does not constitute an invasion of privacy.<sup>107</sup> Courts have held similarly where a rental car service used a tracking device on its rental car,<sup>108</sup> and a wife used a tracking device on her husband's car during their divorce proceedings.<sup>109</sup> However, the

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103. White & Montgomery, *supra* note 9, at 3.

104. *Id.*

105. *Id.*

106. *Id.*

107. See *Alexandre v. New York City Taxi and Limousine Com'n*, No. 07 Civ. 8175, 2007 WL 2826952 at \*1, (S.D.N.Y. 2007); see also *Elgin v. St. Louis Coca-Cola Bottling Co.*, No. 4:05CV970-DJS, 2005 WL 3050633 at \*3, (E.D. Mo. 2005).

108. See *Turner v. Am. Car Rental, Inc.*, 884 A.2d 7, 8 (Conn. App. 2005).

109. See *Villanova v. Innovative Investigations, Inc.*, 21 A.3d 650, 651 (N.J. Super. App. Div. 2011).

relationship between family caretakers and individuals with dementia is fundamentally different from an employer's relationship with its employee or a rental car service's relationship with its customer since these relationships are financially motivated. Moreover, the caretakers' relationships with the individuals with dementia are non-adversarial, whereas the parties in a divorce proceeding are wholly adversarial.<sup>110</sup>

#### VI. CONCLUSION

Wandering is a serious concern for individuals with dementia, and the large population of family members providing unpaid care for these individuals lacks the time and resources to keep a constant watch over the individuals to prevent wandering.<sup>111</sup> With advances in technology, electronic tracking has provided these caretakers a way to locate wandering individuals through satellite technology.<sup>112</sup> Tracking may also allow individuals with dementia more freedom since their caretakers no longer need to personally monitor them at all times, thereby affording them more mobility. Furthermore, using a tracking device may prevent institutionalization and allow an individual with dementia to keep living at home.

However, the legal and ethical concerns may not justify this use. This type of electronic tracking may constitute an invasion of privacy, particularly the torts of intrusion upon seclusion and dissemination of private information, though plaintiffs alleging violations of these torts in

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110. When a lawyer represents an individual with dementia, the client may express to the lawyer certain wishes that conflict with what the client's family members want. But unlike typical adversarial cases, these family member caretakers often seek to act in the best interest of the individual with dementia. Thus, the situation between individuals with dementia and their caretakers is a unique one. Fleming & Morgan, *supra* note 83, at 747.

111. See Michael et al., *supra* note 13, at 4.

112. White & Montgomery, *supra* note 9, at 2.

various contexts have largely been unsuccessful.<sup>113</sup> Other issues that may arise with obtaining consent, as well as the possible infringements of personal autonomy that may occur, further discourage the use of tracking devices. The use of electronic tracking devices on individuals with dementia presents both potential benefits and consequences. Therefore, the determination of whether to use a tracking device depends largely on the consideration of a number of factors, including the particular individual's living situation, the nature and severity of the dementia, and the individual's consent or lack thereof.

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113. *See supra* Part III.A.

End of Life Care: Why Living Wills are Ineffective  
and Why Death with Dignity Acts are a More  
Effective Approach

*Ashley Whitefield\**

I. INTRODUCTION

End of life choices for terminally ill patients are among the most challenging decisions made by patients and their families.<sup>1</sup> Patients and their families must make complex decisions that balance the needs of the patient, the family, and his or her values about end of life care. These patients will not recover from their illnesses, and while physicians cannot give these patients a cure, they should be able to give them control over how to spend the remainder of their life. Some terminal diseases may leave patients in severe pain or in a vegetative state, which is why many take advantage of existing laws or actively petition courts to expand their laws to give patients a right to die with dignity.<sup>2</sup>

Due to the severity of these terminal illnesses, many patients feel the need to regain control and make pertinent decisions regarding their end of life care. To avoid suffering or loss of control at the end of their life, some patients request to have ventilation machines or nutritional tubes removed,<sup>3</sup> while others prefer to obtain a lethal prescription from their physician to

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1. *End of Life Issues and Care*, AMERICAN PSYCHOLOGICAL ASSOCIATION (Mar. 22, 2013), <http://www.apa.org/topics/death/end-of-life.aspx>.

2. See Kathryn L. Tucker, *Health Law Symposium: When Dying Takes Too Long: Activism For Social Change To Protect And Expand Choice At The End Of Life*, 33 WHITTIER L. REV. 109, 114 (2011).

3. James Estrin & John Schwartz, *Living For Today, Locked In A Paralyzed Body*, N.Y. TIMES (Nov. 7, 2004), available at [http://www.nytimes.com/2004/11/07/health/07ALS.html?\\_r=0](http://www.nytimes.com/2004/11/07/health/07ALS.html?_r=0).

bring about a peaceful death. Based on evidence that terminally ill patients want the right to make decisions regarding care, most states have adopted statutes addressing patient rights to end of life care.<sup>4</sup>

Many states adopted living will statutes. Living wills state how an individual wants to be treated in end-of-life situations or if declared incompetent.<sup>5</sup> But, as this article will explore, these documents are often ineffective because they fail to address many of the concerns of terminal patients; and evidence shows that physicians do not always honor these wills.<sup>6</sup> In an effort to provide patients with more control over their death, some states have adopted right-to-die laws or “death with dignity” legislation.<sup>7</sup> For example, Washington and Oregon have adopted Death with Dignity Acts (the “Acts”). Under these laws, terminally ill adults may request a prescription for a lethal medication, which is ingested to bring about a peaceful death.<sup>8</sup> These Acts protect physicians from civil or criminal liability when acting in compliance with the act, and affords patients an additional option. Regardless of the viewpoint that physicians should not assist their patients in dying, terminal patients should at least be afforded the option of dying with dignity, when this option has been proven to be successful and effective. In many cases, simply being provided with an additional option or choice about their end of life care can provide comfort for a terminal patient. Although living wills provide terminal patients with some control about their end of life care, this article will

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4. Kimberly Dayton, et al., *Living Will Statutes*, 3 *ADVISING THE ELDERLY CLIENT* §33:40 (2012).

5. *JESSE DUKEMINIER ET AL., WILLS, TRUSTS, AND ESTATES* 457 (Vicki Been et al. eds., 8th ed. 2009).

6. See Jack Schwartz, *Living Wills: Time to Say Goodbye*, 5 *MD. B.J.* 6, 8-9 (2005).

7. Cyndi Bollman, *A Dignified Death? Don't Forget About the Physically Disabled and Those Not Terminally Ill: An Analysis of Physician-Assisted Suicide Laws*, 34 *S. ILL. U. L.J.* 395, 398 (2010).

8. Tucker, *supra* note 2, at 115.

demonstrate that right to die laws are a more effective solution to meeting patients needs giving them more control over their illness and treatment.

## II. TERMINAL ILLNESSES AND THE FIGHT FOR CONTROL

Families and patients must prepare for the inevitable end of a terminal illness. Many terminal illnesses can cause unbearable pain and suffering, and often result in financial and emotional hardship.<sup>9</sup> For example, Amyotrophic Lateral Sclerosis (ALS), a neurodegenerative disease most commonly known as Lou Gehrig's disease, involves the progressive degeneration of motor neurons that allow the brain to control muscle movement.<sup>10</sup> ALS is often described as "living death" because the physical body goes flaccid while the mind remains completely aware.<sup>11</sup> As these neurons degenerate, they can no longer control muscle movement, which affects arms, legs, speaking, swallowing and breathing.<sup>12</sup> The average life expectancy of a person with ALS is two to five years.<sup>13</sup> Patients with this disease are twenty-five times more likely to die with physician-assisted suicide than patients with other diseases.<sup>14</sup> Leaving patients paralyzed and completely reliant on others or machines to eat and breathe, this disease has driven many to commit suicide.<sup>15</sup>

These patients face psychological issues such as fear of the unknown. In fact, family members and patients cite fear of cognitive and physical deterioration, pain, and emotional suffering as the basis for requesting

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9. Stephen K. Bushong & Thomas A. Balmer, *Breathing Life Into the Right to Die*, 11 ISSUES L. & MED. 269, 269 (1995).

10. THE ALS ASSOC. WHAT IS ALS? <http://www.alsa.org/about-als/what-is-als.html> (last visited Mar. 23, 2013) [hereinafter WHAT IS ALS?].

11. Estrin & Schwartz, *supra* note 6.

12. WHAT IS ALS?, *supra* note 10.

13. THE ALS ASSOCIATION, FACTS YOU SHOULD KNOW, <http://www.alsa.org/about-als/facts-you-should-know.html> (last visited March 23, 2013).

14. Estrin & Schwartz, *supra* note 11.

15. *Id.*

physician assisted suicide.<sup>16</sup> Additionally, the Oregon Public Health Division reported that the three most common end-of-life concerns were loss of dignity, loss of autonomy, and the decreasing ability to participate in activities that made life enjoyable.<sup>17</sup> These fears may cause patients to desire to regain control over their life and choose to die on their own terms rather than being controlled by the disease.

### III. THE LIVING WILL AND ITS INEFFICIENCIES

Living wills afford patients the right to make a written statement instructing their physician to withhold or withdraw life-sustaining procedures in the event of a terminal condition.<sup>18</sup> Living wills emerged because “people feared that they would receive undesirable or painful life support at a time that they were unable to make a decision to refuse it.”<sup>19</sup> It is a well-established policy that patients have a right to refuse medical treatment, but a living will expresses the patient’s wishes after they are declared incompetent or after any loss of capacity.<sup>20</sup> Therefore, these living wills only become effective when the patient is in a coma or otherwise declared incompetent by at least one physician.

Forty-seven states have enacted living will statutes with various requirements, but for the same underlying purpose.<sup>21</sup> Washington, which has enacted requirements similar to a majority of states, requires that the individual acknowledge that they are signing the directive willfully and

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16. Barry Rosenfeld, *Assisted Suicide, Depression, and the Right to Die*, 6 PSYCHOL. PUB. POL’Y & L. 467, 468 (2000).

17. Oregon Public Health Division, *Oregon’s Death with Dignity Act 2012*, 2 (2013), <http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year15.pdf>.

18. Schwartz, *supra* note 6, at 6.

19. Rebecca Dresser, *Symposium: Precommitment Theory in Bioethics and Constitutional Law: Bioethics: Precommitment: A Misguided Strategy for Securing Death with Dignity*, 81 TEX. L. REV. 1823, 1844 (2003).

20. Schwartz, *supra* note 6 at 6.

21. Dayton et al., *supra* note 4.

voluntarily.<sup>22</sup> In order for the directive to become effective, two physicians must verify in writing that the patient has a terminal condition or is in a permanent unconscious position.<sup>23</sup> To validate the will, the attending physician must certify that the patient's death is imminent except for death delaying procedures, and two witnesses must sign it.<sup>24</sup> In the absence of the individual's ability to give directions concerning life-sustaining treatment, the individual must confirm that it is her intention that the physician and family members honor this document.<sup>25</sup> Additionally, like many states, if the patient is pregnant and the fetus is viable, the patient's living will declaration will not be honored until the patient is no longer pregnant.<sup>26</sup> Although there are minor differences between the requirements of other states, such as the number of physicians that need to verify the patient's condition, or the number of witnesses required to sign the document, the underlying purpose of these wills is to prevent death delaying procedures. Though designed to give patients a right to determine their end of life care, it is unlikely that these instruments are effective in carrying out every patient's true intentions.

There are several recognized problems with these wills, such as vagueness, stability across time, and lack of enforcement.<sup>27</sup> Many living will statutes are limited or have been narrowly construed.<sup>28</sup> Language that instructs a physician to withhold or withdraw medical interventions can be vague. The physician may be unfamiliar with the patient's views causing

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22. WASH. REV. CODE. ANN. §70.122.030 (2012).

23. *Id.*

24. *Id.*

25. *Id.*

26. *Id.*

27. Schwartz, *supra* note 6, at 8-9.

28. Jennifer A. Zima *Assisted Suicide: Society's Response to a Plea for Relief or a Simple Solution to the Cries of the Needy?* 23 RUTGERS L.J. 387, 394 (1992).

the physician to misinterpret the will.<sup>29</sup> For example, in a Washington case, a woman who lived in a nursing home drafted a living will stating that she did not want to receive extraordinary measures if she was dying.<sup>30</sup> Later, a nurse mistakenly gave her the wrong medication, which caused severe complications.<sup>31</sup> However, the nursing home staff did not take her to the hospital because the physician misinterpreted her will to mean that she would not want treatment and she died that night.<sup>32</sup>

Another drawback to living wills is the inability to determine whether the patient has changed their mind.<sup>33</sup> A living will may have been made long before an incapacitation has occurred, and the patient's feelings and desires may be unknown or may have changed.<sup>34</sup> In some states, living wills must be written or notarized by an attorney. Attorney's fees can make it expensive to make changes to living wills.<sup>35</sup> As a result, costs may deter or delay a patient from updating their will to truly reflect their intentions.<sup>36</sup>

One major concern of living wills is that they are not always honored.<sup>37</sup> A 1995 study showed that less than half of the critically ill patients who requested do not resuscitate orders on their living wills actually got them.<sup>38</sup> Family members are often unaware of a living will, or if they are aware, they often do not want it upheld because they fear losing their loved one.

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29. Rita Marker, *Are Living Wills a Good Idea?*, (June 9, 2008) <http://euthanasia.procon.org/view.answers.php?questionID=000178>.

30. *Id.*

31. *Id.*

32. *Id.*

33. Schwartz, *supra* note 6, at 8.

34. Marker, *supra* note 29.

35. Patti Walden, *Living Wills: Not Always the Right Answer*, YAHOO VOICES, <http://voices.yahoo.com/living-wills-not-always-right-answer-6262930.html>.

36. *Id.*

37. Kristie Jernigan, *Pros and Cons of the Living Will*, LIVESTRONG (Dec. 18, 2009), <http://www.livestrong.com/article/60586-pros-cons/>.

38. *Are Living Wills Honored?*, BEFORE I DIE: LIVING WILLS, <http://www.wnet.org/bid/sb-livingwills.html> (last visited Feb. 16, 2013).

When the family does not want to honor the will, physicians often refrain from fighting with those who contest the living will.<sup>39</sup> This may result in expensive and time-consuming legal battles. In order to avoid litigation, medical staff often does not honor the living will and will follow the wishes of family members instead.<sup>40</sup> However, ignoring a patient's living will is a big risk and it may lead to severe consequences. In Michigan, a family was awarded over sixteen million dollars because the hospital ignored a patient's living will.<sup>41</sup> The patient had suffered a series of strokes, which left her with a serious brain disorder.<sup>42</sup> She expressed that she did not want to be saved if she could not be restored to her former state, yet these wishes were not honored.<sup>43</sup> The patient is currently completely disabled, in constant pain, unable to take care of herself, and unable to be returned to her former state.<sup>44</sup> Even with the medical profession's official endorsement of patient rights in living wills when deciding whether to use life-sustaining machines, some healthcare institutions will not honor a patient's wishes.<sup>45</sup>

Another problem with living wills is that each state has their own statute and requirements, meaning that a will in one state may not be effective in another state. Additionally, certain terms have different definitions. For example, "treatment" is defined under state law, and in some states medically assisted nutrition and hydration are both considered treatment.<sup>46</sup>

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39. Jernigan, *supra* note 37.

40. *Id.*

41. Are Living Wills Honored, *supra* note 38.

42. *Id.*

43. *Id.*

44. *Id.*

45. Willard H. Pedrick, *Arizona Tort Law and Dignified Death*, 22 ARIZ. ST. L.J. 63, 68 (1990).

46. Marker, *supra* note 29.

IV. DEATH WITH DIGNITY – A PEAK AT WHAT  
OREGON AND WASHINGTON HAVE ENACTED

Right to die laws include euthanasia, which is the administration by a physician of a lethal injection, and physician-assisted suicide, a lethal medication for self-administration by the patient.<sup>47</sup> Right to die laws, or aid in dying, involve terminally ill or elderly loved ones suffering with painful debilitating and life-ending illnesses.<sup>48</sup> Due to the physical and mental suffering of patients and their families, these deaths are often desired not only to avoid a painful or undesirable death, but also to avoid a meaningless and hopeless life.

Unlike living wills, which only become effective when the patient is incompetent or otherwise incapable of making health care decisions for his or herself, a person requesting aid in dying must retain the capacity and the ability to affirmatively request this treatment.<sup>49</sup> Therefore, rather than waiting to become incompetent in order for a living will to go into effect, right to die laws allow patients to receive their preferred end of life treatment while they are still coherent. Additionally, living wills only permit the removal of feeding tubes or other life-sustaining treatment, whereas aid in dying allows a patient to request a lethal prescription that the patient can choose to ingest.

Some opponents to right to die laws show concern because the suicide rates among person over sixty are high and steadily increasing.<sup>50</sup> However, these facts may also show that people would rather submit to illegal activity than suffer or become a victim to their own disease. In fact, some patients

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47. Lara L. Manzione, *Is There a Right to Die?: A Comparative Study of Three Societies (Australia, Netherlands, United States)*, 30 GA. J. INT'L & COMP. L. 443, 445 (2002).

48. *Id.* at 444.

49. Bollman, *supra* note 7, at 399.

50. Zima, *supra* note 28, at 398 (citing Erwin Ringel in MARY ROSE BARRINGTON, *APOLOGIA FOR SUICIDE IN SUICIDE: THE PHILOSOPHICAL ISSUES* 90 (M. Pabst Battin & C. Mayo, eds. 1980) at 208).

have killed themselves to avoid a horrifying death or to avoid being a burden to family and loved ones.<sup>51</sup> Additionally, public approval of physician assisted suicide and euthanasia has grown.<sup>52</sup> In a 1990 study, sixty-four percent of the surveyed adults supported physician-assisted suicide;<sup>53</sup> and a 1993 study showed that twenty-six percent of physicians had received at least one request for assisted suicide or euthanasia.<sup>54</sup> Additionally, in September of 2012, New Jersey proposed a bill to legalize physician-assisted suicide for terminally ill patients.<sup>55</sup> And in Montana, courts have stated that physician assisted suicide is legal, but with several restrictions. The Montana legislature is still attempting to structure a right to die law.<sup>56</sup> Currently, Oregon, Washington, and Montana have right-to-die laws that afford patients with terminal diseases the right to determine their own death.<sup>57</sup>

#### A. *The Oregon Death with Dignity Act*

Oregon was the first state to legalize physician-assisted suicide. Since Oregon passed the Death with Dignity Act (“DWDA”) in 1997, a total of 1,050 people have had DWDA prescriptions written and 673 patients have died from ingesting medications prescribed under the DWDA.<sup>58</sup> In 2012, 115 people received prescriptions and there were 77 known deaths.<sup>59</sup> Under the DWDA, “[a]n adult who is capable, is a resident of Oregon, and has

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51. *Id.* at 395.

52. Rosenfeld, *supra* note 16, at 471.

53. *Id.* at 470.

54. *Id.* at 477.

55. *NJ Could Become 3rd State to Legalize Right to Die*, FOXNEWS.COM, Sept. 27, 2012, at 1, <http://www.foxnews.com/health/2012/09/27/nj-could-become-3rd-state-to-legalize-right-to-die/>

56. *Id.*

57. *Montana Joins Short List of States Allowing Assisted Suicide*, 3 COMP. & BENEFITS L. BULLETIN No. 2 (2010).

58. Oregon Public Health Division, *supra* note 17, at 2.

59. *Id.* at 1.

been determined by the attending physician and consulting physician to be suffering from a terminal disease, and who has voluntarily expressed his or her wish to die, may make a written request for medication for the purpose of ending his or her life in a humane and dignified manner. . . .<sup>60</sup> Two witnesses must sign the request, and at least one of the witnesses cannot be a relative or someone who could be financially affected by the patient's death.<sup>61</sup> The statute does not require physicians to honor the patient's request, but if they choose to do so, they must fulfill a variety of requirements to protect themselves from civil or criminal liability,<sup>62</sup> such as: (1) determining that the patient has a terminal disease and has made this end of life request voluntarily, (2) obtaining confirmation by a second physician, (3) offering the patient optional counseling, (4) adhering to a fifteen day waiting period between the oral and written requests and (5) giving the patient the prescription.<sup>63</sup> Patients are also asked if they have informed their family of their decision.<sup>64</sup> Lastly, patients are reminded that they have the right to rescind the request at any time.<sup>65</sup>

Contrary to opinions that DWDAs would target low-income uneducated patients looking to receive this treatment to avoid hefty medical bills, most patients had a high level of education and over ninety percent of the patients had either private insurance, Medicare or Medicaid.<sup>66</sup> Additionally, the option of aid in dying has brought peace of mind to many healthy and terminally ill individuals in Oregon.<sup>67</sup> The availability of this option gives terminally ill patients autonomy, control and choice, and it gives healthy

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60. OR. REV. STAT. §127.805 (2012).

61. Bushong & Balmer, *supra* note 9, at 272.

62. *Id.*

63. *Id.*

64. *Id.*

65. OR. REV. STAT. §127.897 (2012).

66. Tucker, *supra* note 2, at 117.

67. *Id.* at 120.

individuals peace of mind knowing that if they are diagnosed with a terminal illness, they will have this end of life option.<sup>68</sup> Ultimately, however, many patients who elect to have the prescription do not follow through with taking it.<sup>69</sup> In fact, in Oregon, more than one-third of the patients who received a prescription did not consume it.<sup>70</sup>

*B. The Washington Death with Dignity Act*

In 2008, Washington followed Oregon's lead and became the second state to make physician-assisted suicide legal.<sup>71</sup> The Washington legislature had attempted to pass this legislation since 1991.<sup>72</sup> Based on studies and the success in Oregon showing that the right to die option would not jeopardize patients, put vulnerable populations at risk, or undermine quality end of life care, this DWDA was passed by the significant margin of fifty-eight percent to forty-two percent.<sup>73</sup>

In Washington, an adult resident who is competent, determined by two physicians to be suffering from a terminal disease, and who voluntarily expressed his or her wish to die, is legally capable of making a written request for medication to self-administer to end his or her life in a humane and dignified manner.<sup>74</sup> Two individuals, one of whom is not a relative of the patient, entitled to any portion or the patient's estate, or an owner or employee of a health care facility where the patient is receiving treatment, must witness the request.<sup>75</sup> Similar to the Oregon DWDA, Washington requires a minimum of fifteen days between the patient's request and the

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68. *Id.*

69. *Id.* at 118

70. *Id.*

71. Bollman, *supra* note 7, at 403-4.

72. Tucker, *supra* note 2, at 115, 121-122

73. *Id.*

74. WASH. REV. CODE. ANN. § 70.245.020 (2009).

75. WASH. REV. CODE. ANN. § 70.245.030 (2009).

writing of a prescription.<sup>76</sup> In 2011, physicians and pharmacies gave lethal medication to 103 individuals, and 70 patients ingested the medication.<sup>77</sup> Of these patients, seventy-four percent had some college education and ninety percent had either cancer or a neurodegenerative disease, such as ALS.<sup>78</sup>

#### V. CONCLUSION

Living wills are not appropriate to meet the needs and demands of people with terminal illnesses because of the vagueness, inconsistent enforceability, and because right to die laws do not afford patients more options about their end of life care. As one court has noted, there is no living will that specifically refers to administering any artificial substance.<sup>79</sup> Evidence in Oregon and Washington demonstrates that patients do desire these DWDAs and they appear to be an effective solution to patients suffering from terminal illnesses. More states should look to the public demands and the success of these right-to-die laws in other states to provide patients with terminal illnesses a right to their own life.

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76. WASH. REV. CODE. ANN. § 70.245.110 (2009).

77. WASHINGTON STATE DEPARTMENT OF HEALTH 2011 DEATH WITH DIGNITY ACT REPORT EXECUTIVE SUMMARY 1, 2 (2012), *available at* <http://www.doh.wa.gov/portals/1/Documents/5300/DWDA2011.pdf>.

78. *Id.* at 5.

79. Schwartz, *supra* note 6, at 6.

End-of-Life Care: The Legal, Cultural, and  
Interdisciplinary Barriers Hindering the Effective  
Use of Advance Directives

*Rachelle Sico\**

I. INTRODUCTION

With the advent of medical technology allowing individuals to live longer, the need for end-of-life planning is an important issue facing people in America. End-of-life planning is an intelligent and forward-thinking action to take in order to ensure the patient's wishes are followed. However, many individuals are not actively pursuing advance directives, a legal process to aid in end-of-life care, for themselves and their family members. It is important when exploring end-of-life planning at an academic and societal level that the focus be rooted in three areas: the law, cultural factors and interdisciplinary considerations regarding physicians. These three areas are inextricably linked in understanding why end-of-life planning and the use of advance directives have not proven to be effective methods at helping minority populations. The lack of cultural considerations and concern regarding intersectional factors; that compose an individual patient and inform their decision making about end-of-life

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care, are not being addressed through the legal construct of an advance directive. In order to better assess the underlying reasons why cultural differences make a difference in the low utilization of advance directives, it is necessary to look at three key areas: (1) the legal foundation for the advance directive and the standards used today; (2) the role language plays in presenting barriers to advance directive use; and (3) the role providers play in integrating advance directive participation within their end-of-life discussions with their patients.

## II. LEGAL OVERVIEW

Before discussing the role cultural factors and interdisciplinary considerations factor into end-of-life planning, it is necessary to touch upon the legal history and key areas of the law that contribute to the effectiveness of end-of-life planning for culturally and ethnically diverse individuals. An advance directive is a powerful tool that individuals can utilize to ensure that their families and doctors honor their rights when their health conditions render them unable to advocate for themselves.<sup>1</sup> First, it is necessary to explore the way the federal government and the Supreme Court stands on this issue through the landmark case of *Cruzan v. Director, Missouri Dept. of Health* and the Patient Self Determination Act. Secondly, implementation of the federal standards to the state level will be explored

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1. 42 U.S.C.A. § 1395cc (2011) (contains written instruction of care for a patient when they are incapacitated, i.e. a living will, that is recognized under State Law).

by analyzing Illinois's Living Will Act, Power of Attorney Act and Health Care Surrogate Act.

Ultimately, the push towards proactive end-of-life planning came with the landmark case of *Cruzan v. Director, Missouri Dept. of Health*.<sup>2</sup> In *Cruzan*, the Supreme Court established that competent individuals have the right to plan for future incapacity and that the states have the discretion to balance the patient interests against the state interest.<sup>3</sup> Shortly after the Court decided *Cruzan*, Congress passed the federal Patient Self Determination Act of 1990 ("Patient Self Determination Act").<sup>4</sup> The Patient Self Determination Act aimed to homogenize the way that the states conducted end-of-life care planning and delineated the steps that providers need to take when assisting a patient with this process.<sup>5</sup> The Patient Self Determination Act requires Medicaid and Medicare providers to include and abide by certain provisions in the advance directives that they help prepare for beneficiaries.<sup>6</sup>

While the Patient Self Determination Act provided a basis for end-of life

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2. *Cruzan v. Dir., Mo. Dept. of Health*, 497 U.S. 261, 278 (1990).

3. LAW REFORM COMMISSION, *BIOETHICS: ADVANCE CARE DIRECTIVES*, 1, 13-14 (2009), available at [http://www.lawreform.ie/\\_fileupload/Reports/rBioethics.pdf](http://www.lawreform.ie/_fileupload/Reports/rBioethics.pdf).

4. Patient Self Determination Act of 1990, Pub. L. No. 101-508, 104 Stat. 1338 (1990) (enacted) (citing to the text of the actual bill, this act was passed as an amendment to the Omnibus Budget Reconciliation Act of 1990) available at <http://thomas.loc.gov/cgi-bin/query/z?c101:H.R.4449.IH>.

5. *Id.*

6. *Id.* (certain guidelines must be followed when providers inform patients that they have the right to make decisions and appoint an agent or surrogate in their advance directive).

planning that the states must follow, the states must individually address other legal issues, including the specifications for a living will, the requirements for appointing a power of attorney for health care, and the qualifications for health care surrogates.<sup>7</sup> Under the Illinois Living Will Act (“Living Will Act”) a living will is defined as a “written declaration instructing his or her physician to withhold or withdraw death delaying procedures in the event of a terminal condition.”<sup>8</sup> Execution of this will must include the following elements: (1) the patient looking to execute the will must be mentally competent and to have reached the age of majority, (2) the document must be signed by the patient, or another at his or her direction, and witnessed by two individuals of 18 years or older, and (3) the patient must notify her physician of the living will, which the physician will then include within the individual’s medical records.<sup>9</sup> Generally, civil penalties apply to those who conceal, damage, or falsify a revocation to the living will without consent of the individual.<sup>10</sup> If a patient dies due to another’s willful concealment or withholding of knowledge of a revocation the perpetrator will be convicted of involuntary manslaughter.<sup>11</sup> Illinois state law provides further measures to identify and hold an individual

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7. Advance Directive Information, Pub. L. No. 097-0382, § 2310-600 (2012) *available at* <http://www.ilga.gov/legislation/publicacts/fulltext.asp?Name=097-0382>.

8. Illinois Living Will Act, 755 ILCS § 35/1 (1997).

9. *Id.* at §35/3(a)-(b), (d).

10. *Id.* at §35/8(a).

11. *Id.* at §35/8(b).

legally responsible for following through with the best wishes of the patient at the end of their life.

In addition to the Living Will Act, there are two acts that allow a patient to designate a person to care for their end-of-life decisions. The primary difference between the Illinois Power of Attorney Act (“Power of Attorney Act”) and the Illinois Health Care Surrogate Act (“Health Care Surrogate Act”) lies in the extent and scope of authority given to the individuals who assume the respective positions.<sup>12</sup> Under the Power of Attorney Act, when a patient designates a person as his or her power of attorney, that person becomes that patient’s designated agent and has the authority to make all-encompassing medical decisions for the patient.<sup>13</sup> A designated agent has the power to consent to treatment, and withdraw and admit the patient from the provider facility.<sup>14</sup> Additionally, the agent has the same access as the patient, to the patient’s medical records authorized by Health Insurance Portability and Accountability Act of 1996 (“HIPAA”), and has the ability to authorize organ donations and disposition of the individual’s remains.<sup>15</sup> The power of attorney designation, unless specified, will continue for the duration of the individual’s lifetime.<sup>16</sup>

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12. Illinois Power of Attorney Act, 755 ILCS § 45 (2011); *see also* Illinois Health Care Surrogate Act, 755 ILCS § 40(2010).

13. 755 ILCS § 45.

14. *Id.* at § 45/4-10(b).

15. *Id.*

16. *Id.*

Under the Health Care Surrogate Act, a surrogate is sought out only after the physician has identified that there is no existence of a living will, advance directive, or power of attorney.<sup>17</sup> A health care surrogate is only applicable when the patient has a “qualifying condition”<sup>18</sup> and does not have the ability to make decisions for herself concerning medical treatment.<sup>19</sup> The Health Care Surrogate Act aims to ensure that the surrogate can follow through with any of the patient’s preferred decisions regarding sustaining life through extraordinary means without involving judicial action.<sup>20</sup> However, since the patient does not expressly choose the health care surrogate,<sup>21</sup> the surrogate must balance the burdens and benefits of life-sustaining treatment through close conformation to the individual’s personal perspectives on religion, morality, ethics, life and death.<sup>22</sup>

In addition to state-specific forms designating a power of attorney and health care surrogates and creating a living will, the patient can also fill out other forms touching on specific instances of end-of-life care.<sup>23</sup> Specifically, Illinois abides by a “Uniform Do-Not-Resuscitate (DNR)

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17. Illinois Health Care Surrogate Act, 755 ILCS § 40 (2010).

18. *Id.* at § 40/10 (including terminal conditions, permanent unconsciousness and incurable or irreversible conditions).

19. *Id.* at § 40/5(b).

20. *Id.*

21. *Id.* at § 40/25(a) (priority in this order: guardian, spouse, adult son or daughter, parents, brother or sister, adult grandchild, close friend, and guardian of the estate).

22. *Id.* at § 40/20(b)(1).

23. IL. DEP’T OF PUB. HEALTH, UNIFORM DO-NOT-RESUSCITATE (DNR) ADVANCE DIRECTIVE: GUIDANCE FOR INDIVIDUALS, 1 (2013), available at <http://www.idph.state.il.us/public/books/advin.htm>.

Advance Directive”.<sup>24</sup> All hospital and Emergency Medical Technician (EMT) personnel honor this boilerplate advance directive at all facilities as long as the form is complete and appears valid.<sup>25</sup>

### III. OBSTACLES TO EFFECTIVE END-OF-LIFE PLANNING

End-of-life care is of great concern to the American health care industry because it is generally administered without clear guidelines for patients whose cultural traditions present a barrier to making health decisions for themselves.<sup>26</sup> In part, because of culture-specific issues barring the use of advance directives, the nation as a whole has seen large numbers of patients avoid and neglect end-of-life care planning.<sup>27</sup> Two different barriers to the effective use of advance directives in end-of-life planning are culturally insensitive language within the form itself, and the role providers play in presenting advance directives to patients from varying cultural backgrounds.

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24. *Id.*

25. IL. DEP'T OF PUB. HEALTH, UNIFORM DO-NOT-RESUSCITATE (DNR) ADVANCE DIRECTIVE: GUIDANCE FOR HEALTH-CARE PROVIDERS AND PROFESSIONALS (2013), available at <http://www.idph.state.il.us/public/books/advin.htm> (unless “VOID” is expressly written).

26. Leigh Turner, *Bioethics and End-of-Life Care in Multi-Ethnic Settings: Cultural Diversity in Canada and the USA*, 7 MORTALITY 285 (2002), available at [http://www.academia.edu/507737/Bioethics\\_and\\_end-of-life\\_care\\_in\\_multi-ethnic\\_settings\\_cultural\\_diversity\\_in\\_Canada\\_and\\_the\\_USA](http://www.academia.edu/507737/Bioethics_and_end-of-life_care_in_multi-ethnic_settings_cultural_diversity_in_Canada_and_the_USA).

27. Kevin B. O'Reilly, *76% of Patients Neglect End-Of-Life Care Planning*, AM. MED. ASSOC. NEWS (Feb. 27, 2012), <http://www.ama-assn.org/amednews/2012/02/27/prsb0227.htm> (roughly 8% of patients actively seek out advanced directives during medical appointments, although 80% believed having end-of-life plans was important).

*A. Cross-Cultural Perspectives on Advance Directives*

Title VI of the Civil Rights Act of 1964 states, “ No person in the United States shall, on the ground of race, color, or national origin be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance.”<sup>28</sup> The Patient Self Determination Act should ensure that no racial bias would stand in the way of obtaining advance directives and end-of-life care for minority populations.<sup>29</sup> However, inherent cultural differences and responses to the universal legal standards embodied in the law of advance directives act as a barrier towards effective end-of-life planning in the United States.<sup>30</sup> Culture is defined as “the values, beliefs, and behaviors that a people hold in common, transmit across generations, and use to interpret their experiences.”<sup>31</sup> The terminology and objectives of the advance directive are supposedly universally understood: an advance directive is a listing of the patient’s wishes that should be followed after she has either died or become medically incapacitated and can no longer make

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28. Civil Rights Act of 1964, Pub. L. No. 88-352, 78 Stat. 101, 601 (1964).

29. Patient Self Determination Act of 1990, Pub. L. No. 101-508, 104 Stat. 1338 (1990) (enacted) (citing to the text of the actual bill, this act was passed as an amendment to the Omnibus Budget Reconciliation Act of 1990) available at <http://thomas.loc.gov/cgi-bin/query/z?c101:H.R.4449.IH>.

30. Turner, *supra* note 26, at 292-98.

31. Perkins et. al., *Cross-Cultural Similarities and Differences in Attitudes About Care Planning*, 17 J GEN INTERN MED, 48-57 (2002), available at [http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1494998/pdf/jgi\\_01032.pdf](http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1494998/pdf/jgi_01032.pdf).

decisions for herself.<sup>32</sup>

The structure of the language in advance directives is not culturally sensitive, and potentially leads to individuals deciding not fill them out.

For example, the Illinois Declaration of a Living Will states,<sup>33</sup>

I direct that such procedures which would only prolong the dying process to be withheld or withdrawn, and that I be permitted to die naturally with only the administration of medication, sustenance, or the performance of any medical procedure deemed necessary by my attending physician to provide me with comfort care.

Navajo culture draws attention to word meaning and conversation.<sup>34</sup> They believe that the ability to shape reality and control events can be done through the use of negative and positive language.<sup>35</sup> Therefore, although federal and Illinois law support the aforementioned statement, a Navajo Indian would take issue with the fact that the language is negative information and could be deemed as harmful.<sup>36</sup> A Navajo Indian patient would not be likely to prepare an advance directive.<sup>37</sup>

Another example of the way cultural considerations prevent minority groups from filling out advance directive forms is seen this statement taken from the Living Will Act<sup>38</sup>,

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32. Illinois Living Will Act, 755 ILCS § 35/1 (1997).

33. *Id.*

34. Turner, *supra* note 26, at 292.

35. *Id.*

36. *Id.*

37. *Id.*

38. Illinois Living Will Act, 755 ILCS § 35/1 (1997).

In the absence of my ability to give directions regarding the use of such death delaying procedures, it is my intention that this declaration shall be honored by my family and physician as the final expression of my legal right to refuse medical or surgical treatment and accept the consequences from such refusal.

This frank statement regarding the realities of death and attempts to make plans for end-of-life scenarios causes ethnic groups, such as Mexican American and Korean American patients, to shy away from these advance care planning methods because they do not feel that preparing one would bring them, or their family, any benefit for a situation that they believe is out of their hands.<sup>39</sup>

To ignore an individual's cultural background within the context of end-of-life care harms effective advance directive planning.<sup>40</sup> The emphasis on culture is particularly important in this context because an individual identifies the most with cultural considerations in the last moments of her life.<sup>41</sup> Therefore, lawmakers and medical providers must consider cultural factors when creating policies that determine an individual's well-being at the end of their life.<sup>42</sup>

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39. Turner, *supra* note 26 at 293.

40. Robert Blank, *End-Of-Life Decision Making Across Cultures*, 39 J.L. MED. & ETHICS 201, 204 (2011).

41. *Id.*

42. *Id.* at 206.

A closer look at the Power of Attorney Act demonstrates that the Illinois Generally Assembly did not consider culturally competent language when drafting these documents.<sup>43</sup> The Power of Attorney Act states that “The purpose of this Power of Attorney is to give your designated ‘agent’ broad powers to make health care decisions for you, [ . . . ] You may name successors but you may not name co-agents.”<sup>44</sup> In the case of Japanese American patients, Japanese culture has the tradition of including the family in the “culture of making decisions” when it comes to terminal illness and end-of-life care.<sup>45</sup> This same understanding is seen in Latino elderly, who prefer broad family decisions about how to move forward with end-of-life care.<sup>46</sup> Therefore, to restrict all decision making authority to a singular person through a power of attorney would be contrary to the interests of the terminally ill patient.

In some instances, the legal language can work cohesively with cultural expectations because of broad and general wording. For example, the Health Care Surrogate Act states that “In determining the patient’s best interests, the surrogate shall weigh the burdens on and benefits to the patient of the treatment against the burdens and benefits of that treatment and shall take into account any other information, including the views of

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43. Illinois Power of Attorney Act, 755 ILCS § 45 (2011).

44. *Id.*

45. Blank, *supra* note 40, at 204.

46. *Id.* at 205.

family and friends, that the surrogate decision believes the patient would have considered if able to act for herself or himself.”<sup>47</sup> Both Mexican Americans and African Americans share the belief that family dynamics significantly influence the choice of proxy for end-of-life decision-making.<sup>48</sup> A closer look within these two cultural groups further demonstrates gendered constructs of expectation that is not considered on the advance directive forms. This includes the preference that men within the Mexican culture hold proxy status because of the belief that the women have other commitments in the home that hinder their ability to make rapid decisions for their loved ones concerning health care.<sup>49</sup>

The examination of Illinois’ advance directives reveals that more patients do not participate in end-of-life planning because they do not take into account the cultural and religious factors that play a role in end-of-life decision making.<sup>50</sup> The universality of death as a human experience makes this event an intrinsic part of the beliefs of any culture.<sup>51</sup> Therefore, the way a patient reacts to advance care planning can be influenced by intangible factors linked to cultural beliefs rooted in morality and superstition.<sup>52</sup> Because of this, the language of the advance directive needs to be sensitive

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47. Illinois Health Care Surrogate Act, 755 ILCS § 40 (2010).

48. Perkins et. al., *supra* note 31, at 53.

49. *Id.*

50. Turner, *supra* note 26, at 298.

51. Perkins et. al., *supra* note 31, at 50.

52. *Id.* at 51-52.

to the cultural hesitance to discuss end-of-life planning. If the objective of the advance directive is to aid the person once sickness has progressed to the point of incompetence, then it is necessary that the language in the advance directive take into account this barrier. For example, the Living Will Act states, “ If at any time I should have an incurable and irreversible injury, disease or illness judged to be a terminal condition [ . . . ] and [the attending physician] has determined that my death is imminent except for death delaying procedures[ . . . ]”<sup>53</sup> The language presented here conjures powerful connotations of the inevitable nature of death. In African American culture, discussing treatments that an individual may want at death is adamantly avoided.<sup>54</sup> The reasoning behind this position against discussing end-of-life planning is the belief that one should not speak concretely about uncertain future events.<sup>55</sup> The belief that discussing these plans might bring one bodily harm; causes some Mexican American and African American individuals to wait until the day comes to make final decisions concerning end-of-life treatment.<sup>56</sup> Moreover, many do not believe they are terminally ill, thus preferring intensive and potentially futile treatment.<sup>57</sup>

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53. Illinois Living Will Act, 755 ILCS § 35/1 (1997).

54. Perkins et. al., *supra* note 31, at 52.

55. *Id.*

56. *Id.*

57. Smith et. al., *Racial and Ethnic Differences in Advance Care Planning Among Patients with Cancer: Impact of Terminal Illness Acknowledgement, Religiousness, and*

The use of advance directives for patients with different cultural backgrounds can lead to barriers and inequities of end-of-life care.<sup>58</sup> Cultural standards regarding moral obligations also differ and care must be taken to avoid harm to one's wishes.<sup>59</sup> An example of unethical treatment that may be accepted in a patient's cultural traditions is euthanasia.<sup>60</sup> Euthanasia is a criminal act of homicide in the United States; however, it is a legally acceptable practice in the Netherlands, Belgium and Colombia.<sup>61</sup> Indigenous people employed natural methods of euthanasia that coincided with their cultural and religious beliefs.<sup>62</sup> The Caribs of Grenada practiced euthanasia because they believed that evil spirits possessed individuals who were terminally ill.<sup>63</sup> Conversely, the Aborigines of Australia took part in this practice because they believed that people who were terminally ill were undergoing the process of transmutation, or subsequent reincarnation back into the world of nature.<sup>64</sup> They supported the notion that an individual

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*Treatment Preferences*, 26 J CLINICAL ONCOLOGY 25, 4131, 4136 (2008).

58. Turner, *supra* note 26, at 298-99.

59. *Id.*

60. *AMA Policy on End-of-Life Care*, AM. MED. ASSOC. (April 28, 2013) available at <http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/about-ethics-group/ethics-resource-center/end-of-life-care/ama-policy-end-of-life-care.page> (termination of a patient's life through the use of a lethal agent by a non-medical provider to relieve the patient's intolerable and incurable suffering).

61. Stanley Krippner & Stefan Kasian, *Cross-Cultural Perspectives on Euthanasia and Physician Assisted Suicide*. (April 28, 2013) available at <http://drstefanjkasian.weebly.com/cross-cultural-euthanasia.html>.

62. *Id.*

63. *Id.*

64. *Id.*

should not fear death but accept the will of the supernatural.<sup>65</sup> Attempting to bridge the cultural gaps in advance directives requires an understanding that religious and cultural practices will vary by individual and ethnic group, and that patients' wishes as informed by their culture, should be accommodated.<sup>66</sup> However, patient autonomy does not solely define the standards of ethical medical care.<sup>67</sup>

Physicians also need to ensure that they are following the ethical considerations of their profession. The ethical practice within the medical community hinges upon the Hippocratic Oath, pledged by every physician. The Hippocratic Oath<sup>68</sup> states,

I will respect the privacy of my patients, for their problems are not disclosed to me that the world may know. Most especially must I tread with care in matters of life and death. If it is given me to save a life, all thanks. But it may also be within my power to take a life; this awesome responsibility must be faced with great humbleness and awareness of my own frailty. Above all, I must not play at God.

According to the American Medical Association's policy on end-of-life care, physicians hold no ethical obligation to provide care that they believe will not have a reasonable chance of benefitting the patient.<sup>69</sup> Overall, physicians must be committed to sustaining the life and relieving the

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65. *Id.*

66. Turner, *supra* note 26, at 298-99.

67. *Id.*

68. Louis Lasagna, *Hippocratic Oath: Modern Version (1964)*, (March 2013) available at <http://guides.library.jhu.edu/content.php?pid=23699&sid=190964>.

69. AM. MED. ASSOC., *supra* note 60.

suffering of the patient.<sup>70</sup> They are also obligated to provide comfort and care to the patient at the end of their life, while taking into consideration the best treatment for the patient's condition.<sup>71</sup> Patient autonomy should be kept as a priority when assessing end-of-life decisions in the pre-planning and advancing stages of illness and death. However, medical provider obligations to their patient should also coincide with the standards of their profession, even when dealing with complex, morally conflicting, emotionally charged and time-sensitive situations.<sup>72</sup>

The need to incorporate greater awareness of a patient's cultural considerations at the terminally ill stage can be accommodated; however, accommodation must be done in a way that also adheres to the obligations of the medical providers caring for those patients.<sup>73</sup> Adjusting the language stated in the advance directive forms is just one way to surmount the cultural barriers that deter minority populations from participating in advance directives. The next step towards the greater effectiveness of advance directives would be to explore the role that providers play in culturally competent care during the end-of-life planning process.

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70. *Id.*

71. *Id.*

72. Turner, *supra* note 26, at 292-98.

73. *Id.* at 299.

*B. The Role Physicians Play in Expanding  
Participation in Advance Directives*

An advance directive, alone, is not the cure-all solution for addressing the cultural disparities that exist in end-of-life planning. A physician's implementation of advance directives into the physical patient examination is necessary to ensure that the advance directive will lead to a positive health outcome for the individual. The process for integrating advance directives into the physician- patient conversation has not undergone any significant improvements because physicians are taught to save end-of-life care dialogues for the end of the medical examination and to bring up these issues more blatantly only when they are dealing with a critically ill patient.<sup>74</sup>

In order for physicians to navigate cultural considerations in end-of-life planning with their patients, they should employ these three guidelines: (1) prioritize end-of-life planning, (2) initiate and integrate the discussion of end-of-life planning into their patient's physical exams through the use of advance directives, and (3) continuously work to promote end-of-life planning.<sup>75</sup> First, it is necessary that the impetus towards advance directives be from the physician or primary care provider.<sup>76</sup> Many cultures,

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74. Daniel Swagerty, *Advanced Directives*, KY. UNIV. MED. CENTER (Feb. 20, 2013), available at <http://www2.kumc.edu/coa/Education/AMED900/AdvanceDirectives.htm#LIVING>.

75. Perkins et. al., *supra* note 31, at 56.

76. *Id.*

such as Hispanics and European Americans, have a strong belief that the health care system will abide by their wishes.<sup>77</sup> Therefore, these cultural groups would likely be persuaded to use an advance directive if it was coming from a medical provider.<sup>78</sup>

Secondly, physicians act as the gatekeepers of using the advance directives as legal documents, and they should take the time to collaborate with their patients and attempt to listen and define the factors that will contribute to their patients' wishes.<sup>79</sup> A common occurrence is that the form is given to the patient prior to the appointment but never discussed during the appointment.<sup>80</sup> The advance directive form itself is not easily accessible, or easy to read and understand.<sup>81</sup> Many individuals hold cultural bias that would prevent them from taking an advance directive seriously without further explanation.<sup>82</sup> A patient's understanding of an advance directive and its legal implications may be hindered by environmental obstacles or social dynamics, therefore it is necessary for a physician to review the document with the patient one-on-one and provide additional information regarding their concerns.<sup>83</sup> An individual's needs and desires for her future are constantly changing; however, an advance

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77. *Id.*

78. *Id.*

79. *Id.*

80. *Id.*

81. *Id.*

82. *Id.* at 52.

83. *Id.* at 56.

directive is a tangible document that is not changeable unless the physician and patient take the time to make those changes.<sup>84</sup>

The Physician Orders for Life-Sustaining Treatment (“POLST”) form presents a new opportunity to remedy the gaps in advance directives because of differing cultural standards. However, instead of being more culturally sensitive, the objective of this form is to improve treatment by converting the preferences of a patient to medical actions that remain consistent throughout the patient’s health care systems.<sup>85</sup> The POLST contains medical language and is directed towards incorporating explicit, patient-directed instructions for health care providers.<sup>86</sup> The form works in conjunction with any advance directives that the patient already has in place and will not replace an advance directive’s conference of power of attorney status.<sup>87</sup> Since these forms are medically relevant and outline specific actions that can be taken at the end of an individual’s life, it is even more important that physicians take the time to understand what their patients want at the end of their lives.<sup>88</sup> The inclusion of POLST forms in end-of-life planning signifies that the physicians are now a responsible and

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84. *Id.*

85. Hickman et. al., *The POLST (Physician Orders for Life-Sustaining Treatment) Paradigm to Improve End-of-Life Care: Potential State Legal Barriers to Implementation*, 36 J.L. MED. & ETHICS 119, 119-20 (2008).

86. *Id.* (including treatment orders for resuscitation, medical interventions, artificial nutrition and antibiotics).

87. *Id.*

88. Perkins et. al., *supra* note 31, at 56.

intrinsically linked contributor to an individual's end-of-life plans.<sup>89</sup>

#### IV. CONCLUSION

The use of an advance directive without a primary provider's support, guidance, and human connection is an ineffective and flawed tool. If the lawmakers and physicians can collaborate on advance directives, then advance directives might have a chance to be used widely by populations throughout this nation. By having the lawmakers reformat the structure of the advance directive's language use and encouraging physicians to increase their engagement and commitment to the advance directive and end-of-life planning, then there might be a chance of breaking down the legal, social and cultural barriers that have stood in the way of minority populations accessing and producing well thought out, descriptive end-of-life plans. However, to marginalize culturally competent considerations in an attempt to provide a universal answer to end-of-life problems might further alienate minority populations from taking part in advance directive planning measures altogether.<sup>90</sup>

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89. California Academy of Family Physicians, *Physician Orders for Life Sustaining Treatment Form* (April 28, 2013), available at <http://www.familydocs.org/resources/public-health/polst>.

90. Blank, *supra* note 40, at 211.

Alzheimer's Disease and Decision-Making:  
Are Mental Health Directives Appropriate for  
Illinois Residents?

*Meghan Funk\**

I. INTRODUCTION

Many Americans fear the prospect of being diagnosed with Alzheimer's disease because it progressively destroys a person's memory and other mental functions.<sup>1</sup> Alzheimer's falls under the umbrella of diseases classified as dementia because it results in the loss of intellectual and social skills.<sup>2</sup> A patient diagnosed with Alzheimer's may eventually lack the ability to complete even the simplest of tasks, to recognize loved ones, and to communicate her needs.<sup>3</sup> Both the causes of this disease and methods of prevention are still not fully understood.<sup>4</sup> Further, Alzheimer's has no cure, and its debilitating progress is irreversible.<sup>5</sup> The average age of diagnosis is sixty years old; however it can appear in patients as young as thirty years old.<sup>6</sup> Sadly, over five million Americans are currently suffering from

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1. See MAYO FOUNDATION FOR MEDICAL EDUCATION AND RESEARCH, *Alzheimer's Disease* (Jan 19, 2013), <http://www.mayoclinic.com/health/alzheimers-disease/DS00161>, [hereinafter MAYO FOUNDATION]; see also Chad S. Dodson, *Alzheimer's disease and memory-monitoring impairment: Alzheimer's patient show a monitoring deficit that is greater than their accuracy deficit*, 49 NEUROPSYCHOLOGIA 2609, 2609 (2011) (remarking upon the memory deficit found in Alzheimer's patients).

2. MAYO FOUNDATION, *supra* note 1.

3. NATIONAL INSTITUTES OF HEALTH, ALZHEIMER'S DISEASE FACT SHEET 1, (July 2011), available at [http://www.nia.nih.gov/sites/default/files/alzheimers\\_disease\\_fact\\_sheet\\_0.pdf](http://www.nia.nih.gov/sites/default/files/alzheimers_disease_fact_sheet_0.pdf) [hereinafter FACT SHEET] (explaining that Alzheimer's is a form of dementia, the loss of cognitive functioning and that dementia interferes with a person's daily life and activities).

4. FAMILY CAREGIVER ALLIANCE, *Alzheimer's Disease & Caregiving*, [http://www.caregiver.org/caregiver/jsp/content\\_node.jsp?nodeid=567](http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=567), (last visited Feb. 18, 2013).

5. FACT SHEET, *supra* note 3; MAYO FOUNDATION, *supra* note 1.

6. See FAMILY CAREGIVER ALLIANCE, *supra* note 4.

Alzheimer's.<sup>7</sup> Of the five million Americans affected by the disease, an estimated 211,000 live in Illinois.<sup>8</sup> Researchers in Illinois are active in researching the disease and discovering ways to improve services for residents afflicted with Alzheimer's.<sup>9</sup> Additionally, a need exists to help the caregivers of Alzheimer's patients with decision-making for these patients.

Once a patient is diagnosed with Alzheimer's, planning for the future is especially important.<sup>10</sup> A patient diagnosed with Alzheimer's lives, on average, eight years.<sup>11</sup> Some patients have been known to live over twenty years after diagnosis.<sup>12</sup> This disease affects patients and their caregivers for years, particularly in the area of decision-making. Over time, an Alzheimer's patient's memory fades and decision-making ability diminishes, until eventually he requires the help of others to make nearly all of his decisions.<sup>13</sup> These decisions include where to live, with whom to be romantically involved, and how to manage property and money.<sup>14</sup> Making these decisions presents both ethical and legal dilemmas to patients and their caregivers.<sup>15</sup> Ethical and legal dilemmas exist concerning how a patient's wishes may differ significantly as the disease progresses and

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7. ILLINOIS DEPARTMENT OF PUBLIC HEALTH, *Health Beat*, <http://www.idph.state.il.us/public/hb/hbalzheimer.htm>, (last visited Feb. 18, 2013).

8. *Id.*

9. 410 ILL. COMP. STAT. 405/2 (2013). The Alzheimer's Disease Assistance Act seeks to establish a program for conducting research regarding the cause, cure, and treatment of Alzheimer's. *Id.* It also seeks to establish a comprehensive, statewide system of regional and community-based services to diagnose and treat those with Alzheimer's. *Id.*

10. MAYO FOUNDATION, *supra* note 1.

11. *Health Beat*, *supra* note 7.

12. *Id.*

13. See FAMILY CAREGIVER ALLIANCE, *supra* note 4 (explaining through the use of a chart the progression of Alzheimer's); see also Lisa Brodoff, *Planning for Alzheimer's Disease with Mental Health Advance Directives*, 17 Elder L.J. 239, 240 (2010); FACT SHEET, *supra* note 3.

14. Brodoff, *supra* note 13, at 240.

15. FAMILY CAREGIVER ALLIANCE, *supra* note 4.

affects his or her mental capacities.

This article examines how current Illinois law and policy affects patients with Alzheimer's and their caregivers, specifically guardianship law and Illinois's Physician Orders for Life-Sustaining Treatment (POLST) form.<sup>16</sup> This article focuses on the option of using mental health advanced directives (MHADs), in addition to or as an alternative to guardianship and a POLST form, for Alzheimer's patients in Illinois. Current Illinois law falls short in assisting patients with Alzheimer's and their caregivers with decision-making. In many instances, MHADs are the best option for Alzheimer's patients because it is a planning tool that gives the patient more control over their quality of life in the future.

## II. CAREGIVING FOR ALZHEIMER'S PATIENTS

Alzheimer's is a disease that affects a vast number of Americans, whether through a personal diagnosis, or through playing the role of caregiver for a friend or loved one.<sup>17</sup> In the early stages of the disease, many caregivers are the patient's own family, relatives, or friends.<sup>18</sup> In 2011, nearly fifteen million Americans provided unpaid caregiving to those living with Alzheimer's.<sup>19</sup> The United States Department of Health and Human Services ("HHS") predicts that unpaid family caregivers will become the largest source of long-term care services in the country.<sup>20</sup> Accordingly, it is important that these caregivers understand the legal and

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16. Illinois provides other advanced directives to its residents. See ILL. DEP'T OF PUBLIC HEALTH, *Statement of Illinois Law on Advanced Directives and DNR Orders*, <http://www.idph.state.il.us/public/books/advdir4.htm> (last updated Aug. 2, 2011). Illinois currently regulates the following advanced directives: health care power of attorney, living wills, mental health treatment preference declarations, and do-not-resuscitate (DNR) orders. *Id.* None of these advanced directives completely address the needs of Alzheimer's patients.

17. Brodoff, *supra* note 13, at 240.

18. FAMILY CAREGIVER ALLIANCE, *supra* note 4.

19. *Id.*

20. Debra H. Kroll, *To Care or Not to Care: The Ultimate Decision for Adult Caregivers in a Rapidly Aging Society*, 21 TEMP. POL. & CIV. RTS. L. REV. 403, 404 (2012).

ethical issues surrounding the care of their loved ones.

A large part of caregiving involves helping a patient with decision-making.<sup>21</sup> The decisions a person would make prior to being diagnosed with Alzheimer's diverge from those that he or she makes once the disease advances.<sup>22</sup> A person with Alzheimer's may want to start a new romantic relationship, even if married, sell his or her property without considering the consequences, or protest being placed in a long-term care facility.<sup>23</sup> Caregivers must often make these financial and emotional decisions without the express consent of the person for whom they are caring.<sup>24</sup> As dementia progresses, conflict often arise between what a caregiver believes is in the best interest of his or her loved one and what the patient actually wants.<sup>25</sup> Illinois law gives some guidance to caregivers on what to do in these situations, but leaves caregivers a lot of discretion causing them to face ethical dilemmas.<sup>26</sup>

### III. ILLINOIS GUARDIANSHIP LAW

As a last resort, a caregiver of an Alzheimer's patient may consider petitioning for guardianship over the patient.<sup>27</sup> While it should not be used merely for convenience by the caregiver, this sort of control over a patient's decisions is used in Illinois for a sound and necessary purpose.<sup>28</sup> Every

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21. See FAMILY CAREGIVER ALLIANCE, *supra* note 4.

22. Brodoff, *supra* note 13, at 240-41.

23. *Id.* at 240.

24. *Id.* at 241.

25. See *id.* at 240-41.

26. See generally *Statement of Illinois Law on Advanced Directives and DNR Orders*, *supra* note 16.

27. IL GUARDIANSHIP AND ADVOCACY COMMISSION, *Guardianship Facts*, <http://gac.state.il.us/osg/osgfs.html>, (last visited Feb. 18, 2013); 755 ILL. COMP. STAT. 5/11a-3 (2004).

28. *Id.* The Office of the State Guardian explains that guardianship should be used as a last resort and only for a "sound and necessary purpose" because guardianship fully takes away one's legal rights. *Id.*

state has laws that govern guardianships.<sup>29</sup> Illinois guardianship law is considered unique and progressive.<sup>30</sup> Once a caregiver, or other individual, submits a petition for guardianship, a hearing takes place in Illinois Probate Court.<sup>31</sup> This hearing can involve lawyers, witnesses, and a jury if the patient opposes the guardianship, and the process can be costly.<sup>32</sup> The Illinois Probate Court may determine that a guardianship is not required, or it can appoint a “person guardianship” or “estate guardianship.”<sup>33</sup>

Although appointing a guardian for a patient with Alzheimer's is, at times, a viable option, it often does more harm than good.<sup>34</sup> Usually family members and caregivers only consider guardianship after the patient has entered the advanced stages of the disease.<sup>35</sup> Under Illinois law, the patient must receive a copy of the petition and notice of the hearing, but he or she will likely be unable to understand the documents or comprehend the proceedings.<sup>36</sup> Although Illinois allows the person with Alzheimer's to participate in his guardianship hearing and states the court will take his opinions into consideration, this participation is largely a farce.<sup>37</sup> Some guardians abuse their positions of authority and fail to protect the interests of their wards.<sup>38</sup> At least forty-five states report cases of financial

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29. Vaughn E. James, *No Help for the Helpless: How the Law has Failed to Serve and Protect Persons Suffering from Alzheimer's Disease*, 7 J. HEALTH & BIOMEDICAL L. 407, 414 (2012).

30. IL GUARDIANSHIP AND ADVOCACY COMMISSION, *supra* note 27.

31. *Id.*

32. *Id.*

33. *Id.* The court appoints a “guardianship of the person” to make decisions concerning medical treatment, place of residence, and other needs. *Id.* On the other hand, a “guardianship of the estate” is appointed to make decisions concerning the patient's finances and estate. *Id.*

34. James, *supra* note 29, at 417-20.

35. *Id.* at 420.

36. *Id.*; 755 ILL. COMP. STAT. 5/11a-10(e) (2012).

37. James, *supra* note 29, at 420; *see also* IL THE OFFICE OF STATE GUARDIAN, *supra* note 24; 755 ILL. COMP. STAT. 5/11a-11 (1995).

38. James, *supra* note 29, at 423.

exploitation and physical abuse by guardians.<sup>39</sup> The U.S. Government Accountability Office (“GAO”) found that guardians across the nation stole millions of dollars in assets from their wards between 1990 and 2010.<sup>40</sup> The GAO discovered flaws in Illinois’s guardianship system when it conducted an experiment; it used two fictitious identities, one with bad credit and one with the Social Security number of a deceased person to petition to be guardians in the state.<sup>41</sup> These fictitious identities were accepted as guardians in Illinois<sup>42</sup>, which leads to question of whether Illinois adequately protects its most vulnerable citizens, especially those with Alzheimer’s. MHAD’s, used in conjunction with or as an alternative to guardianships, may be able to better protect Illinois’ residents with Alzheimer’s.<sup>43</sup>

#### IV. ILLINOIS POLST FORM

Illinois recognizes that its laws and policy concerning advanced directives needs updating.<sup>44</sup> Illinois demonstrates this understanding with the implementation of the POLST (Physician Orders for Life-Sustaining Treatment) Paradigm.<sup>45</sup> The POLST Paradigm is a method to facilitate end-of-life planning based on conversations between patients, loved ones, and medical providers.<sup>46</sup> Its goal is to ensure that seriously ill patients can choose the treatments they wish to receive at the end of their life and that

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39. U.S. GOV’T ACCOUNTABILITY OFFICE, CASES OF FINANCIAL EXPLOITATION, NEGLECT, AND ABUSE OF SENIORS 5 (2010) available at <http://www.gao.gov/assets/320/310741.pdf>.

40. *Id.* at 7.

41. *Id.* at 25.

42. *Id.*

43. See discussion *infra* Part VI.

44. 20 ILL. COMP. STAT. 2310/2310-600 (2012).

45. *Id.*

46. For information about the national POLST Paradigm, please refer to <http://www.polst.org/about-the-national-polst-paradigm/>.

their wishes are honored by their medical providers.<sup>47</sup> Using the POLST paradigm, the patient fills out a brightly-colored POLST form, which is to travel with the patient across the continuum of care.<sup>48</sup> All but four states are currently developing or have already implemented a POLST paradigm.<sup>49</sup> In the spring of 2013, the Illinois Department of Public Health (IDPH) published a revised version of the IDPH Uniform DNR Advance Directive, which is now referred to as a POLST form.<sup>50</sup> Medical providers are required by law to honor the treatment choices written on a POLST in order to promote patient autonomy.<sup>51</sup>

The use of a POLST form is an excellent resource for terminally ill patients in Illinois. However, the POLST form is not an appropriate resource for patients with Alzheimer's. A POLST form should only be used for patients for whom death within the next year is expected.<sup>52</sup> Given that Alzheimer's patients live on average eight years after initial diagnosis, a POLST form is inappropriate for Illinois residents with Alzheimer's.<sup>53</sup> It is not advantageous for a patient with Alzheimer's to wait until a year before death to fill out an advanced directive that will enable them to make end-of-life decisions. Alzheimer's patients' memory and decision-making ability erode over a period of years.<sup>54</sup> An Alzheimer's patient should complete an advanced directive, such as an MHAD, while an Alzheimer's

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47. *Id.*

48. CHICAGO END-OF-LIFE CARE COALITION. Physician Orders for Life Sustaining Treatment (POLST) <http://www.cecc.info/resource-links/physicians-order-for-life-sustaining-treatment-polst> (last visited March 25, 2013).

49. See POLST, *Programs in Your State* <http://www.polst.org/programs-in-your-state/> (last visited March 25, 2013). The four states that are not currently developing or implemented a POLST paradigm are Arkansas, Mississippi, South Dakota, and Washington D.C. *Id.*

50. See CHICAGO END-OF-LIFE CARE COALITION, *supra* note 48.

51. *Id.*

52. *Id.*

53. See discussion *supra* Part I.

54. See MAYO FOUNDATION *supra* note 1.

patient still has the cognitive ability to make sound decisions.

#### V. MHADS

Since a mandated guardianship over a patient with Alzheimer's should be used as a last resort, and a POLST form is only appropriate for Illinois residents for whom death is expected within the next year, it is advantageous for a patient and caregiver to instead use a different planning method closer to the patient's diagnosis. It is important to formulate such a strategy together well in advance of the patient's final days to ease the burden of decision-making as the disease progresses. Illinois law and policy fails to facilitate such planning because the advanced directives available to Alzheimer's patients are geared towards end-of-life medical planning,<sup>55</sup> but they fail to address other important social decisions such as where to live and with whom to be romantically involved.<sup>56</sup>

MHADs are the best option to help Alzheimer's patients and their caregivers with long-term decision-making. Typically, MHADs are used by patients with mental disabilities such as bipolar disorder and severe depression in order to make predictions about what kind of care he or she would likely need and want in the future.<sup>57</sup> MHADs are also useful for patients in the early stages of Alzheimer's.<sup>58</sup> Attorneys, patients, and caregivers can work together while the patient is in an early stage of Alzheimer's to discuss predictable future decisions that the patients will face and draft a MHAD.<sup>59</sup> One of the most important aspects of a MHAD is that it should include a section discussing the patient's personal history

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55. *Statement of Illinois Law on Advanced Directives and DNR Orders*, *supra* note 16. (listing the current advanced directives available in Illinois).

56. *See generally Statement of Illinois Law on Advanced Directives and DNR Orders*, *supra* note 16.

57. Brodoff, *supra* note 13 at 241.

58. *Id.* at 242.

59. *Id.*

and core values.<sup>60</sup> With the use of this section, caregivers will better understand the decision that a patient would make in various situations, even those not explicitly stated in the MHAD.<sup>61</sup> MHADs can be used to plan the patient's wishes concerning finances and estate-planning, in-home care, and when out-of-home care would be required.<sup>62</sup> MHADs can facilitate planning for appropriate responses to aggressive behaviors and intimate relationships.<sup>63</sup>

It is important to note that even with a MHAD, care of a patient with Alzheimer's can present ethical dilemmas. One can only imagine the difficulty of telling a patient in advanced stages of Alzheimer's that they are not allowed to do things they would like to do, especially when the patient is a family member. The person with Alzheimer's disease may insist that he changed his mind concerning a decision that has already been made in the MHAD.<sup>64</sup> The caregiver is then torn between making the final days of the person's life peaceful, and following his wishes prior to the advanced stages of dementia. This dilemma shows that even with a MHAD, the care of a patient with Alzheimer's is difficult, but utilizing a MHAD may help alleviate the burden on patients and their caregivers as the disease progresses.

This article does not seek to advocate the use of MHADs with all Alzheimer's patients. MHADs should not be mandated by Illinois law as necessary in all instances when a patient is diagnosed with Alzheimer's. However, Illinois should recognize MHADs as an option for such patients and by doing so regulate the use of this advanced directive to better help the

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60. *Id.* at 260-61.

61. *Id.* at 261.

62. *Id.* at 262-79.

63. *Id.*

64. *See id.* at 240-1.

residents of this state. Until this action is taken by Illinois, Alzheimer's patients and their caregivers will be left largely unaware of this unique planning tool for long-term decision-making.

#### V. CONCLUSION

Caring for a person afflicted with Alzheimer's disease is both physically and emotionally demanding, and this caregiving can even negatively affect the caregiver's health.<sup>65</sup> It is important for caregivers to not only understand the disease, but to have a flexible strategy in place to provide the best care possible as the disease progresses.<sup>66</sup> Illinois law and policy is currently inadequate for providing patients and caregivers this type of flexible strategy.<sup>67</sup> There is not, and likely never will be, one plan that best fits the needs of all Alzheimer's patients in Illinois. However, when a viable option, a MHAD is an excellent strategy that a patient and caregiver can use as guidance as Alzheimer's progresses. It is impossible to predict all decisions that will need to be made a patient's disease progress, but a MHAD can still be an effective planning tool.

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65. MAYO FOUNDATION, *supra* note 1.

66. FACT SHEET, *supra* note 3.

67. *See Statement of Illinois Law on Advanced Directives and DNR Orders, supra* note 16.

Bridging the Title VI Gap: How Can the Affordable  
Care Act Address Racial Inequity in Nursing  
Homes?

*Shana M. Scott, MPH\**

I. INTRODUCTION

Evidence of racial and ethnic health disparities have been documented in the American healthcare system for decades.<sup>1</sup> The Centers for Disease Control and Prevention (CDC) defined health disparities as “preventable differences in the burden of disease, injury, violence, or opportunities to achieve optimal health that are experienced by socially disadvantaged populations”.<sup>2</sup> The CDC leading health indicators have demonstrated little improvements in disparities over the last decade.<sup>3</sup> Furthermore, a study by the Institute of Medicine (IOM) found that racial and ethnic minorities had poorer health and consistently received lower quality care, even when not accounting for factors such as insurance status and income.<sup>4</sup>

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1. See Stephen B. Thomas et al., *Less Talk More Action: Accelerating Innovative Strategies to Eliminate Racial and Ethnic Health Disparities*, 55 HOW. L.J. 705 (2012) (providing historical context for understanding racial and ethnic disparities in the United States).

2. *Health Disparities*, CENTERS FOR DISEASE CONTROL AND PREVENTION <http://www.cdc.gov/healthyouth/disparities/index.htm> (last updated July 24, 2012).

3. This is according to a recent analysis of the *Healthy People 2010* objectives, which is a national health promotion and disease prevention initiative aimed at addressing health disparities. DEPT. OF HEALTH & HUMAN SERVS., HHS ACTION PLAN TO REDUCE RACIAL AND ETHNIC HEALTH DISPARITIES: A NATION FREE OF DISPARITIES IN HEALTH AND HEALTH CARE, 2 (2011), available at [http://minorityhealth.hhs.gov/npa/files/Plans/HHS/HHS\\_Plan\\_complete.pdf](http://minorityhealth.hhs.gov/npa/files/Plans/HHS/HHS_Plan_complete.pdf).

4. Rene Bowser, *The Affordable Care Act and Beyond: Opportunities for Advancing Health Equity and Social Justice*, 10 HASTINGS RACE & POVERTY L.J. 69, 69-70 (2013). In 1999 Congress asked the Institute of Medicine to investigate disparities in health and health status among racial and ethnic minorities. See INSTITUTE OF MEDICINE, UNEQUAL TREATMENT: CONFRONTING RACIAL AND ETHNIC DISPARITIES IN HEALTH CARE (Nat'l

As disparities cross over into many health care industries, the prognosis is the same for the long-term care industry and nursing home facilities.<sup>5</sup> Despite these barriers, the proportion of African Americans in nursing home facilities has steadily increased over the past 4 decades.<sup>6</sup> Even though African Americans have closed the gap in nursing home use rates since the year 2000, there has been little gain in equity as access to quality facilities still remain limited for minorities.<sup>7</sup>

To combat these issues, the successes of early civil rights litigation, specifically Title VI of the 1964 Civil Rights Act<sup>8</sup>, was seen as a significant avenue for addressing racial inequity in nursing home quality of care and admissions.<sup>9</sup> However, despite the requirements of Title VI, many federally funded hospitals, nursing homes, health plans, and even physicians have

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Academy Press 2002), available at <http://www.iom.edu/Reports/2002/Unequal-Treatment-Confronting-Racial-and-Ethnic-Disparities-in-Health-Care.aspx>.

5. See David Barton Smith et al., *Racial Disparities in Access to Long-Term Care: The Illusive Pursuit of Equity*, 33 J. HEALTH POL. POL'Y & L. 5, 861 (2008) (finding that there exists a high degree of segregation and disparity in the quality of nursing homes that are used by African Americans). See also S. C. Reed et al., *Concentrated Poverty and Nursing Home Bed Supply in Chicago*, 12 J. HEALTH CARE POOR & UNDERSERVED 1, 88-102 (2001).

6. Daniel L. Howard et al., *Distribution of African Americans in Residential Care/Assisted Living and Nursing Homes: More Evidence of Racial Disparity?*, 92 AM. J. PUB. HEALTH 1272, 1272 (2002). African American use of formal services have changed over time due to the implementation of anti-discrimination laws and the increase in access to nursing homes and home health services as a result of public funding programs. SHEEL PANDYA, RACIAL AND ETHNIC DIFFERENCES AMONG OLDER ADULTS IN LONG-TERM CARE SERVICE USE, AARP PUBLIC POLICY INSTITUTE (June 2005), available at [http://www.aarp.org/home-garden/livable-communities/info-2005/fs119\\_ltc.html](http://www.aarp.org/home-garden/livable-communities/info-2005/fs119_ltc.html).

7. See Smith et al., *supra* note 5.

8. Pub. L. No. 88-352, 78 Stat. 252 (codified at 42 U.S.C. §§ 2000d-2000d-4 (1982)). "Title VI and its implementing regulations prohibit both intentional discrimination and policies that appear neutral but have a discriminatory effect". *Title VI, Prohibition Against National Origin Discrimination Affecting Limited English Proficient Persons*, NATIONAL (2004), <http://www.archives.gov/eo/laws/title-vi.html> ARCHIVES [hereinafter NATIONAL ARCHIVES]. Congress passed Title VI to prohibit segregation and other forms of discrimination in any organization receiving federal funds. Sidney D. Watson, *Reinvigorating Title VI: Defending Health Care Discrimination – It Shouldn't Be So Easy*, 58 FORDHAM L. REV. 939, 941 (1989-1990).

9. Dayna Bowen Matthew, *A New Strategy to Combat Racial Inequality in American Health Care Delivery*, 9 DEPAUL J. HEALTH CARE L. 793, 796 (2005-2006).

continued to provide inferior healthcare to minority Americans.<sup>10</sup> Consequently, Title VI has been repeatedly criticized as ineffective in addressing nursing home inequity and disparities.<sup>11</sup> With this in mind, this article suggests that if properly executed sections 1557, 4302, 6102, and 10303 of the Patient Protection and Affordable Care Act (PPACA) could bridge the Title VI gap and substantially improve access to quality of healthcare for minorities in nursing home facilities.

## II. RACIAL INEQUITY IN NURSING HOMES

In the past, nursing homes facilities traditionally served a predominantly White population and the use of formal long-term care services by Blacks, Hispanics, and Asians, age sixty-five and older, were shown to be substantially lower than that of non-Hispanic Whites.<sup>12</sup> While both Medicare and Medicaid require that nursing home residents receive quality care,<sup>13</sup> for minority elders quality of care is far less when compared to their

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10. See generally Vernellia Randall, *Racial Discrimination in Health Care in the United States as a Violation of the International Convention on the Elimination of All Forms of Racial Discrimination*, 14 U. FLA. J.L. & PUB. POL'Y. 45 (2002-2003).

11. See generally Ruqaiijah Yearby, *Is it Too Late for Title VI Enforcement?: Seeking Redemption of the Unequal United States' Long Term Care System through International Means*, 9 DEPAUL J. HEALTH CARE L. 971, 972 (2005-2006) (examining the United States' disregard for elderly African Americans' right to equality). Professor Yearby has argued that because the root cause of the nursing home disparities stem from institutional racism it then becomes the normal practices of these facilities to limit the number of African American beds that become available. *Id.* at 973. She goes on to argue that because this is an institutional racism issue that we should move beyond Title VI and access the International Convention on the Elimination of All Forms of Racial Discrimination (CRED) as the source for combatting the issue. *Id.* When member states of CRED are in violation for failing "to implement measures to eradicate intentional and unintentional forms of racial discrimination" private parties now have a cause of action. *Id.*

12. Pandya, *supra* note 6.

13. See generally Social Security Act, 42 U.S.C. §§ 1395i-3(b)(2) (2006). As mandated by the Nursing Home Reform Act, the Secretary of Health and Human Services is required to regulate the actual care provided to residents to ensure that nursing homes "provide services and activities to attain or maintain the highest practicable physical, mental, and psychosocial well-being of each resident." David R. Hoffman, *The Role of the Federal Government in Ensuring Quality of Care in Long-Term Care Facilities*, 6 ANNALS HEALTH

White counterparts.<sup>14</sup> Additionally, there is documentation of pervasive racial, ethnic, and class disparities in both nursing home use and nursing home quality of care for minority elders.<sup>15</sup> African American nursing home rates have now surpassed Whites' rates, but there has been little gain in equity.<sup>16</sup> When compared to White elders, African American elders continue to reside in lower-quality nursing homes.<sup>17</sup> Additionally, the informal practices of private pay facilities often further contribute to these disparities as they continue to limit the admission of Medicaid patients, of whom a disproportionate amount are elderly African-American and minority patients.<sup>18</sup>

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L. 147, 149 (1997).

14. Mary L. Fennell et al., *Facility Effects on Racial Differences in Nursing Home Quality of Care*, 15 AM. J. MED. QUALITY 174, 174 (2000). "Controlling for differences in severity of conditions, socioeconomic status, and patient preference minority nursing home residents are less likely to receive medically appropriate treatments". *Id.* at 174.

Decades of studies have shown that "elderly African Americans are on average two times more likely to reside in poor quality nursing homes than Whites". Ruqaiijah Yearby, *Striving for Equality, But Settling for the Status Quo in Health Care: Is Title VI More Illusory Than Real?*, 59 RUTGERS L. REV. 429, 435 (2007). Furthermore, other studies have shown that African American's access to necessary rehabilitative treatment provided by quality nursing homes is impeded because of their race. *Id.* Minority nursing home residents are less likely to receive medically appropriate treatments. *Id.* at 435.

15. See generally, Adaeze B. Akamigbo & Fredric D. Wolinsky, *New Evidence of Racial Differences in Access and Their Effects on the Use of Nursing Homes among Older Adults*, 45 MED. CARE 7, 672 (2007). Data compiled from Medicare forms show that African-Americans are more likely to reside in nursing homes with "lower ratings of cleanliness/maintenance and lighting." Yearby, *supra* note 14, at 461. "Moreover, being African-American meant that the patient was twice as likely to be admitted to a primarily Medicaid payer nursing home and increased the probability of the nursing home deficiencies by 24%". *Id.* For instance, prior to implementation of Medicare and Medicaid in 1966, nursing homes in the South were totally segregated by Jim Crow laws while in the North patterns of use and admission practices also perpetuated these same disparities. David Barton Smith et al., *Separate and Unequal: Racial Segregation and Disparities in Quality Across U.S. Nursing Homes*, 26 HEALTH AFF. 1448, 1449 (2007). Section 622(f) of the Hill-Burton Act proscribed federal funding for "separate but equal" health care services. Yearby, *supra* note 14, at 433. Segregated facilities were eligible to receive federal funding as long as they certified that there was a "separate but equal" facility available to treat blacks. Watson, *supra* note 8 at 940.

16. Smith et al., *supra* note 5, at 871.

17. *Id.*

18. Yearby, *supra* note 11, at 972 (arguing that as a result elderly African-American

### III. WHAT HAS TITLE VI DONE FOR ADDRESSING HEALTH INEQUITIES?

The Department of Health and Human Services (HHS) promulgated Title VI regulations on December 4, 1964,<sup>19</sup> and prohibited intentional discrimination policies and practices that appear neutral but have a discriminatory effect.<sup>20</sup> The foundation of Title VI is that “no person shall be subjected to discrimination on the basis of race, color, or national origin under any program or activity that receives federal financial assistance”.<sup>21</sup> Under Title VI, health care entities are prohibited from “utiliz[ing] criteria or methods of administration which have the effect of subjecting individuals to discrimination because of their race, color, or national origin, or have the effect of defeating or substantially impairing accomplishment of the objectives of the program as respect individuals of a particular race, color, or national origin”.<sup>22</sup> While Title VI has ended blatant forms of health care discrimination, there are still subtle barriers that prevent minorities from fully accessing these facilities.<sup>23</sup>

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patients are often times placed in nursing homes with a high proportion of Medicaid patients, which traditionally provide substandard care). “The disparate impact of placing elderly African-Americans in substandard quality nursing homes based on their payment status is overshadowed by the institutional racism that is the underlying reason for these practices”.  
*Id.*

19. Yearby, *supra* note 14, at 448.

20. U.S. GOVERNMENT PRINTING OFFICE ELECTRONIC CODE OF FEDERAL REGULATIONS. PART 80 – DISCRIMINATION UNDER PROGRAMS RECEIVING FEDERAL ASSISTANCE THROUGH DEPARTMENT OF HEALTH AND HUMAN SERVICES EFFECTUATION OF TITLE VI OF THE CIVIL RIGHTS ACT OF 1964 *available at* <http://www.ecfr.gov/cgi-bin/text-idx?c=ecfr&sid=4f19a78b9f025ef7dede0f0838b07a60&rgn=div5&view=text&node=45:1.0.1.1.39&idno=45>.

21. *Id.* This specifically applies to any public or private entity that receives this federal financial assistance, either directly from the federal government or through another recipient, but does not include the ultimate beneficiaries of the programs that receive federal financial assistance. *Id.*

22. *Id.* With the enactment of Title VI of the Civil Rights Act, Congress made compliance mandatory before a nursing home could become eligible to receive Medicare or Medicaid Funding. Yearby, *supra* note 14, at 433.

23. Watson, *supra* note 8, at 941.

*A. How Has Title VI Been Ineffective in Addressing Race-Related Disparities in Nursing Homes?*

Title VI of the 1964 Civil Rights Act prohibits the use of federal funds for any activities for which there is evidence of discrimination<sup>24</sup> however, the federal government has failed to effectively use this legislation as a means to addressing this discrimination.<sup>25</sup> Furthermore, under Title VI, there has been a long history of non-enforcement.<sup>26</sup> The Office of Civil Rights (“OCR”), a division of HHS is responsible for enforcing Title VI in health care.<sup>27</sup> In its history, the agency has never terminated a nursing home that has violated Title VI.<sup>28</sup> Moreover, since the Supreme Court held in 2001 that “disparate impact” liability claims could not be filed by private parties under Title VI the regulation has been essentially sidelined.<sup>29</sup>

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24. See David Barton Smith, *Addressing Racial Inequities in Health Care: Civil Rights Monitoring and Report Cards*, 23 J. HEALTH POL. POL’Y & L. 1, 78 (1998).

25. See Yearby, *supra* note 14, at 433-39 (noting that the government has failed to implement suggestions of how to effectively use Title VI). She mentions Professor Dayna Bowen Matthews who has suggested using the False Claims Act to sue government entities for falsely certifying compliance with Title VI as a method to put an end to racial discrimination and collect money for aggrieved parties. *Id.* Professor Yearby has also proposed the use of the Medicaid Act, Fair Housing Act, and the International Convention on the Elimination of All Forms of Discrimination. *Id.*

26. HHS is the federal agency in charge of enforcing Title VI compliance for health care entities. Ruqaiyah Yearby, *Litigation, Integration, and Transformation: Using Medicaid to Address Racial Inequities in Health Care*, 13 J. HEALTH CARE L. & POL’Y 325, 332 (2010). Duties have been delegated to its Office of Civil Rights (OCR), however, this agency has been inadequately staffed and funded to investigate private complaints and in conducting mandatory system-wide compliance reviews. *Id.* States have also been changed with enforcement of Title VI compliance, however, the efforts have also been minimal on the state level as well. *Id.* at 329. “The federal government has never issued extensive health-related civil rights guidance. . .” Sara Rosenbaum et al, *U.S. Civil Rights Policy and Access to Health Care by Minority Americans: Implications for a Changing Health Care System*, 57 MEDICAL CARE RESEARCH AND REVIEW 236, 238 (2000).

27. Sara Rosenbaum & Joel Teitelbaum *Addressing Racial Inequality in Health Care, in* POLICY CHANGES IN MODERN HEALTH CARE 137 (David Mechanic, et al., eds. 2005), available at [http://www.investigatorawards.org/publications/policy\\_challenges/pdf/Chapter%209.pdf](http://www.investigatorawards.org/publications/policy_challenges/pdf/Chapter%209.pdf).

28. U.S. Commission on Civil Rights, *Federal Title VI Enforcement to Ensure Nondiscrimination in Federally Assisted Programs*, No. 005-910-00024-2, 220-221 (1996). Yearby, *supra* note 11, at 975.

29. In *Alexander v. Sandoval*, the United States held that the Title VI statute only

*B. Can We Still Use Title VI as a Viable Tool for Addressing  
Nursing Home Disparities?*

Despite these set-backs there are a number of recommendations for ways that both the state and federal government can use Title VI specifically to address racial disparities in nursing homes and other long term care facilities.<sup>30</sup> One professor has suggested that HHS and the states aggressively monitor and sanction perpetrators in order to end discriminatory practices.<sup>31</sup> She also suggests that Medicaid patients seeking admission to or residing in nursing homes file 42 U.S.C. § 1983 class action suits against the Secretary of HHS and the states alleging civil rights violations.<sup>32</sup> Another suggestion has been to file racial impact claims against those recipients of federal government funding.<sup>33</sup> Moreover, OCR could be mandated to collect racial data or admission flow data, as well as regulate nursing home's admission practices, or survey the racial makeup of nursing homes as required by Title VI.<sup>34</sup> While Title VI litigation has proved to be of little assistance,<sup>35</sup> with the creation of PPACA there stands

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prohibits intentional discrimination. *Alexander v. Sandoval*, 532 U.S. 275, 280 (2001). Rosenbaum & Teitelbaum, *supra* note 27. Philip Tegeler, *Title VI Enforcement in the Post-Sandoval Era*, 19 *POVERTY & RACE* 5, 5 (2010).

30. Yearby, *supra* note 26, at 333.

31. *Id.*

32. *Id.*

33. Tegeler, *supra* note 29, at 5. However, with respect to private Title VI cases filed in court they are now limited to claims of intentional discrimination prohibited by the statute itself. *Id.*

34. Yearby, *supra* note 11, at 975. According to Professor Yearby, OCR has had a long history of failing to fulfill Title VI mandates even after receiving complaints from private individuals. *Id.* at 994. She maintains that OCR does not collect racial data or survey the racial makeup of nursing homes as required by Title VI. *Id.* at 975. Instead of implementing fines on noncompliant nursing homes, OCR has resolved the issues through voluntary cease and desist practices. *Id.* at 994.

35. *Generally* Watson, *supra* note 8, at 942 (arguing that Title VI's implementing regulations proscribe facially neutral policies and practices that, in operation, have the effect of disproportionately excluding minorities, regardless of the defendant's lack of subjective discriminatory intent.). Furthermore, lower courts have allowed health care facilities to defend too easily such policies and federally funded defendants have been allowed to defend

to be new opportunities for enforcement and regulation.<sup>36</sup>

#### IV. THE AFFORDABLE CARE ACT PROVISIONS ADDRESSING RACIAL DISPARITIES

PPACA is the first comprehensive legislation, since the Nursing Home Reform Act (NHRA),<sup>37</sup> to expand quality of care-related requirements for nursing homes that participate in Medicare and Medicaid and improve federal and state oversight and enforcement.<sup>38</sup> PPACA includes various provisions that explicitly intend to reduce health disparities and improve health of racially and ethnically diverse populations.<sup>39</sup>

##### A. *What Sections of the ACA Specifically Address Health Inequalities*

Section 1557 prohibits health insurers and health care providers from discriminating on the basis of race and ethnicity along with gender,

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such policies with a disproportionate adverse racial impact by showing that the policies are rationally related to any legitimate, non-discriminatory purpose. *Id.*; *see also* Matthew, *supra* note 9, at 796.

36. Section 1557 of the ACA creates a new health-specific anti-discrimination prohibition that reaches beyond Title VI. ACA, 42 U.S.C. § 18116 (); Sidney D. Watson, *Section 1157 of the Affordable Care Act: Civil Rights, Health Reform, Race, and Equity*, 55 *How. L.J.* 855, 870 (2012).

37. The purpose of the Nursing Home Reform Act “is to ensure that residents of nursing homes receive quality care that will result in their achieving or maintaining their ‘highest practicable’ physical, mental, and psychosocial well-being.” Martin Klauber & Bernadette Wright, *The 1987 Nursing Home Reform Act*, AARP PUBLIC POLICY INSTITUTE (February 2001), [http://www.aarp.org/home-garden/livable-communities/info-2001/the\\_1987\\_nursing\\_home\\_reform\\_act.html](http://www.aarp.org/home-garden/livable-communities/info-2001/the_1987_nursing_home_reform_act.html).

38. KAISER COMMISSION ON MEDICAID AND THE UNINSURED. IMPLEMENTATION OF AFFORDABLE CARE ACT PROVISION TO IMPROVE NURSING HOME TRANSPARENCY, CARE QUALITY, AND ABUSE PREVENTION (January 2013), *available at* <http://www.kff.org/medicare/upload/8406.pdf>.

39. JOINT CENTER FOR POLITICAL AND ECONOMIC STUDIES. PATIENT PROTECTION AND AFFORDABLE CARE ACT OF 2010 at 1 (2010). *See also*, Watson, *supra* note 36, at 858 (discussing racial segregation in health insurance and health care delivery). *See also* Patient Protection and Affordable Care Act (ACA), Pub. L. No. 111-148 § 4302(a), 124 Stat. 119 (2010) (codified as amended at 42 U.S.C. § 18001 (2006)). In general, the ACA also includes numerous provisions meant to increase transparency in the nursing home sector overall. Edward Alan Miller, *The Affordable Care Act and Long-Term Care: Comprehensive Reform or Just Tinkering Around the Edges?* 24 *J. OF AGING & SOCIAL POL’Y* 101, (2012).

disability, and age.<sup>40</sup> Though Section 1557 does not define prohibited discrimination it does adopt language from Title VI that is mirrored in Title IX, Section 504, and the Age Discrimination Act, providing that an individual shall not, on the grounds prohibited by the statute be “*excluded from participation in, be denied the benefits of, or be subjected to discrimination under*” any health program or activity.<sup>41</sup>

Section 4302 of Title IV of PPACA amends the Public Health Service Act and is relevant to understanding and responding to racial and ethnic health disparities.<sup>42</sup> Section 4302 requires the Secretary of HHS to collect data and to track health disparities under Medicaid and Medicare. This section of PPACA would fill the data collection gap of the OCR and provide for uniformity in collection and reporting procedures.<sup>43</sup> The section requires HHS adopt new criteria for collecting data related to “race, ethnicity, sex, primary language, and disability status”.<sup>44</sup>

Pursuant to section 6102 of the PPACA, each skilled nursing facility (SNF) and nursing facility (NF) is required to develop a compliance and ethics program and participate in a quality assurance and performance improvement program.<sup>45</sup> The section imposes an ethics and compliance program requirement and mandates that these facilities establish these

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40. Watson, *supra* note 36, at 859. See also ACA § 1557(a).

41. Watson, *supra* note 36, at 872. See also 42 U.S.C. § 12132 (2011); accord 42 U.S.C. § 2000h-2 (2011), 29 U.S.C. § 701 (2011?), 42 U.S.C. § 2000d-2 (2011).

42. Howard K. Koh, et al, *Reducing Racial and Ethnic Disparities: The Action Plan from the Department of Health and Human Services*, 30 HEALTH AFF 10, 1825 (2011).

43. U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES OFFICE OF MINORITY HEALTH. REDUCING HEALTH DISPARITIES WITH IMPROVED DATA COLLECTION: NEW REFINED DATA STANDARDS FOR RACE, ETHNICITY, SEX, PRIMARY LANGUAGE, AND DISABILITY STATUS available at <http://minorityhealth.hhs.gov/templates/content.aspx?ID=9232&lvl=2&lvlID=208>.

44. Koh, et al, *supra* note, 42 at 1825.

45. Sec. 6102. Accountability Requirements for Skilled Nursing Facilities and Nursing Facilities. Cms.gov - these programs are consistent with the goals of the ACA to promote accountability for patient care and to redesign care process to ensure high quality and efficient service delivery.

compliance programs in a manner that effectively prevents and detects violations and promotes quality of care.<sup>46</sup>

Looking back at recommendations by previous scholars requesting OCR create quality measures to assess health disparities, Section 10303 does an excellent job of filling this gap as it specifically provides for the creation of quality development measures that allow the assessment of health disparities.<sup>47</sup> Section 10303 further authorizes HHS to enter into a contract with the IOM to “identify existing and newly-created clinical practice guidelines”.<sup>48</sup>

#### *B. Recommendations For Addressing Nursing Home Disparities*

Addressing and eliminating health disparities demand a multifaceted approach including both education and advocacy. While Title VI has had some shorting comings addressing racial disparities in nursing home facilities, the PPACA can be an effective tool in improving minority access.<sup>49</sup> Section 1557 is one of the post promising sections as it goes beyond the realms of Title VI and specifically prohibits “discrimination in three types of health programs and activities: (1) those in which any part is receiving Federal financial assistance, including credits, subsidies, or contracts of insurance, (2) those administered by an Executive Agency, and

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46. Corrine Propas Parver & Allison Chonen, *Affordable Care Act: Strengthening Compliance through Health Care Fraud Provisions*, 5 HEALTH L. & POL’Y BRIEF 5, 16 (2011). The Act also requires NFs and SNFs to collect and disclose to the HHS Secretary information about ownership and control of the facilities. *Id.* In order to carry out these reporting requirements, the Act directs the Secretary to develop a program to report direct care staffing and auditable data. *Id.* at 19.

47. AMERICAN MEDICAL ASSOCIATION, H.R. 3590 PATIENT PROTECTION AND AFFORDABLE CARE ACT [hereinafter AMA] at 15 available at <http://www.ama-assn.org/ama1/pub/upload/mm/399/hr3590-summary-of-provisions.pdf>.

48. *Id.*

49. PPACA contains provisions which allow for documentation of racial disparities, “including racial segregation in health insurance and health care delivery”. Watson, *supra* note 36, at 858.

(3) those established under Title I of the PPACA”.<sup>50</sup> This would suggest that any nursing home facility receiving federal funding or payments via federal funding would be barred from discrimination and potential suits could be brought under the PPACA.<sup>51</sup>

Section 1557 provides that the enforcement mechanisms available under Title VI, Title IX, Section 504 *or* the Age Discrimination Act are available to redress violations of Section 1557.<sup>52</sup> As such, plaintiffs asserting a violation under Section 1557 appear to have their choice of process: they have either direct access to federal court for claims of intentional discrimination as provided by Title VI, Title IX, and Section 504, or an agency hearing with an opportunity for judicial review for claims of both disparate impact and intentional discrimination.<sup>53</sup>

#### V. CONCLUSION

While PPACA generates various opportunities<sup>54</sup> for lasting and comprehensive systems change, Section 1557 specifically allows for far greater actions than was previously allowed under Title VI.<sup>55</sup> Health care providers who do not accept federal financial assistance will be prohibited from discriminating on the basis of race and furthermore, federal government health programs and activities will also be prohibited from discriminating on the basis of race. Furthermore, individuals should attack a precise policy that has a disparate impact on minority patients and provide

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50. See ACA § 1557(a); *see also* Watson, *supra* note 36, at 872-73.

51. Watson, *supra* note 36, at 873.

52. *Id.* at 880.

53. *Id.*

54. Bowser, *supra* note 4, at 69.

55. Section 1557 reaches both intentional discrimination and policies and practices that have a disparate impact on minorities and provides for a private right of action to enforce claims of both intentional and disparate impact discrimination. Watson, *supra* note 36, at 880.

clear statistical evidence that show the disparate impact alleged.

Baby Boomers and Electronic Health Records:  
Will PPACA's Provisions Increase Adoption in  
Time to Meet Demand?

*Alexander Mikulaschek\**

With the implementation of the Patient Protection and Affordable Care Act (PPACA), the federal government declared that it would decrease the cost of health care, improve the quality of delivered care, and expand healthcare coverage to many uninsured Americans.<sup>1</sup> Much of the focus has been on the expansion of coverage and the individual mandate because of the legal battles and the PPACA's financial implications;<sup>2</sup> meanwhile the aging baby boomers are looming on the horizon.<sup>3</sup> Beginning in 2010, the roughly seventy-eight million baby boomers began turning sixty-five at a rate of three to four million per year leading to growing concerns over meeting their healthcare demands.<sup>4</sup> This impending tide of elderly appears set to inundate the healthcare market and put pressure on an already-strained system.<sup>5</sup> Through efforts such as the PPACA, the government is trying to gain control of healthcare costs now and maintain them going

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1. Dinsmore & Shohl LLP, *Breaking Down the Affordable Care Act*, NAT'L LAW REV. (June 11, 2012), <http://www.natlawreview.com/article/breaking-down-affordable-care-act>.

2. Richard Cauchi, *State Legislation and Action Challenging Certain Health Reforms*, NAT'L CONF. OF ST. LEGIS. (Apr. 2013), <http://www.ncsl.org/issues-research/health/state-laws-and-actions-challenging-ppaca.aspx>.

3. Ardis Dee Hoven, *Coping with Baby Boomers and Staggering Statistics*, AMEDNEWS.COM (Sept. 20, 2010). Two-thirds of seniors at least sixty-five years old have one chronic disease and see seven different physicians, while as much as twenty percent of those over sixty-five have five chronic diseases and see fourteen doctors. *Id.*

4. *Id.*

5. U.S. GOV'T ACCOUNTABILITY OFF., GAO-13-281, PATIENT PROTECTION AND AFFORDABLE CARE ACT EFFECT ON LONG-TERM FEDERAL BUDGET OUTLOOK LARGELY DEPENDS ON WHETHER COST CONTAINMENT SUSTAINED 1 (2013).

forward.<sup>6</sup> Until recently, health information technology, specifically electronic health records (EHRs), while greatly adopted throughout most of health care, was not widely promoted in long-term care, especially nursing homes.<sup>7</sup> The PPACA has now changed this with a few provisions encouraging nursing homes to adopt EHR technology,<sup>8</sup> but whether or not these efforts will be sufficient to help against the influx of baby boomers remains to be seen.<sup>9</sup> Part I of this article will discuss how EHRs benefit nursing homes, while Part II will identify the reasons why nursing homes have not widely adopted EHRs. Part III will detail the PPACA's efforts to promote EHR adoption in consideration of the costs of such implementation. Part IV will further analyze the effect of the PPACA on EHR adoption, specifically the necessity of nursing homes utilizing EHR technology to contribute in the new healthcare landscape. Finally Part V will consider the baby boomer's impact on health care and conclude that the PPACA's efforts to promote the use of EHRs in nursing homes may be insufficient to have a significant influence in the immediate future.

#### I. EHRs' BENEFIT TO NURSING HOMES

EHRs, in general, refer to software with a full range of functionalities to store, access, and use patient medical information.<sup>10</sup> For a variety of

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6. *Id.* at 2.

7. Ken Terry, *EHRs Certified For Long-Term Care, Post-Acute Care*, INFORMATIONWEEK (Nov. 10, 2011), <http://www.informationweek.com/healthcare/electronic-medical-records/ehrs-certified-for-long-term-post-acute/231902752>.

8. Patient Protection and Affordable Care Act, Pub. L. No. 111-148, § 124 Stat. 602, 676 (2010) [hereinafter PPACA].

9. LEGIS. ANALYSTS OFF, THE PATIENT PROTECTION AND AFFORDABLE CARE ACT: AN OVERVIEW OF ITS POTENTIAL IMPACT ON STATE HEALTH PROGRAMS (May 13, 2010), [http://www.lao.ca.gov/reports/2010/hlth/fed\\_healthcare/fed\\_healthcare\\_051310.aspx](http://www.lao.ca.gov/reports/2010/hlth/fed_healthcare/fed_healthcare_051310.aspx).

10. *An Introduction to Electronic Health Records*, THE MCGRAW-HILL COMPANIES, INC. 2 (2011), [http://highered.mcgraw-hill.com/sites/dl/free/0077477553/805092/Chapter01\\_rev19.pdf](http://highered.mcgraw-hill.com/sites/dl/free/0077477553/805092/Chapter01_rev19.pdf). EHRs provide various functions depending on the user and contain such information as patient demographics, medications, vital signs, past medical history, immunizations, laboratory data, radiology reports, scheduling, e-prescribing, evaluation and

reasons providers have been reluctant to switch from a paper-based system,<sup>11</sup> but starting in the early 2000s the federal government began financially incentivizing providers to adopt EHRs.<sup>12</sup> Congress recognized that EHRs lead to better clinical information, accessibility, patient safety, care, overall efficiency, and savings.<sup>13</sup> Thus, Congress took great strides to increase the adoption of EHRs through the American Recovery and Reinvestment Act (ARRA) of 2009, specifically in the Health Information Technology for Economic and Clinical Health (HITECH) Act.<sup>14</sup> Despite all the benefits that EHRs could provide to long-term care facilities, Congress did not include nursing homes as one of the providers that could receive bonuses upon adoption of the technology.<sup>15</sup>

Numerous studies have been conducted on the costs and benefits of implementing an EHR system within nursing homes and various types of vendor software have been deemed beneficial for both patients and providers.<sup>16</sup> The Agency for Healthcare Research and Quality (AHRQ), with the help of seven long-term care organizations, conducted a study on the influence of EHR technology in nursing homes.<sup>17</sup> This project

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management coding, care alerts, evidence-based decision support, and health maintenance. *Id.* at 4.

11. *See infra* Part II.

12. THE MCGRAW-HILL COMPANIES, INC., *supra* note 10, at 7.

13. *Id.* at 8-11.

14. *Id.*

15. CENTERS FOR MEDICARE & MEDICAID SERVICES, *Electronic Health Record Incentive Program FAQs* 15 (2012), [http://www.cms.gov/Regulations-and-Guidance/Legislation/EHRIncentivePrograms/Downloads/FAQs\\_Oct\\_2012.pdf](http://www.cms.gov/Regulations-and-Guidance/Legislation/EHRIncentivePrograms/Downloads/FAQs_Oct_2012.pdf) [*hereinafter* CMS].

16. Melanie Au et al., *Using Health IT: Eight Quality Improvement Stories*, AGENCY FOR HEALTH CARE RESEARCH AND QUALITY, 11, 13 (2010), [http://healthit.ahrq.gov/sites/default/files/docs/page/EightSuccessStories\\_092810.pdf](http://healthit.ahrq.gov/sites/default/files/docs/page/EightSuccessStories_092810.pdf); Andrew Kramer et al., *Understanding the Costs and Benefits of Health Information Technology in Nursing Homes and Home Health Agencies: Case Study Findings*, U.S. DEP'T OF HEALTH AND HUMAN SERVICES, 15 (2009), <http://aspe.hhs.gov/daltcp/reports/2009/HITcsf.pdf>; LEADINGAGE CAST, *Electronic Health Record (EHR) Implementation, Use, and Impacts: Provider Case Studies*, LEADINGAGE, 7-9 (2012), [http://www.leadingage.org/uploadedFiles/Content/About/CAST/Resources/CAST\\_EHR\\_Case\\_Studies-2012.pdf](http://www.leadingage.org/uploadedFiles/Content/About/CAST/Resources/CAST_EHR_Case_Studies-2012.pdf).

17. Melanie Au et al., at 11, 13.

evaluated the impact of adopting the “On-Time Quality Prevention Program for Long-Term Care” in fifteen nursing homes.<sup>18</sup> The program provided closer bed monitoring which led to a decrease in pressure ulcers and improved supervision for skin condition, nutrition, and incontinence in patients.<sup>19</sup> Not only did the patients benefit, but the staff also reported improved job satisfaction.<sup>20</sup> Another study conducted by the U.S. Department of Health and Human Services reported numerous improvements from EHR software utilization in nursing homes.<sup>21</sup> The nursing homes reported such advantages as: simultaneous anytime and anywhere access to patient information by multiple care team members, enhanced quality in care coordination and communication, improved decision-making, reduced response time to negative events, reduced duplicative diagnostic tests, and potentially reduced ER visits and re-hospitalizations.<sup>22</sup> EHRs also improved billing efficiency, provided physicians off-site access, allowed more information recording than the previous paper charts and enabled the staff to spend more time with residents thus leading to better care experience for patients.<sup>23</sup> Seeing the positive results from studies such as these has led to increased adoption of EHR technology among healthcare providers and has allowed vendors to create testimonials for their own unique software which can meet the specific needs of individual nursing homes.<sup>24</sup> For instance, the Fort Hudson Nursing Center in New York adopted the PointClickCare system and eliminated seventy-five to eighty percent of its paper-based processes,

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18. *Id.* at 11.

19. *Id.*

20. *Id.*

21. Andrew Kramer et al., *supra* note 16, at 15. The study recorded the influence of EHR technology in four different nursing homes. *Id.*

22. *Id.*

23. *Id.* at 15-16.

24. Melanie Au et al., *supra* note 16, at 11, 13.

improved its medication administration by having quick access to all residents' information, increased efficiency with twenty-four hour reports, and even noted faster reimbursement for Medicare Part A and B submissions due to the quick and accurate automatic billing process.<sup>25</sup> Given the benefits that EHRs can provide to most of the nation's nursing homes, it begs the question, "why has there been a delay in embracing such technology?"

## II. BARRIERS TO ADOPTION

Based upon the studies and testimonials,<sup>26</sup> one would think that providers would be eager to implement EHRs in their organizations. However, this is not the case, as many physicians believe EHRs adversely affect the quality of patient care.<sup>27</sup> While most nursing homes have some form of a computer system, these are limited to mainly administrative tasks, such as billing and reporting patients' "minimum data sets" to the federal government.<sup>28</sup> Concerns over implementing and maintaining an EHR system (in addition to planning and instituting new care procedures) cause providers to hesitate in implementing such software.<sup>29</sup> Also, the necessity and amount of training for staff may deter facilities considering the technology.<sup>30</sup> Additionally, the costs for hardware, data storage, software licenses, and hiring additional information systems personnel may deter providers from

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25. LEADINGAGE CAST, *supra* note 16, at 7-9.

26. *See supra* Part I.

27. Erin McCann, *Physicians Doubt Benefits of ACA, EHRs*, HEALTHCARE FIN. NEWS (June 14, 2012), <http://www.healthcarefinancenews.com/news/physicians-doubt-benefits-aca-ehrs>.

28. Ken Terry, *Why Federal \$\$ for Nursing-Care IT Would be a Good Investment*, BLUESTEP (Jan. 7, 2011), [http://www.bluestep.net/shared/content/story.jsp?\\_event=view&\\_id=445502\\_U137143\\_\\_244974](http://www.bluestep.net/shared/content/story.jsp?_event=view&_id=445502_U137143__244974).

29. Kramer et al., *supra* note 16, at 22.

30. *EHR Adoption in LTC and the HIM Value*, J. OF AHIMA 82, No.1 (2011), available at [http://library.ahima.org/xpedio/groups/public/documents/ahima/bok1\\_048551.hcsp?dDocName=bok1\\_048551](http://library.ahima.org/xpedio/groups/public/documents/ahima/bok1_048551.hcsp?dDocName=bok1_048551) [*hereinafter* J. OF AHIMA].

changing over to EHRs.<sup>31</sup> Furthermore, concerns regarding ineffectiveness during system downtime or surveyor's reluctance to read electronic records (preferring instead the paper system) were cited as problems with EHR adoption within nursing homes.<sup>32</sup>

While the costs, both monetary and otherwise, of EHRs are a major hurdle for nursing homes to overcome in implementing an EHR system, all of these barriers cannot take the sole blame for the lack of adoption. The federal government can be held responsible in part for enacting legislation focusing on other sectors and leaving nursing homes to fend for themselves.<sup>33</sup> As mentioned earlier, the HITECH Act provided incentives for hospitals and physicians to adopt EHR systems while ignoring nursing homes completely.<sup>34</sup> By not including the nursing homes as eligible providers, Congress left nursing homes completely responsible for the cost of the installing such technologies, while certain eligible providers received reimbursement for their expenses.<sup>35</sup> While it may not be the sole responsibility of the federal government to force nursing homes to adopt new beneficial technology, aiding the process through financial incentives has promoted adoption in other areas of the healthcare market.<sup>36</sup>

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31. Kramer et al., *supra* note 16, at 21-22.

32. *Id.* at 22-23.

33. Jane Hyatt Thorpe & Teresa Cacio, *Improving Care Coordination – Spurring the Use of Health Information Technology in Long-Term Care*, HEALTH REFORM GPS (Nov. 14, 2012), <http://www.healthreformgps.org/resources/improving-care-coordination-spurring-use-of-health-information-technology-in-long-term-care/>.

34. Terry, *supra* note 7; Health Information Technology for Economic and Clinical Health Act, 42 U.S.C. §§17901-39 (2009) [*hereinafter* HITECH]; CMS, *supra* note 15; Neville M. Bilimoria, *ACOs and Long-Term Care: Don't Get Left Behind*, JD SUPRA LAW NEWS (Dec. 28, 2012), <http://www.jdsupra.com/legalnews/acos-and-long-term-care-dont-get-left-09413/>. The federal government did not recognize certifications for long-term and post-acute care facilities because they were unable to receive reimbursement under the ARRA's HITECH Act provisions. Terry, *supra* note 7.

35. CMS, *supra* note 15; CMS, *EHR Incentive Programs* (Feb. 20, 2013) <http://www.cms.gov/Regulations-and-Guidance/Legislation/EHRIncentivePrograms/index.html?redirect=/ehrincentiveprograms/> [*hereinafter* CMS].

36. *See* Press Release, CMS, More Than 100,000 Health Care Providers Paid For Using

## III. LEGISLATION AND COST

The PPACA does promote some EHR adoption in nursing homes through a couple provisions.<sup>37</sup> However, when compared to the reimbursement incentives within the HITECH Act, the PPACA provisions appear woefully insufficient.<sup>38</sup> The PPACA first states that the Secretary of Health and Human Services shall conduct two demonstration projects to determine the “best practices” for the use of technology and grant awards to skilled nursing facilities that are either “involved in the culture change movement” or use “information technology to improve resident care.”<sup>39</sup> Furthermore, the PPACA will provide 67.5 million dollars over the four-year term of the grant program.<sup>40</sup> While this will certainly help to a degree, it may not be enough for the nursing homes to catch up with the other providers, who, through the HITECH Act, already invested in their own EHRs and are currently forming Accountable Care Organizations (ACOs).<sup>41</sup>

Considering the funding that the nursing homes will now be able to receive under the PPACA,<sup>42</sup> an analysis of the actual financial burden that implementing an EHR system places on a nursing home is necessary. Two studies (one conducted by the Texas Tech University Health Sciences

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Electronic Healthcare Records (June 19, 2012), <http://www.cms.gov/apps/media/press/release.asp?Counter=4383&intNumPerPage=10&checkDate=&checkKey=&srchType=1&numDays=3500&srchOpt=0&srchData=&keywordType=All&chkNewsType=1>. Over one hundred thousand healthcare providers use EHRs and have benefitted from the Medicare and Medicaid EHR Incentive Programs. *Id.*

37. PPACA, Pub. L. No. 111-148, § 124 Stat. 602, 676 (2010).

38. *Id.*; HITECH, 42 U.S.C. §§17901-39 (2009); THE MCGRAW-HILL COMPANIES, INC., *supra* note 10, at 11. Nineteen billion was invested in the EHR incentive program. *Id.*

39. PPACA § 124 Stat. at 602.

40. PPACA § 124 Stat. at 676.

41. CMS, ACCOUNTABLE CARE ORGANIZATIONS (Mar. 22, 2013), <http://www.cms.gov/Medicare/Medicare-Fee-for-Service-Payment/ACO/index.html?redirect=/aco/>. ACOs are formed by groups of doctors, hospitals, and other healthcare providers who come together to deliver coordinated care to patients. *Id.* The theory is that through coordination proper care can be delivered on time while simultaneously saving money by avoiding duplication of services and preventing errors. *Id.* HITECH, 42 U.S.C. §§17901-39 (2009); Neville M. Bilimoria, *supra* note 34.

42. § 124 Stat. 602, 676 (2010).

Center and the other conducted by the Chief Information Officer Consortium (CIOC)) help demonstrate the actual costs of investing in an EHR system.<sup>43</sup> The CIOC study, in anticipation of the HITECH Act, designed a hypothetical, for-profit long-term care system based out of North Carolina and Florida and projected the five-year costs for such an organization.<sup>44</sup> The results were based upon the implementation of one of three different EHR systems: a third-party hosted solution, a vendor-hosted software as service, and an in-house hosted solution.<sup>45</sup> Over the course of five years, CIOC estimated that the cost per patient per day for a third-party hosted option would be \$1.35, the vendor software option would cost \$1.38, and finally the in-house solution would total \$1.89.<sup>46</sup>

The Texas Tech University Health Sciences Center study also evaluated the implications of adopting EHR technology in long-term care facilities.<sup>47</sup> The study only incorporated two different adoption models: a remotely-hosted business model and a locally-hosted business model.<sup>48</sup> While the locally-hosted business model required a greater up front payment, the study reported that the long-term costs per patient day would be roughly one dollar for both systems.<sup>49</sup>

When evaluating the results of these studies, it is hard to determine the significance of these low costs per patient day in relation to the PPACA's

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43. CIO CONSORTIUM, ELECTRONIC MEDICAL RECORDS (EMR) COST STUDY FINAL REPORT 1 (2011), [http://www.leadingage.org/uploadedFiles/Content/About/CAST/Resources/CIO\\_Consortium\\_EMR\\_CostStudy.pdf](http://www.leadingage.org/uploadedFiles/Content/About/CAST/Resources/CIO_Consortium_EMR_CostStudy.pdf); Barbara Cherry, *Long-Term Care Facilities Adoption of Electronic Health Record Technology: A Qualitative Assessment of Early Adopters' Experiences Final Report*, TX. TECH UNIV., 6 (2009).

44. CIO CONSORTIUM, *supra* note 43, at 7.

45. *Id.* at 6.

46. *Id.* at 9.

47. Cherry, *supra* note 43, at 6. A qualitative assessments was conducted to provide a comprehensive description of the experiences, challenges, and benefits of EHR adoption in Texas and to identify the EHR functionalities currently being used in adopter facilities; and address policy implications related to EHR adoption and HIT in Texas LTC facilities. *Id.*

48. *Id.* at 25-26.

49. *Id.* at 25.

allocation of \$67.5 million dollars nationally over a four-year period. Even when using the estimated cost of implementing EHR technology within a single facility,<sup>50</sup> the precise effectiveness of the PPACA's monetary distribution towards EHR adoption cannot be determined until more time has passed.<sup>51</sup> Undoubtedly the grants will help, although they may be insufficient to incentivize enough long-term care providers to make the change to the EHR technology.<sup>52</sup> This change is critical, though, if the nursing homes wish to coordinate with those providers who have access to the nineteen billion dollars allocated by the HITECH Act.<sup>53</sup> This is a cause for concern as the American healthcare system aims to change to a preventive philosophy where coordinated care will be critical in keeping costs to a minimum.<sup>54</sup>

#### IV. CARE COORDINATION AND EHR

The PPACA has proposed several programs that focus upon controlling costs by increasing care coordination throughout the healthcare system and key among those efforts will be ACOs.<sup>55</sup> Coordinated care requires timely exchange of accurate information between providers and the increased implementation of health information technology, such as EHRs, is

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50. CIO CONSORTIUM, *supra* note 43, at 8. The report estimated that the installation cost for a single facility would be roughly \$254,279. *Id.*

51. LEGIS. ANALYSTS OFF., *supra* note 9.

52. Leslie Schwalbe, *Behavioral Health Providers: Expenditures, Methods and Sources of Payment, Electronic Health Record Incentive Payments for Certain Behavioral Health Providers Policy Descriptions*, DEP'T HEALTH AND HUMAN SERVS. 18 (2010), <http://aspe.hhs.gov/daltcp/reports/2010/behhp.pdf>. Health providers in the past have noted that insufficient reimbursement led to reluctance to adopt health information technology. *Id.*

53. THE MCGRAW-HILL COMPANIES, INC., *supra* note 10, at 11.

54. Terry, *supra* note 28.

55. HEALTHCARE.GOV, *New Affordable Care Act Tools Offer Incentives for Providers to Work Together When Caring for People with Medicare* (Oct. 26, 2011), <http://www.healthcare.gov/news/factsheets/2011/10/accountable-care10202011a.html>. The programs noted to help providers coordinate care: Partnership for Patients, Bundled Payments, Comprehensive Primary Care Initiative, Pioneer Accountable Care Organization Model, Advanced Primary Care Practice Demonstration. *Id.*

facilitating this exchange.<sup>56</sup> Nursing homes will need to exchange data with those providers who have already met the meaningful use standards of the HITECH Act, if they want to function successfully in the future healthcare market, especially among the ACOs.<sup>57</sup> The initial proposed rule from the Centers for Medicare and Medicaid Services (CMS) for ACOs stated that nursing homes would not be designated as eligible participants in the ACOs.<sup>58</sup> This proposed rule caused hospitals to neglect nursing homes in deliberations, as hospital CEOs and physician groups focused on their own partnerships in anticipation of the final regulations.<sup>59</sup> While it was later ruled that nursing homes could participate in the ACOs, the level of collaboration between nursing homes and other providers does not compare to that of hospitals and physician practices.<sup>60</sup>

Hospitals' and physicians' unwillingness to include nursing homes within ACOs may stem from a number of factors. One thought is that the hospitals and physician practices are focused upon creating the best possible ACOs at the physician level in order to acquire the savings that the ACO payment plans provide.<sup>61</sup> This approach could prove foolish as nursing homes may be able to provide the necessary care that can reduce expensive hospital readmissions, thus saving an ACO money overall.<sup>62</sup>

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56. J. of AHIMA, *supra* note 30.

57. Neil Versel, *Long Term Care Providers Still Need Data Exchange*, INFORMATIONWEEK (June 25, 2012), <http://www.informationweek.com/healthcare/interoperability/long-term-care-providers-still-need-data/240002624>.

58. Bilimoria, *supra* note 34.

59. *Id.*

60. *Id.*

61. *Id.*

62. *Id.* It is estimated that forty-five percent of the readmissions of Medicare and Medicaid patients receiving care in nursing homes could be avoided, and for 2011 these costs were estimated to be between seven and eight billion dollars. Ken Terry, *Feds Bet on Health IT For Nursing Homes*, INFORMATIONWEEK (Oct. 8, 2012), <http://www.informationweek.com/healthcare/interoperability/feds-bet-on-health-it-for-nursing-homes/240008675>.

Another possibility is the lack of compatibility in EHR technology.<sup>63</sup> Not all vendors' software is compatible; therefore, a nursing home or ACO may be reluctant to go to the expense of implementing a new system to ensure coordination throughout the organization.<sup>64</sup> Software that would convert the data sets and allow nursing facilities to exchange information between care settings has yet to become widespread in post-acute care.<sup>65</sup> Whether it comes through government plans or providers' own efforts, coordination between nursing homes and other healthcare providers certainly needs to continue to improve, and EHR technology will be critical in these efforts.<sup>66</sup>

#### V. MEETING THE DEMANDS OF BABY BOOMERS

After reviewing the factors influencing the adoption of EHR technology in nursing homes, one must now consider them in relation to the incoming wave of baby boomers. Reports from the Administration on Aging project that the population of Americans over the age of sixty-five will increase from about forty million in 2010 to seventy-two million in 2030.<sup>67</sup> This is an increase in the percentage of total population makeup from twelve to nineteen percent, and due to the current state of the nation's health as well

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63. Terry, *supra* note 62. The vendors who supply EHR technology in hospitals often do not make similar technology available to nursing homes. *Id.*

64. *Id.* There is currently limited exchange of electronic data between hospitals and post-acute-facilities despite the frequency with which patients go between the two. *Id.*

65. Ken Terry, *Long-Term Care Facilities Join the Health Information Exchange*, INFORMATIONWEEK (Aug. 17, 2012), <http://www.informationweek.com/healthcare/interoperability/long-term-care-facilities-join-health-in/240005757>. For example, the Keystone Beacon Community in Pennsylvania has established a connection between hospitals and long-term care facilities through software that converts the data and allows for transfer to other facilities. *Id.*

66. Ken Terry, *supra* note 28. For ACOs to manage cost and quality of care for Medicare patients, they'll have to monitor the status of patients in nursing homes, and therefore coordination between doctors caring for patients in hospitals and post-acute-care facilities is necessary. *Id.*

67. ADMINISTRATION ON AGING, *Projections of the Population by Age and Sex for the United States: 2010 to 2050* (2008), [http://www.aoa.gov/aoaroot/aging\\_statistics/profile/2009/4.aspx](http://www.aoa.gov/aoaroot/aging_statistics/profile/2009/4.aspx).

as chronic disease trends in older individuals this is a serious issue.<sup>68</sup> The stress that the baby boomers will put on the healthcare system leads to financial concerns, especially because projections by the Congressional Budget Office (CBO) have such spending at higher levels than ever before.<sup>69</sup>

The PPACA will hopefully provide a solution to this impending problem, but the PPACA's provisions to promote EHRs in nursing homes may be too late to have a meaningful impact in the near future. The significance of the effect this technology will have in controlling the costs of treatment for the baby boomers is largely uncertain.<sup>70</sup> Between the extreme demands of the baby boomers<sup>71</sup> and the unknowns associated with EHR adoption,<sup>72</sup> such efforts to address the situation should have been applied much sooner. Due to the close timing of the introduction of the PPACA's provisions and the incoming baby boomers, the influence of the EHR technology may not be felt initially and could take some time to produce the desired results.<sup>73</sup>

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68. Steve Yoder, *The Coming Nursing Home Shortage*, FISCALTIMES (Jan. 26, 2012), <http://www.thefiscaltimes.com/Articles/2012/01/26/The-Coming-Nursing-Home-Shortage.aspx#page1>. Fifty-five percent of all cancers are diagnosed in individuals sixty-five and older. *Id.* According to the Alzheimer's Association, those sixty-five and older suffering from Alzheimer's will increase fifty percent to nearly eight million by 2030. *Id.* Additionally, by 2025, the number of those sixty-five and older with diabetes is projected to almost double to nearly eleven million. *Id.*

69. CONG. BUDGET OFF., Pub. No. 4569, *Choices for Deficit Reduction 6* (2012). In 2020, Social Security and other major health programs projected to be 11.5 percent of GDP, up from 9.6 in 2012 and 7.1 over past forty years. *Id.*

70. U.S. GOV'T ACCOUNTABILITY OFF., *supra* note 5, at 38. Estimating future costs of health care is difficult because the effect of drivers, such as technological change, are hard to predict due to the costs associated with implementation as well as their development and incorporation. *Id.*

71. Yoder, *supra* note 65.

72. U.S. GOV'T ACCOUNTABILITY OFF., *supra* note 5, at 38.

73. LEGIS. ANALYSTS OFF., *supra* note 9.

## VI. CONCLUSION

Larry Minnix, the President and CEO of LeadingAge<sup>74</sup> stated, “the current way we’re taking care of seniors in this country is unsustainable and unaffordable. . . the only way out is innovation.”<sup>75</sup> If Mr. Minnix is correct, then innovations, such as EHR technology, will be critical to meet the demands of the baby boomers as they enter nursing homes.<sup>76</sup> While the initial costs may appear significant, there is sufficient evidence to demonstrate that the benefits make the implementation of such a system worth the price.<sup>77</sup> Over the past decade nursing homes have been slow to adopt such technology, but the rapidly approaching baby boomer population and their future needs have spawned efforts to improve future elder care.<sup>78</sup> The PPACA looks to address many issues within the nation’s healthcare system in hopes of lowering the overall cost of care.<sup>79</sup> One can only hope that the government’s efforts to encourage nursing homes to accept EHRs<sup>80</sup> in collaboration with the other initiatives are sufficient to address the issues presented by the baby boomers. Otherwise, it seems the country will have to endure the hardships of paying for the baby boomers’ health care while it waits for the benefits of EHRs to eventually take effect.

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74. LEADINGAGE, [http://www.leadingage.org/About\\_LeadingAge.aspx](http://www.leadingage.org/About_LeadingAge.aspx) (last visited Apr. 28, 2012). LeadingAge is an association of six thousand not-for-profit organizations that focus on advocacy, research, education, and in general support the well being of seniors, children, and those with special needs. *Id.*

75. LONG-TERM LIVING, LTC LEADERS ANALYZE IMPACTS OF ACA DECISION (June 28, 2012), <http://www.ltlmagazine.com/article/ltc-leaders-analyze-impacts-aca-decision>.

76. Terry, *supra* note 62. It is difficult for physicians to visit patients in nursing homes when they are needed and to spend the time necessary to avoid patient hospitalization. *Id.*

77. *See supra* I-II.

78. *See supra* V.

79. O’Neil, *supra* note 1.

80. PPACA, Pub. L. No. 111-148, § 124 Stat. 602, 676 (2010).

Extension of Liability for Abuse Against Nursing Home Residents Under the Nursing Home Care Act

*Meghan Murray\**

I. INTRODUCTION

Abuse prevention in nursing homes is a developing area of long-term care, with legislation evolving quickly in recent years due to the unfortunate increase in reports of resident abuse.<sup>1</sup> Less than thirty-five years ago there was tremendous concern over increasing reports of “inadequate, improper and degrading treatment of patients in nursing homes.”<sup>2</sup> Yet, Illinois legislation in place at the time did not provide an adequate remedy for nursing home residents abused in state long-term care facilities.<sup>3</sup> The Illinois Legislative Investigation Commission (the “Commission”) conducted a statewide investigation of nursing homes to determine proper legislative reform.<sup>4</sup> In 1979, the Commission developed the current Nursing Home Care Act (the “Act”), which provides an express statutory right for nursing home residents to be free from any abuse or neglect *and* to be able to pursue the long-term care provider for civil remedies.<sup>5</sup> In 1986, the Institute of Medicine Report conducted a national investigation into nursing homes and documented an alarming number of reports of abuse.<sup>6</sup> In

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1. *Harris v. Manor Healthcare Corp.*, 111 Ill.2d 350, 357-58 (1986) (quoting Senate Debates, 81st Ill. Gen. Assem., May 14, 1979, at 184 (statement of Senator Karl Berning)).

2. *Id.*

3. Steven M. Levin, et al., *Protecting the Rights of Nursing Home Residents through Litigation*, 84 ILL. BAR J. 36, 37 (1996).

4. *Id.*

5. 210 ILCS 45/2-101 (1980).

6. Levin, 84 ILL. BAR J. at 37.

response to this report, Congress passed landmark federal nursing home legislation in 1987, known as OBRA (Omnibus Budget Reconciliation Act), to meet nursing home residents' needs.<sup>7</sup>

The Act's revision, and similar federal regulations, have greatly heightened nursing home liability and continue to increase litigation regarding resident abuse.<sup>8</sup> However, newly developed resident rights and the Act create an uncertain extension of liability.<sup>9</sup> Litigation and recent research regarding nursing home legislation reveal that the Act extends liability to nursing homes for inflicting abuse, failing to prevent abuse, or operating their facility in a way that directly threatens the resident.<sup>10</sup> However, the Act falls short in imposing liability due to its uncertain and vague guidelines.

This article will first discuss the parts of the Act that detail a nursing home resident's guaranteed right to be free from intentional abuse. Next, this article will detail how the Act protects nursing home residents from the negligence of nursing home facilities. Both sections will detail the shortcomings of the Act and how legislatures and courts are left without a bright line rule to protect nursing home residents.

## II. THE ACT GUARANTEES RESIDENTS THE RIGHT TO BE FREE FROM INTENTIONAL INFLICTION OF ABUSE.

The Act extends strict liability to nursing homes when a resident is a victim of an intentional tort (e.g. physically assaulting a resident.)<sup>11</sup> An

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7. *Id.*

8. Kira Anne Larson, *Nursing Homes: Standards of Care, Sources of Potential Liability, Defenses to Suit, and Reform*, 37 *DRAKE L. REV.* 699, 699-700 (1987-1988); *see generally* 42 C.F.R. § 483.25 (2005).

9. *Id.* at 701.

10. *See infra* Childs v. Pinnacle Health Care, LLC 399 Ill.App.3d 167, 180 (2010); Myers v. Heritage Enterprises, Inc., 354 Ill.App.3d 241, 248 (2004); Mason v. Dep't of Pub. Health, 326 Ill.App.3d 616, 623 (2001).

11. 210 ILCS 45/3-601 (1980).

intentional tort can be inflicted on a nursing home resident by the nursing home itself—represented by the owner of the nursing home, other residents of the nursing home, or third parties not affiliated with the nursing home.<sup>12</sup> In *Childs v. Pinnacle*, the court found that the Act does not extend liability to the nursing home itself where employees of the nursing home commit intentional torts; and therefore, those lawsuits must be asserted independently of the Act.<sup>13</sup> In addition, Illinois courts have held that in order to charge a nursing home entity rather than a specific employee with abuse, the resident must show that the nursing home operated or maintained its facility in a manner that was “directly threatening to the health, safety, or welfare of a resident.”<sup>14</sup> Illinois case law directly speaks to extension of liability to a nursing home entity; however, the Act itself is silent as to how residents can pursue the nursing home entity in regards to negligent hiring or where the employer failed to take action when it had knowledge that the employee presented a risk of harm to others.<sup>15</sup>

Notwithstanding the silence of the Act and other federal long-term care facility regulations, a resident can pursue a nursing home entity for intentional torts committed by its employees. For instance, under federal law, a nursing home facility can be held liable in a court of law or through the State’s nurse aide registry for abuse inflicted on its residents by an employee when it employs staff with previous convictions of abuse, negligence, or mistreatment.<sup>16</sup> The Act requires nursing homes to participate in a federal and state regulated licensure system, thereby

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12. *Id.*

13. *Childs*, 399 Ill.App.3d at 180.

14. 210 ILCS 45/1-103 (1980); *Mason v. Dep’t of Pub. Health*, 326 Ill.App.3d 616, 622-23 (2001) (quoting *Alden Nursing Center-Morrow, Inc. v. Lumpkin*, 259 Ill.App.3d 1027, 1032 (1994)).

15. Stephen C. Buser, Harriet A. Hamilton, *Overview of Illinois Nursing Home Litigation*, 88 ILL. BAR J.316, 356 (2000).

16. *See* 42 C.F.R. § 483.13(c)(1)(ii) (2013).

requiring all nursing homes statewide to abide by long-term care facility regulations and actively ensuring that nursing home residents are free from abuse.<sup>17</sup> Nursing home lawsuits have increased exponentially across the country as a result of these regulations, the public attention to nursing home abuse, and the desire of families of nursing home residents to seek damages for abuse against their loved one.<sup>18</sup> Newly developed regulations, such as the Act, reflect the demand for change in nursing home facilities and have opened up nursing homes to an immense amount of liability for torts committed by its employees.

Although the Act extends a great deal of liability to nursing homes for torts committed by its employees, other legislation enacted amidst the drastic nursing home liability reform has created setbacks for plaintiffs. Most notably, the Health Care Worker Background Check Act strips plaintiffs of the ability to recover treble damages.<sup>19</sup> This aspect of nursing home legislative reform is unique to Illinois and indicates that the Illinois legislature and courts sought to restrict the extension of liability that nursing homes were facing all over the country as a result of sweeping reform.<sup>20</sup> Yet, the Act still exposes nursing homes to ambiguous, and at times, unprecedented negligence liability.

### III. ILLINOIS NURSING HOMES MUST PREVENT ANY HARM FROM ITS RESIDENTS AS A REASONABLY CAREFUL FACILITY WOULD.

Modern interpretations of the Act require nursing homes to act as a “reasonably careful” facility when assisting with the personal care of its

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17. 210 ILCS 45/3-101 (1985).

18. Stephen C. Buser, *Illinois Nursing Home Litigation 2000*, 88 ILL. BAR J. 302 (2000).

19. Stephen C. Buser, Harriet A. Hamilton, *Overview of Illinois Nursing Home Litigation*, 88 ILL. BAR J.316, 318 (2000); *See Darden v. Heartland Manor, Inc.*, 186 Ill.2d 291, 299 (1999) (holding that the treble damages remedy is not a vested right of a nursing home plaintiff).

20. Stephen C. Buser, *Illinois Nursing Home Litigation 2000*, 88 ILL. BAR J. 302 (2000).

residents.<sup>21</sup> This provision can create liability for an immense amount of injuries and issues affecting its residents. First, nursing homes can be liable under common law theories of negligence, or as of recently in other states, through state statutory law.<sup>22</sup> Typical negligence actions deriving from the Act, the Illinois Administrative Code, and the OBRA regulations are those “in which the resident developed pressure ulcers, suffered malnutrition or dehydration, wandered away from the nursing home and suffered injuries, was administered medication to the point of chemical restraint, or fell.”<sup>23</sup> The Act does not determine how far this liability extends to nursing home facilities, especially where residents of nursing homes are prone to such injuries due to age and illness.

Illinois case law extends liability to a nursing home under the Act if the nursing home fails to assist with personal care as a reasonably careful facility would.<sup>24</sup> In most jurisdictions, statutes such as the Act establish the standard of care nursing homes in the state must abide by.<sup>25</sup> For instance, the Act defines “personal care” as

Assistance with meals, dressing, movement, bathing or other personal needs or maintenance, or general supervision and oversight of the physical and mental well-being of an individual, who is incapable of maintaining a private, independent residence or who is incapable of managing his person whether or not a guardian has been appointed for such individual.<sup>26</sup>

The Act appears to incorporate the idea that nursing home residents are at a higher risk for injury or illness because of their feeble condition; yet it makes no account for how this weakened condition may lead to injuries

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21. *Myers*, 354 Ill. App. 3d at 248.

22. FROLIK & BROWN, *ELDERLY OR DISABLED CLIENT*, (Nursing Homes and Long-Term Care Insurance, 1, 1, 2nd ed. ch. 15.03 2012).

23. Buser & Hamilton, *supra* note 19, at 356.

24. *Myers*, 354 Ill. App. 3d at 248.

25. Robert J. Rice, *Nursing Home Liability*, 24 AM. JUR. POF 3d §6 (1994).

26. 210 ILCS 45/1–120 (1980).

sustained in a nursing home. The Act's disregard for a resident's preexisting condition is unique to negligence claims because it seems to soften the influence contributory or comparative negligence has on a nursing home resident's recovery from a nursing home.

The Act also creates a broad spectrum through which a resident may pursue a nursing home.<sup>27</sup> Other negligence theories of liability against nursing homes for its own actions are: failure to provide adequate staff, failure to provide proper nutrition, meals, and hydration, failure to properly prescribe, fill, and administer drugs and medication, and failure to provide elopement.<sup>28</sup> Further, nursing home residents whose rights have been violated can also pursue nursing homes for a breach of contract, wrongful death, fraud, and loss of chance.<sup>29</sup> Nursing homes are obligated to post signs in visible areas in the nursing home listing all the state and federally mandated requirements of care and treatment the facility owes to its residents, ensuring that residents are informed of the many ways they can bring a cause of action against a facility.<sup>30</sup>

The Act also potentially imposes liability to nursing homes where a third party inflicts abuse on a nursing home resident. Nursing homes and their residents constitute a special relationship on which Illinois case law imposes a duty to protect another from a reasonably foreseeable criminal attack by a third party.<sup>31</sup> Liberal interpretation of the Act and case law indicate that where a criminal third party not associated with the nursing home enters the facility and abuses a resident, that resident has the right to

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27. Daniel J. Penofsky, *Litigating Nursing Home Negligence and Wrongful Death Cases*, 110 AM. JUR. TRIALS 1 §30 (Feb. 2013).

28. *Id.*

29. *Id.*

30. *Id.*

31. See *Hernandez v. Rapid Bus Co.*, 267 Ill.App.3d 519, 524 (1994) (listing voluntary custodian and protectee as one of the four special relationships imposing such liability).

pursue the nursing home for civil damages.<sup>32</sup> Thus, a nursing home has exclusive control of its residents, and residents place themselves under its exclusive control with the expectation that the nursing home will protect them. This liability-imposed relationship in concert with the Act opens nursing homes up to tremendous liability through negligence, or even *res ipsa loquitur*.<sup>33</sup> Nursing homes must prevent all outside threats of violence against its residents; however, how nursing homes are to prevent attacks of abuse by other residents or self-inflicted abuse is a more complex matter.

A nursing home must protect its residents from criminal conduct by other residents and even themselves.<sup>34</sup> The Act and federal statutes extend a duty to nursing homes to properly monitor and supervise residents to prevent abuse against its residents.<sup>35</sup> Supervision can become especially difficult where nursing homes commonly provide care and housing to residents with mental illness or who have criminal histories.

The Act requires nursing homes to pre-screen all potential residents and determine whether they can safely co-exist with residents and employees.<sup>36</sup> The Act requires that a psychiatrist, psychologist, registered nurse certified in psychiatric nursing, professional counselor, or social worker conduct the screening.<sup>37</sup> The screening must determine a diagnosis of any mental health disorder, a proper treatment plan, and determination of whether the facility is able to meet the needs of the individual.<sup>38</sup> The screening also determines whether a nursing home can provide an array of community mental health

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32. 210 ILCS 45/2-101 (1980).

33. See *Heastie v. Roberts*, 226 Ill.2d 515, 538 (2007) (citing *Napoli v. Hinsdale Hospital*, 213 Ill.App.3d 382, 388 (1st Dist. 1991)) (explaining that *res ipsa loquitur* applies “where it can be shown that the defendant was responsible for all reasonable causes to which the accident could be attributed.”).

34. 210 ILCS 45/2-201.5.

35. Penofsky, *supra* note 21, at §26.

36. 210 ILCS 45/2-201.5.

37. *Id.*

38. *Id.*

services that would enable the resident to humanely live in the community; such as, permanent supportive housing, assertive community treatment, or peer support services.<sup>39</sup> Nursing homes are also required to run criminal background checks on all possible residents.<sup>40</sup> Where a resident has a criminal history, the nursing home must fingerprint the resident and report the resident to the Illinois Department of Public Health, which prepares a Criminal History Report.<sup>41</sup>

Analysis of the Act reveals that there are strict guidelines for the admittance of potentially dangerous residents; however, the Act is markedly silent as to the regulation of these residents once they are in the facility.<sup>42</sup> The Act focuses on admittance of mental health residents to ensure that highly dangerous residents do not live in the facility.<sup>43</sup> However, the Act does not speak to the proper monitoring and safety measures a nursing home must take when a mental health resident resides in the facility, including prevention of the onset, or worsening, of dangerous mental health disorders.<sup>44</sup> The steps a nursing home must take in order to ensure its potentially dangerous residents are separated from the rest of the facility is unclear and creates a large and ambiguous area of liability.

Nursing homes also have a duty to keep the nursing home free from all hazards so residents cannot self-inflict harm.<sup>45</sup> Nursing homes must take the proper precautionary steps to prevent residents from inflicting harm on themselves.<sup>46</sup> This includes removing all physical objects that can result in self-harm attempts and providing proper care and treatment to residents to

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39. *Id.*

40. *Id.*

41. *Id.*

42. *Id.*

43. *Id.*

44. *Id.*

45. 42 C.F.R. § 483.25(h) (2005).

46. *Id.*

prevent self-harm ideation.<sup>47</sup> Nursing homes often successfully combat liability in this area by claiming that the resident inflicted self-harm due to a pre-existing condition.<sup>48</sup> Nevertheless, it is crucial that a nursing home properly monitor and treat the mental health of all of its residents in order to avoid liability for resident self-harm.

#### IV. CONCLUSION

The Act requires Illinois nursing homes to provide proper treatment for all of its residents. Further, the Act extends a statutory duty to all nursing homes to ensure that its residents are free from abuse and neglect. The numerous areas of care and treatment a nursing home provides and the seemingly never-ending list of potential threats to residents creates an immense amount of liability for nursing homes. While the newly reformed Act helps to ensure that residents are protected from threats of abuse and neglect, it falls short in many areas where it does not determine how a facility should act when presented with potential threats. Litigation in this area represents a new and a highly contested issue that continues to evolve along with resident rights. The Act may be able to provide an improved interpretation of liability once resident rights and facility duties are more clearly defined.

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47. 42 C.F.R. § 483.25(h) (2005); Penofsky, *supra* at note 21 §27.

48. Penofsky, *supra* at note 21 §28.

Expanded Home and Community-Based Services  
Under the PPACA and LGBT Elders:  
Problem Solved?

*Will Pridmore\**

There are an estimated three million people over the age of sixty-five that currently identify as Lesbian, Gay, Bisexual and Transgender (LGBT)—a number which could grow as large as four million by 2030.<sup>1</sup> As the Patient Protection and Affordable Care Act (PPACA) has greatly incentivized states to increase home and community-based services (HCBS)<sup>2</sup> and move away from traditional institution-based long term care, growth in the elderly LGBT population portends increased resident abuse, discrimination and substandard care in the HCBS setting. While the prospect of aging “in place” is appealing to all Americans,<sup>3</sup> there are significant dangers posed to the health of LGBT elders that call into the question the benefits of HCBS.

This article will first describe HCBS and the present Medicaid waiver system; second, the unique health issues LGBT elders face; third, the possible benefits of HCBS for LGBT Elders; fourth, the dangers posed to LGBT elders by HCBS; and fifth, the current means to mitigate these dangers through cultural competency training, the possibility of a private right of action under the Nursing Home Reform Act (NHRA) and the

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1. See Michael J. Ritter, *Quality Care for Queer Nursing Home Residents: The Prospect of Reforming the Nursing Home Reform Act*, 89 TEX. L. REV. 999, 999 (2011).

2. CTR. FOR MED. & MEDICAID SERV., COMMUNITY-BASED LONG-TERM SERVICES & SUPPORTS, <http://www.medicaid.gov/AffordableCareAct/Provisions/Community-Based-Long-Term-Services-and-Supports.html> (last visited Feb. 28, 2013).

3. See Nancy J. Knauer, *LGBT Elder Law: Toward Equity in Aging*, 32 HARV. J. L. & GENDER 1, 55 (2009).

reporting and oversight of HCBS waivers and programs.

### I. INTRODUCTION TO HCBS

HCBS allow persons who are elderly or disabled to receive care in their home or community.<sup>4</sup> State Senator Kevin Kelly, for example, lauds HCBS, both for the potential it holds in cost-savings<sup>5</sup> and the ability to improve quality of life for residents.<sup>6</sup> Residents also favor these programs<sup>7</sup> because they do not have the negative connotations of institutional care and provide a greater sense of autonomy and independence. LGBT elders are no different than their peers in that they too would prefer to age in their home or in a community-based setting.<sup>8</sup> Unfortunately, this desire for home and community-based care clashes with the realities of present HCBS programs.

In 1983, Congress created HCBS waivers through section 1915(c) of the Social Security Act (SSA)—allowing states to circumvent the Medicaid requirements for institutional long-term care.<sup>9</sup> The PPACA now incentivizes states to expand HCBS through Section 1115 Research and Demonstration, or Section 1915(i) Home and Community-Based Services

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4. Home & Community-Based Services, <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Support/Home-and-Community-Based-Services/Home-and-Community-Based-Services.html> (last visited Mar. 24, 2013).

5. See Charlene Harrington et al., *Do Medicaid Home and Community-Based Service Waivers Save Money?*, 30 HOME HEALTH SERVS. Q. 198-213 (2011).

6. See *Senator Kelly: Community-Based Care Would Improve Quality of Life for Connecticut Seniors*, CONN. SENATE REPUBLICANS (last visited Mar. 7, 2013), <http://ctsenaterepublicans.com/2013/03/senator-kelly-community-based-care-would-improve-quality-of-life-for-connecticut-seniors/#.UXbMkSuFSCK> (stating that “[a]ging in place and community-based care have the potential to transform and improve life for members of our aging population.”).

7. See Tracy Bach, *Choices For Care: Consumer Choice and State Policymaking Courage Amid Medicaid’s Shifting Entitlement to Long-Term Care*, 9 MARQUETTE ELDER’S ADVISOR 269, 274, 276 (2008).

8. See Knauer, *supra* note 3, at 55.

9. Home & Community-Based Services, *supra* note 4.

State Plan waivers.<sup>10</sup> As a result of those incentives, the majority of states are currently increasing the availability of HCBS programs.<sup>11</sup>

Through the present system, states can submit amendments for review to change their state plans and create a 1915(i) HCBS benefit.<sup>12</sup> These mechanisms—1115, 1915(c), and 1915(i)—allow states to expand coverage for services to elders in their homes and communities, as opposed to the more traditional, institutional setting. It is this expansion – and the amplifying effect it may have on the unique health and economic factors in the LGBT community – that raises concern.

## II. UNIQUE HEALTH AND ECONOMIC ISSUES AMONG LGBT ELDERS

The dangers posed to LGBT elders by HCBS arise from some of the specific health and economic trends that impact the LGBT community. The CDC notes that the overall LGBT population is medically underserved and suffers from significant health disparities.<sup>13</sup> Among the LGBT elderly, there are elevated rates of chronic health problems, including “asthma, diabetes, HIV/AIDS, obesity, rheumatoid arthritis and certain illnesses such as cancer.”<sup>14</sup> While Medicare coverage mitigates health access issues among the uninsured once they reach the age of 62, there are still persistent health issues among the LGBT elderly<sup>15</sup> that would be exacerbated by

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10. *See generally* KAISER COMM’N ON MEDICAID AND THE UNINSURED, MOVING AHEAD AMID FISCAL CHALLENGES: A LOOK AT MEDICAID SPENDING, COVERAGE AND POLICY TRENDS – RESULTS FROM A 50-STATE MEDICAID BUDGET SURVEY FOR STATE FISCAL YEARS 2011 AND 2012 49 (2011), *available at* <http://www.kff.org/medicaid/upload/8248.pdf>.

11. *Id.* (referring to the twenty-nine states in 2011 and twenty-seven states in 2012 that expanded HCBS programs).

12. *Id.*

13. MO. FOUND. FOR HEALTH, HEALTH EQUITY SERIES: RESPONDING TO LGBT HEALTH DISPARITIES 7 (2012), *available at* <http://www.mffh.org/mm/files/LGBTHealthEquityReport.pdf>

14. SERV. & ADVOCACY FOR GAY, LESBIAN, BISEXUAL & TRANSGENDER ELDERS, LGBT OLDER ADULTS AND HEALTH DISPARITIES 6 (2010), *available at* <http://www.lgbtagingcenter.org/resources/pdfs/LGBTOlderAdultsandHealthDisparities.pdf>.

15. MO. FOUND. FOR HEALTH, *supra* note 13, at 12.

increase HCBS.

These health issues are further impacted by economic circumstances. The lack of dual incomes from a partner or the economic support from adult children leaves many LGBT elders without an adequate support network.<sup>16</sup> Additionally, pension and spousal plans usually do not extend survivorship benefits to same-sex partners.<sup>17</sup> As a disproportionate number of LGBT elders are without traditional support systems, many who enter long-term care institutions are reliant upon state and federal aid,<sup>18</sup> like Medicaid. These factors indicate why LGBT elders are vulnerable to emotional and physical abuse by their caregivers in an institutional long-term care setting.

### III. POSSIBLE BENEFITS OF HCBS TO LGBT ELDERS

Over the past decade there has been repeated discussion of the development of LGBT-specific long-term care facilities.<sup>19</sup> In theory, HCBS waivers create greater opportunities for like-minded people to live together and insulate themselves from discrimination in these kinds of living-arrangements.<sup>20</sup> Unfortunately, there are not many success stories in the LGBT long-term care market.<sup>21</sup> While there have been several successful non-profit LGBT developments that cater to lower-income residents, these represent a small subset of U.S. markets and they have significant waiting

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16. MO. FOUND. FOR HEALTH, *supra* note 13, at 23.

17. Mark Miller, *Retirement Planning Checklist for LGBT Americans*, REUTERS, Jun. 21, 2012, available at <http://www.reuters.com/article/2012/06/21/us-column-miller-lgbt-retirement-idUSBRE85K12N20120621>.

18. NAT'L SENIOR CITIZENS L. CTR., *LGBT OLDER ADULTS IN LONG-TERM CARE FACILITIES* 4 (2010).

19. See Diane C. Lade, *South Florida's First Gay Retirement Home Paving the Way*, SUN-SENTINEL.COM (Mar. 24, 2013) <http://www.sun-sentinel.com/fl-gay-retirement-home-20130320,0,7825360,print.story>.

20. See Jaime E. Hovey, *Nursing Wounds: Why LGBT Elders Need Protection from Discrimination Based on Sexual Orientation and Gender Identity*, 17 ELDER L.J. 95, 122 (2009).

21. *Id.*; see Lade, *supra* note 18 (noting that most attempts at LGBT-specific long-term care have failed).

lists.<sup>22</sup>

In theory, the expansion of HCBS funding could create new opportunities in urban communities to provide LGBT-specific housing for elders covered by Medicaid.<sup>23</sup> The problem with this theory though, is that while the potential of community-based care is emphasized by many LGBT rights groups, present and planned LGBT-specific housing do not meet demand.<sup>24</sup> The financial constraints that have limited growth of LGBT specific long-term<sup>25</sup> care may be aided by increased HCBS funding, but this is not the best course<sup>26</sup> and will not correct the overarching dangers posed to LGBT elders by the expansion of HCBS.

#### IV. DANGERS POSED TO LGBT ELDERS BY HCBS

This move towards community-based care has benefits in diverse, urban communities where LGBT elders can elect to live with other LGBT residents. In most circumstances, though, HCBS may pose danger to LGBT people. Due to the sustained contact and the importance of the resident-caregiver relationship, intolerance or ignorance on the part of the caregiver has a significant impact upon the quality of care for LGBT residents.<sup>27</sup> In smaller, rural communities, or in instances where elders are placed into care without their input, this could create greater potential for harm and isolation.

As there is an increased likelihood of isolation in a home-based

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22. Lade, *supra* note 18.

23. See Home & Community-Based Services, *supra* note 4.

24. Knauer, *supra* note 3, at 55.

25. See Lade, *supra* note 18.

26. See Hovey, *supra* note 20, at 114-15 (stating that “these housing options are often too expensive for many,” and, “private alternative housing for LGBT seniors, while a nice idea, is clearly not going to solve the problem of discrimination for many older members of the gay community who cannot afford it.”).

27. Ritter, *supra* note 1, at 1000.

program,<sup>28</sup> and as isolation creates the potential for inadequate care, the risk of inferior care for LGBT elders receiving HCBS is very real. Placement in nursing care is often rushed and last-minute<sup>29</sup> and there may be no opportunity to self-select for a more welcoming environment.<sup>30</sup> This is especially worrisome in light of mental capacity issues<sup>31</sup> where elders are placed into care quickly and with little research. In states with weaker or non-existent LGBT discrimination laws,<sup>32</sup> moving LGBT elders into decentralized care like HCBS may amplify current problems with discrimination and abuse. These same states are also unlikely to create LGBT-centered care because it would be politicized and stigmatized, thus eliminating on the key benefits of HCBS to LGBT elders.

#### *A. Mistreatment of LGBT Elders*

Mistreatment is broadly defined as constituting physical, emotional, or sexual abuse, or neglect and abandonment by caregivers.<sup>33</sup> LGBT elders are especially vulnerable to mistreatment because, as a stigmatized minority, they are often “the first targets of abuse, neglect, and discrimination in nursing homes.”<sup>34</sup> This vulnerability is exacerbated by the “invisibility” of LGBT elders,<sup>35</sup> and subtler forms of discrimination.

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28. Knauer, *supra* note 3, at 10 (referring to the fact that LGBT elders are more likely to live alone than straight peers, isolation is a clear danger).

29. Ritter, *supra* note 1, at 1005.

30. Hovey, *supra* note 20, at 111 (stating “the decision may not be theirs to make”).

31. See Nancy J. Knauer, “*Gen Silent*”: *Advocating for LGBT Elders*, 19 *ELDER L.J.* 289, 342 (2012).

32. See NAT’L. GAY AND LESBIAN TASK FORCE, STATE NONDISCRIMINATION LAWS IN THE U.S., [http://www.thetaskforce.org/downloads/reports/issue\\_maps/non\\_discrimination\\_1\\_12\\_color.pdf](http://www.thetaskforce.org/downloads/reports/issue_maps/non_discrimination_1_12_color.pdf) (last updated Jan. 20, 2012).

33. NAT’L. INST. OF HEALTH, ELDER ABUSE, <http://www.nia.nih.gov/health/publication/elder-abuse>.

34. Nikki Burrill & Valita Fredland, *The Forgotten Patient: A Health Provider’s Guide to Providing Comprehensive Care for Transgender Patients*, 9 *IND. HEALTH L. REV.* 69, 75 (2012).

35. See *id.*

Unfortunately, there is little reliable data on LGBT elder mistreatment. As of 2009, existing surveys did not account for LGBT people,<sup>36</sup> which has created greater reliance upon anecdotal accounts.

LGBT elders experience mistreatment in the form of verbal and physical harassment by staff and residents, refusals to honor medical power of attorneys (POAs), and even the failure to provide basic care or medical care because of bias.<sup>37</sup> LGBT elders fear long-term care settings because they anticipate that on the basis of their identity, they will be subject to discrimination from care providers and other residents, and receive substandard care.<sup>38</sup> Recent data shows that these are pervasive concerns and that there is a significant risk of mistreatment<sup>39</sup> that could arise in the HCBS setting.

LGBT patients' previous experience of discrimination and anticipation of bias may cause residents not seek out adequate care, communicate risks to their care provider, or delay needed care.<sup>40</sup> Additionally, LGBT individuals may fail to take necessary planning steps—advance directives or POAs—because they fear that doing so would invite bias or discrimination on the part of providers or their employers.<sup>41</sup> Even when the proper planning is in place through the creation of a POA for an LGBT individual, these measures are sometimes ignored by long-term care providers or family

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36. Knauer, *supra* note 3, at 52.

37. *See, e.g.*, NAT'L SENIOR CITIZENS L. CTR., *supra* note 18.

38. Daniel Redman, *They Stood Up For Us: Advocating for LGBT Elders in Long-Term Care*, 21 TEMP. POL. & CIV. RTS. L. REV. 443, 443 (2012).

39. *Id.* (referencing a chart showing many forms of discrimination, from NAT'L SENIOR CITIZENS L. CTR., *LGBT OLDER ADULTS IN LONG-TERM CARE FACILITIES* (2010)).

40. INST. OF MED., *THE HEALTH OF LESBIAN, GAY, BISEXUAL, AND TRANSGENDER PEOPLE: BUILDING A FOUNDATION FOR BETTER UNDERSTANDING* 63 (2011), available at <http://www.iom.edu/~media/Files/Report%20Files/2011/The-Health-of-Lesbian-Gay-Bisexual-and-Transgender-People/LGBT%20Health%202011%20Report%20Brief.pdf>.

41. *See id.*

members.<sup>42</sup> In long-term care this can create pressure to conceal individual LGBT status to avoid discrimination, which in turn fosters a sense of isolation and negatively impacts health outcomes.

Subtler discrimination may include the tendency among long-term care providers to ban non-relatives from electing to live together.<sup>43</sup> This may not be explicitly intended to bar LGBT people from living with their spouses or partners, but it has that effect and concomitant impact upon LGBT residents' mental health. Much of the blame may lie with the taboo placed on elder sexuality and the perception of LGBT people as hypersexualized.<sup>44</sup> This creates significant pressure to hide LGBT sexuality to avoid judgment or danger,<sup>45</sup> especially as there is a higher incidence of homophobia among the elderly non-LGBT population.<sup>46</sup> This attempt to hide LGBT identity in turn fuels isolation and visibility problems,<sup>47</sup> as hiding may only foster the false impression that the average long-term care facility doesn't have LGBT residents.<sup>48</sup>

## V. CURRENT MEANS TO COMBAT PROBLEMS FACING LGBT ELDERS

### *A. Cultural Competency*

One of the barriers to quality care for LGBT residents is that long-term care providers lack the requisite cultural competency to provide services that do not insult the dignity of LGBT residents.<sup>49</sup> Cultural competency can contribute greatly to appropriate, high quality care for individuals of

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42. NAT'L SENIOR CITIZENS L. CTR., *supra* note 18, at 11-13.

43. Knauer, *supra* note 3, at 39.

44. Knauer, *supra* note 31, at 298 (citing Judith C. Barker, LESBIAN AGING: AN AGENDA FOR SOCIAL RESEARCH, in GAY AND LESBIAN AGING 53-54 (2004)).

45. *See* Knauer, *supra* note 3, at 39.

46. *Id.* at 38.

47. *Id.* at 38-39.

48. *See* NAT'L SENIOR CITIZENS L. CTR., *supra* note 18, at 7.

49. *See* Knauer, *supra* note 3, at 38-41; Hovey, *supra* note 20, at 122.

different cultures.<sup>50</sup> Of those institutions that are willing to respond to questions about their treatment of LGBT residents, few have protections or programs in place that train their staff on the needs and rights of LGBT residents.<sup>51</sup>

In one instance where cultural competency training could have prevented harm, a long-term care resident (who was gay) hung himself after his facility placed him in a dementia ward because of complaints from other residents and their families.<sup>52</sup> Unfortunately, LGBT patients are frequently moved due to complaints from other residents and staff.<sup>53</sup> While long-term care providers struggle with the competing interests of protecting LGBT residents, and the morality of being forced to move patients because of bias, the outcome of these moves is a “faster pathway to depression, failure to thrive and even premature death.”<sup>54</sup>

The fear of biased care and a lack of confidence in long-term care professionals among LGBT elders further emphasize this need for cultural competency.<sup>55</sup> Cultural competency programs would train staff to monitor their own biases that may impact the quality of care, and reduce the likelihood of creating a “hostile or confusing environment.”<sup>56</sup> This training would prevent subtler,<sup>57</sup> inadvertent discrimination, and put biased staff on notice that discriminatory and substandard care is unacceptable.

Cultural competency training would additionally help caregivers to

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50. INST. OF MED., *supra* note 40, at 65.

51. Hovey, *supra* note 20, at 109; SERV. & ADVOCACY FOR GAY, LESBIAN, BISEXUAL & TRANSGENDER ELDERS, *The Issues: Aging Programs and Services*, <http://www.sageusa.org/issues/aging.cfm> (last visited Feb. 25, 2013).

52. Jane Gross, *Aging and Gay, and Facing Prejudice in Twilight*, N.Y. TIMES, Oct. 9, 2007, available at <http://www.nytimes.com/2007/10/09/us/09aged.html?pagewanted=all>.

53. *Id.*

54. *Id.* (quoting Dr. Melinda Lantz, chief of geriatric psychiatry at Beth Israel Medical Center in New York).

55. Knauer, *supra* note 3, at 38.

56. MO. FOUND. FOR HEALTH, *supra* note 13, at 13.

57. Ritter, *supra* note 1, at 1015.

understand that LGBT elders need to continue relationships with loved-ones in the long-term care environment.<sup>58</sup> Efforts to combat similar issues in the health care setting have caused advocacy groups, medical associations and the federal government to push for greater cultural competency among health care professionals.<sup>59</sup> While competency training may help prevent subtler forms of bias, it does not hold caregivers accountable for overt acts of discrimination on the basis of LGBT status and raises further concerns with HCBS.

*B. Private Right of Action under the Nursing Home Reform Act*

In theory, there are protections in the Nursing Home Reform Act (NHRA) of 1987 that shield LGBT residents in Medicaid-sponsored long-term care like HCBS from discrimination.<sup>60</sup> In relevant part, the NHRA states that a long-term care provider that takes Medicaid funds is required to “care for its residents in such a manner and in such an environment as will promote maintenance or enhancement of the quality of life of each resident,”<sup>61</sup> and “to provide services and activities to attain or maintain the highest practicable physical, mental, and psychosocial well-being of each resident in accordance with a written plan of care.”<sup>62</sup> Courts have differed in their treatment of these two provisions of the NHRA—whether they create a private right to sue long term-care providers who fail to provide an appropriate level of care.<sup>63</sup>

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58. Evelyn M. Tenenbaum, *Sexual Expression and Intimacy Between Nursing Home Residents with Dementia: Balancing the Current Interests and Prior Values of Heterosexual and LGBT Residents*, 21 TEMP. POL. & CIV. RTS. L. REV. 459, 466 (2012).

59. See INST. OF MED., *supra* note 40, at 65-66.

60. See Natalie Chin et al., *Asserting Choice: Health Care, Housing and Property—Planning for Lesbian, Gay, Bisexual, and Transgender Older Adults*, CLEARINGHOUSE REV. J. OF POVERTY L. AND POL. 526-28 (2010).

61. 42 U.S.C. § 1396r(b)(1)(A) (2011).

62. 42 U.S.C. § 1396r(b)(2) (2011).

63. *Grammer v. John J. Kane Regional Health Centers-Glen Hazel*, 570 F.3d 520, 532

Under Section 1983 of the Civil Rights Act of 1871, a citizen can sue for the violation of “a right secured by the constitution or laws of the United States.”<sup>64</sup> The “quality of life” provision in the NHRA, a federal law, may afford residents greater rights to control aspects of their lives and choose to room with a person of their choice if both parties consent.<sup>65</sup> Additionally, the creation of a private right demanding providers insure resident quality of life gives added protections in the event that there is discriminatory or substandard care on the basis of LGBT status.

The private right to sue under the NHRA could create additional protections that go beyond what is available under tort and contract law, as well as counter the inadequacy of the public-enforcement mechanism.<sup>66</sup> Discretionary leeway under the present system creates little incentive to combat abuse and remedy quality problems.<sup>67</sup>

The private cause of action would remedy these inadequacies. It makes little sense to deny the private right on the basis of a broken public adjudication mechanism and there are positive examples where private suits against long-term care providers have proven successful in effecting change.<sup>68</sup> Without greater clarity on resident rights, there are significant dangers posed to LGBT elders in the HCBS setting that raise red flags.

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(3d Cir. 2009) (establishing that Congress did intend to create a private right of action in the NHRA under § 1983 of the Civil Rights Act of 1871 and in agreement with the standards for rights-creating language laid out by the Supreme Court in *Gonzaga Univ. v. Doe*, 536 U.S. 273 (2001)); *Hawkins v. Cnty. of Bent, Colo.*, 800 F.Supp.2d 1162, 1166 (D. Colo. 2011) (finding no private right under NHRA); *Pantalone ex rel. Pantalone v. Cnty. Of Fulton*, 2011 WL 1457935, at \*8 (N.D.N.Y. Apr. 15, 2011) (finding a private right under NHRA).

64. Ritter, *supra* note 1, at 1012.

65. Chin et al., *supra* note 60, at 527.

66. Ritter, *supra* note 1, at 1013.

67. Ritter, *supra* note 1, at 1015.

68. See Knauer, *supra* note 3, at 310-11 (recounting the story of Clay and Harold, whose settlement with Sonoma County over their mistreatment cause Sonoma County to change their conservatorship procedures to prevent future incidences).

### *C. Oversight and Reporting*

Oversight is also a significant difference between the HCBS and institutional settings. As emotional abuse is often the byproduct of “underpaid, overworked staff, or [a] family member with little training and few resources forced to endure poor working conditions,”<sup>69</sup> the threat of improper or inadequate training and the concomitant stress could create significant dangers for LGBT elders in a community care environment, where there are fewer workers and little oversight. The more training and oversight there is, the greater the expense, and the greater pressure there is on the bottom line for community-based care. While a significant incentive for community-based care is the cost-saving potential it holds,<sup>70</sup> lack of oversight and training standards are certainly concerns that caution against rapid expansion of HCBS.

For a decade, audits of HCBS expansion have found that there is inadequate oversight over the waiver system and the programs that are put in place.<sup>71</sup> In a 2012 study, the Department of Health and Human Services (HHS) found that “seven of the twenty-five states we reviewed did not have adequate systems to ensure the quality of care provided to beneficiaries.”<sup>72</sup> Three of the states that HHS notified of deficiencies failed to correct them in a timely manner.<sup>73</sup> Even with the most recent reforms in long-term care, and movements for greater accountability, serious complaints get delayed or

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69. Hovey, *supra* note 20, at 98.

70. See Harrington et al., *supra* note 5.

71. U.S. GOV'T ACCOUNTABILITY OFFICE, FEDERAL OVERSIGHT OF GROWING MEDICAID HOME AND COMMUNITY-BASED WAIVERS SHOULD BE STRENGTHENED, 1 (2003); U.S. GOV'T ACCOUNTABILITY OFFICE, DESPITE INCREASED OVERSIGHT, CHALLENGES REMAIN IN ENSURING HIGH-QUALITY CARE AND RESIDENT SAFETY 2 (2005); U.S. DEPT. HEALTH HUM. SERV., OFF. INSPECTOR GEN., OVERSIGHT OF QUALITY OF CARE IN MEDICAID HOME AND COMMUNITY BASED SERVICES WAIVER PROGRAMS 1 (2012).

72. U.S. DEPT. HEALTH HUM. SERV., *supra* note 71.

73. *Id.*

inadequate responses.<sup>74</sup> As there are still significant quality-control and reporting issues, the expansion of HCBS and these significant unknowns could have a disastrous impact upon the well-being of LGBT elders.

## VI. CONCLUSION

While there may be cost savings and psychological and health benefits to LGBT elders who are able to get HCBS catered specifically to the LGBT community, these services are limited and do not mitigate the dangers posed to LGBT elders under the majority of HCBS programs. These dangers primarily lie in a system that lacks substantive oversight or remedial power over abuse and may not afford rights to sue.

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74. U.S. GOV'T ACCOUNTABILITY OFFICE, *supra* note 71.

Litigation as a Tool for Forcing Accountability in  
State-Based Long Term Care Settings For the  
Intellectually and Developmentally Disabled: An  
Illinois Focus

*Robert Garner\**

For much of United States history, institutions were the primary method of treating and housing individuals with Intellectual and Developmental Disorders (I/DD).<sup>1</sup> In the 1999 watershed Supreme Court case *Olmstead v. L.C.*, the Court held that mental illness is a form of disability and that unjustified institutional isolation is a form of discrimination under the Americans with Disabilities Act.<sup>2</sup> Since then, individuals with I/DD have increasingly turned to litigation to enforce their rights under *Olmstead*.<sup>3</sup> States have increased efforts to deinstitutionalize, which is a movement that seeks to relocate people out of large state-funded institutions and into smaller, community-based settings.<sup>4</sup> However, Illinois lags behind other states in its own efforts to deinstitutionalize those with I/DD and provide increased community-based care options.<sup>5</sup> Thus, additional legal aid agencies, resources, and guidance should be provided to I/DD individuals to both enforce their rights and to incentivize increased accountability within

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1. See David Braddock & Richard Hemp, *Services and Funding for People with Developmental Disabilities in Illinois: A Multistate Comparative Analysis*, IL. COUNCIL ON DEVELOPMENTAL DISABILITIES 2 (2008), available at [http://www.state.il.us/agency/icdd/communicating/pdf/serv\\_fundingforpwddinil\\_2008.pdf](http://www.state.il.us/agency/icdd/communicating/pdf/serv_fundingforpwddinil_2008.pdf).

2. *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 597 (1999).

3. See generally Samuel R., *The Past and Future of Deinstitutionalization Litigation*, 34 CARDOZO L. REV. 1, 5-8 (2012).

4. *Id.* at 4.

5. See BRADDOCK & HEMP, *supra* note 1, at 4.

the Illinois government to adequately fund community-based resources.

Section I of this article seeks to provide a brief historical overview as to how the deinstitutionalization movement became so pervasive. Section II offers insight into how institutions and community care settings differ. Section III elaborates on the progress that Illinois has made in clarifying its policy surrounding deinstitutionalization, while still remaining comparatively reliant on institutions for the care of its I/DD individuals. Section IV discusses the *Olmstead* case and its deinstitutionalization mandate. Section V focuses on the use of litigation as a tool to both enforce the *Olmstead* mandate and provide Illinois with further incentive to shift funding to community settings. Section VI offers recommendations on how best to support this form of litigation as a means to force accountability. Section VII concludes this article.

#### I. HISTORICAL BACKDROP

State funded institutions have traditionally been the primary provider of care for I/DD individuals.<sup>6</sup> These institutions served to replace the almshouses and jails that offered poor treatment and living conditions for these individuals.<sup>7</sup> The increased development of institutions to treat and house I/DD individuals continued throughout the 20<sup>th</sup> century, with substantial acceleration after the Second World War.<sup>8</sup> In the early 1950s, the conditions at large institutions, and stories of abuse related to anti-psychotic medications, caught the eye of the press and media, and major exposés followed.<sup>9</sup> The media was a powerful force in both shaping public

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6. BRADDOCK & HEMP, *supra* note 1, at 2.

7. BRADDOCK & HEMP, *supra* note 1, at 2.

8. BRADDOCK & HEMP, *supra* note 1, at 2, 3.

9. See BRADDOCK & HEMP, *supra* note 1, at 3; see also E. FULLER TORRY, *OUT OF THE SHADOWS: CONFRONTING AMERICA'S MENTAL ILLNESS CRISIS* (John Wiley & Sons, 1997), available at <http://www.pbs.org/wgbh/pages/frontline/shows/asylums/special/excerpt.html>.

opinion and highlighting the negative qualities of institutional life of I/DD individuals.<sup>10</sup> It was within this particular setting that individuals with I/DD, and their supporters, began to use litigation as a tool to force systemic change. The nation's first class action litigation that addressed the abysmal conditions in institutions was the 1972 case *Wyatt v. Stickney*.<sup>11</sup> This case culminated in a decision that forced the state of Alabama to improve standards of institutional operation.<sup>12</sup> Soon after, further litigation began to require that states not only improve conditions within existing institutions, but also move their residents to more community-based settings.<sup>13</sup>

## II. FUNDAMENTAL DIFFERENCES BETWEEN INSTITUTIONAL AND COMMUNITY-BASED CARE

A recent article titled "People with Disabilities Face Challenges in Finding a home in Illinois" succinctly describes the fundamental differences between institutional and community based settings:

Community-based and institutional housing are fundamentally opposite living environments. Where institutions are more of a hospital setting in which residents are generally segregated from those without disabilities, community-based living is a community-integrated setting that strives for disabled individuals to have non-disabled neighbors.<sup>14</sup>

Institutions, generally described as state mental hospitals, nursing homes, and other large, long-term care facilities, by their very nature, serve to

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10. NAT'L COUNCIL ON DISABILITY, DEINSTITUTIONALIZATION TOOLKIT: STRATEGY-IN DETAIL (2012), available at <http://www.ncd.gov/publications/2012/DIToolkit/Strategy/inDetail/>.

11. BRADDOCK & HEMP, *supra* Note 1, at 3; see generally *Wyatt v. Stickney*, 325 F. Supp. 781(M.D. Ala. 1971).

12. *Id.*

13. *Horacek v. Exon*, 357 F. Supp. 71 (D. Neb. 1973); *Halderman v. Pennhurst State Sch. & Hosp.*, 612 F.2d 84 (3d Cir. 1979).

14. Marisol Rodriguez, *People with Disabilities Face Challenges in Finding a Home in Illinois*, MEDILL REPORTS: CHICAGO (2008), available at <http://news.medill.northwestern.edu/chicago/govt/story.aspx?id=156744>

segregate and deprive their inhabitants from participation in societal life.<sup>15</sup> This fact alone renders community-based care a superior solution to institutionalization for people with I/DD. While institutional settings may be appropriate for extreme cases, many states have closed institutions and reallocated funding to more individualized residential alternatives in community and family settings. Alongside the increasing consensus that community care is a better solution than institutionalization, the number of individuals with I/DD living in six-person or fewer community-based group homes and supervised apartments in the US increased from 4,000 to 376,567 persons between 1960 and 2006.<sup>16</sup>

### III. ILLINOIS HAS APPROPRIATE GOALS FOR INCREASING COMMUNITY-BASED CARE, YET REMAINS COMPARATIVELY RELIANT ON INSTITUTIONS

In the context of this continued national movement toward deinstitutionalization, Illinois has been ranked last among the states in the number of I/DD individuals living in community housing settings of six persons or fewer.<sup>17</sup> Similarly, in 2006, Illinois's use of institutions as the primary care setting exceeded all comparative states and the United States as a whole.<sup>18</sup> In 2008, in partial response to the aforementioned statistics, the Illinois Council on Developmental Disabilities (ICDD), a state agency geared toward addressing the needs of people with I/DD, authored the *Blueprint for System Redesign*.<sup>19</sup> The blueprint offers an extensive analysis of system redesign for Illinois, as well as specific guidelines for progress.

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15. See generally Kevin M. Cremin, *Challenges to institutionalization: The Definition of "Institution" and the Future of Olmstead Litigation*, 17 TEX. J. ON C.L. & C.R. 143, 151-73 (2012) (providing an in-depth discussion of the definition of "institution").

16. BRADDOCK & HEMP, *supra* note 1, at 10.

17. *Id.* at 11.

18. *Id.* at 4.

19. See generally Gary Smith et al., *Blueprint for System Redesign in Illinois*, HUMAN SERVS. RES. INST. (2008), available at [http://www.lifemyway.org/img/c/f188282/Illinois\\_Blueprint\\_-\\_1-29-2008.pdf](http://www.lifemyway.org/img/c/f188282/Illinois_Blueprint_-_1-29-2008.pdf).

While recent reports such as the *Blueprint* are important, they are merely studies of what should be done.<sup>20</sup> The ICDD developed a “Five Year State Plan” in November 2011, which stated as its first goal that “the Illinois service systems [be] rebalanced so that people with developmental disabilities have the supports they need to lead full lives in their communities.”<sup>21</sup>

Further, the Illinois Fiscal Year 2013 Budget highlights the rebalancing of institutional and community care as a primary goal.<sup>22</sup> Finally, Illinois plans to close four “Human Services Facilities” in 2013, as Governor Quinn commits to increasing community care options.<sup>23</sup> Nonetheless, it is important to note that these are goals for future outcomes; they do not represent past statistics of verified improvement in lowering the utilization of institutions in Illinois for I/DD care. Notwithstanding the adoption of the Five Year Plan, and proper policies on deinstitutionalization, Illinois concedes that a disproportionate and unacceptable number of Illinois citizens with I/DD are still being served in institutions.<sup>24</sup>

#### IV. *OLMSTEAD* AND DEINSTITUTIONALIZATION

##### *OLMSTEAD* AND DEINSTITUTIONALIZATION

Deinstitutionalization has been described as both a social and political movement, manifesting itself as different forms of both law and public

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20. See RODRIGUEZ, *supra* note 13, at 2, 3.

21. STATE OF IL. COUNCIL ON DEVELOPMENTAL DISABILITIES, STATE PLAN MISSION STATEMENT (November 2011), available at <http://www.state.il.us/agency/icdd/faq/missionandplan.htm>; see also Michelle R.B. Saddler, *Rebalancing Initiative for State-Operated Developmental Centers*, DEP'T OF HUMAN SERVS., <http://www.dhs.state.il.us/page.aspx?item=59130>.

22. ILLINOIS STATE BUDGET FISCAL YEAR 2013: MOVING FORWARD: STABILIZING OUR BUDGET, BUILDING & GROWING OUR ECONOMY, available at <http://www.state.il.us/budget/>

23. *Id.*

24. See SMITH ET AL., *supra* note 19 at 15; but see *id.* at 16 (projecting that Illinois's institutionalization rate will be inline with the nation by 2014, provided that the recommendations contained in the Report are all adopted).

policy, which seeks to relocate people out of large state-funded institutions and into smaller, community-based settings.<sup>25</sup> *Olmstead* represented a major victory for proponents of continued deinstitutionalization.<sup>26</sup> In *Olmstead*, the Court held that mental illness is a form of disability and that unjustified institutional isolation is a form of discrimination under the Americans with Disabilities Act.<sup>27</sup>

*Olmstead* spurred a wave of litigation that challenged the institutionalization of people with psychiatric, developmental, and other disabilities.<sup>28</sup> This litigation generally sought to allow I/DD individuals to receive care in the least restrictive facilities necessary to accommodate their needs.<sup>29</sup> Previously, advocates who wished to challenge institutionalization through litigation did so on the grounds of individuals' right to due process. *Olmstead*, however, allowed challengers to proceed on the more promising statutory theories of anti-discrimination.<sup>30</sup> These legal theories represented an important shift as they focused on the methodologies through which states allocated their resources, and provided legal incentives for states to fund more community-based programs, rather than focusing on the issue of due process.<sup>31</sup> Fundamentally, the anti-discrimination argument has "more bite" than the due process argument, given that the ADA provides a statutory basis for relief as opposed to the arguments surrounding the right to due process.

Specifically, *Olmstead* held that under Title II of the ADA, States are required to provide community-based treatment for persons with mental

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25. See generally BAGENSTOS, *supra* note 3.

26. See generally *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 597 (1999).

27. *Id.* at 597.

28. See BAGENSTOS, *supra* note 1, at 5.

29. In Illinois, even in involuntary admission situations, the law now requires that the least restrictive alternative for treatment be utilized. See 405 ILL. COMP. STAT. ANN. 5/3-811.

30. See BAGENSTOS, *supra* note 1, at 5-8.

31. *Id.* at 6.

disabilities when (1) the State's treatment professionals determine that such placement is appropriate, (2) the affected persons do not oppose such treatment, and (3) the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with I/DD.<sup>32</sup> The third prong is noteworthy in that it forms the basis of most States' defense in litigation, in that reasonable accommodation is subject to available State resources.<sup>33</sup> However, the Court also qualified its holding in saying, "nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings . . . Nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it."<sup>34</sup> Irrespective of its qualified language, the Court held that unjustified isolation is properly regarded as discrimination based on disability.<sup>35</sup>

Litigation has been heralded as the most powerful tool available to achieve the goal of building a "robust community-based treatment system."<sup>36</sup> The Obama Administration has been a large proponent of further deinstitutionalization, and under this Administration's guidance the Justice Department has filed, joined, or led various "*Olmstead* suits" in over twenty-one states and obtained some significant and far-reaching settlements.<sup>37</sup>

#### V. LITIGATION AS A TOOL IN ILLINOIS

Many who are in favor of continued deinstitutionalization, and are either

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32. *Olmstead*, 527 U.S. 581 at 597.

33. Megan Chambers, *Integration as Discrimination against People with Disabilities? Olmstead's Test Shouldn't Work Both Ways*, 46 CAL. W. L. REV. 177, 181 (2009).

34. *Olmstead*, 527 U.S. 581 at 602.

35. *Id.* at 597.

36. *Id.*

37. BAGENSTOS, *supra* note 3, at 5; *see also* DEPARTMENT OF JUSTICE: DOJ OLNSTEAD LITIGATION (2011), *available at* [http://www.ada.gov/olmstead/olmstead\\_enforcement.htm](http://www.ada.gov/olmstead/olmstead_enforcement.htm).

disenfranchised or upset with a system in Illinois that has failed them, have turned to litigation as a means of holding the state accountable for its lack of community-based living.<sup>38</sup> Generally, these cases take the form of class action suits aimed to defend the constitutional rights of people with I/DD, as clarified by *Olmstead*.<sup>39</sup>

A prime example of how litigation has been properly utilized to force state accountability under *Olmstead* is in *Colbert v. Blagojevich*.<sup>40</sup> In *Colbert*, plaintiffs with general disabilities alleged that Illinois has denied them the “opportunity to live in appropriate integrated settings where they could lead more productive lives in their own communities.”<sup>41</sup> Here, using the *Olmstead* framework, the disabled Illinois institutional residents filed a federal class-action lawsuit (which was certified) that alleged that the state’s failure to provide community-based care was essentially discriminatory on the basis of their disability, and caused them “unjustified isolation.”<sup>42</sup> The *Colbert* complaint further alleged that Illinois unlawfully channeled the state’s Medicaid Program benefits to segregated and institutional settings like nursing homes, essentially cutting off the residents from the ability to participate in the broader community, in violation of the ADA.<sup>43</sup>

The plaintiffs negotiated a Consent Decree, which was entered on December 20, 2011, and gave Medicaid-eligible nursing home residents in Cook County a choice about their living arrangements, thus affording them

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38. See E.G. ENBAR ET AL., A NATIONWIDE STUDY OF DEINSTITUTIONALIZATION & COMMUNITY INTEGRATION 3 (2004); see also BRADDOCK & HEMP, *supra* note 1, at 3.

39. See N.B. *ex rel.* Buchanan v. Hamos, No. 11 C 6866, 2012 WL 1953146 at \*9 (N.D. Ill. May 30, 2012).

40. Later amended to *Colbert v. Quinn*, to reflect the change in Illinois Governorship.

41. *Colbert v. Blagojevich*, No. 07 C 4737, 2008 WL 4442597 at \*1 (N.D. Ill., Sept. 29, 2008).

42. Bulletin, *Illinois Sued over Lack of Community-Based Choices for Nursing Care*, 15 No. 5 ANDREWS HEALTH L. LITIG. REP. 9 (2007).

43. First Amended Complaint, *Colbert v. Blagojevich*, No. 07 C 4737, 2008 WL 4442597 at \*2.

the opportunity to live in their own homes and participate in the community.<sup>44</sup> The Decree further served to promote the development of integrated settings that attempt to maximize individuals' independence, choice, and opportunities.<sup>45</sup> Further, the defendants and plaintiffs filed an Implementation Plan, as required by the Decree, on November 8, 2012, which precisely outlined the "strategies and mechanisms" to implement the Decree.<sup>46</sup> This litigation proved an effective means of advancing the efforts of balancing the long-term care system in Illinois, and while the certified class of this specific suit concerned disabled nursing home individuals, the efficacy of such actions would certainly apply to I/DD individuals as well. *Colbert* was the third in a trio of class actions brought against Illinois on behalf of people with various disabilities, not just I/DD, that have all reached similar court approved settlement agreements.<sup>47</sup>

While the main focus of this article is to expound upon the utility of litigation as a methodology to *remove* I/DD individuals from institutional settings, it is important to note the converse: that litigation can be used with similar efficacy to *remain* in institutions, should a patient desire to do so. In *Ligas ex rel. Foster v. Maram*, a suit was brought on behalf of a number of I/DD people who wished to hasten Illinois "down the road to community-based care."<sup>48</sup> Plaintiffs sought to certify a class and to require the state to provide community care for those class members. Concerned that they were

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44. Consent Decree, *Colbert v. Blagojevich*, No. 07 C 4737, 2008 WL 4442597 at \*2, available at <http://www2.illinois.gov/hfs/PublicInvolvement/Colbert%20v%20Quinn/Pages/default.aspx>

45. *Id.*

46. See generally Implementation Plan, *Colbert v. Quinn*, No. 07 C 4737, 2011 WL 389253, available at <http://www2.illinois.gov/hfs/SiteCollectionDocuments/Filed%20Implementation%20Plan%2011%2008%202012.pdf>

47. *Colbert v. Quinn: Landmark Consent Decree Expands Opportunities for Nursing Home Residents with Disabilities*, <http://accessliving.org/index.php?tray=content&tid=106top1&cid=118ga58u> (last visited April 25, 2013).

48. *Ligas v. Maram*, 478 F.3d 771, 773 (7th Cir. 2007).

about to become part of a class that would be forced to live in community-based care, other individuals intervened in the suit to force a distinction and clarification that they would have a right to remain institutionalized.<sup>49</sup> The District Court, held, and the Court of Appeals later confirmed, that the choice of living situation could certainly be retained if the individuals wished to remain institutionalized.<sup>50</sup> *Ligas*, which was finalized in a groundbreaking Consent Decree on June 15, 2011, gave the individuals certified within the class the choice to move into small community-based settings, while not necessitating removal for those who opposed being part of the class.<sup>51</sup> Barry Taylor, Legal Advocacy Director at Equip for Equality, who served as lead counsel for the plaintiffs, noted that “under this Consent Decree, the State of Illinois will move closer to fulfilling the promise of the ADA to integrate people with disabilities into our society.”<sup>52</sup> *Ligas* effectively demonstrates that litigation can be utilized for both purposes; the Decree was successful in allowing the class of people wishing to leave institutions to do so, and it also clarified for the individuals who wish to remain in these settings that they can do so.<sup>53</sup>

## VI. RECOMMENDATIONS

The legal consensus has repeatedly been that people have a fundamental right to live in the least restrictive environment that meets their particular needs.<sup>54</sup> Deinstitutionalization, or the downsizing of state-operated facilities in favor of increased community integrated living, best fits this legal

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49. *Id.*

50. *Id.* at 774.

51. NATIONAL COUNCIL ON DISABILITY, *supra* note 9.

52. Press Release, Equip for Equality, Court Approves Landmark Agreement Expanding Community Living Opportunities for People with Developmental Disabilities, available at [http://www.equipforequality.org/news/pressreleases/june\\_15\\_2011\\_ligas.php](http://www.equipforequality.org/news/pressreleases/june_15_2011_ligas.php)

53. *See Ligas*, 478 F.3d at 774.

54. *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 597 (1999).

consensus. With the frustrations of bureaucracy, the disenfranchised are turning to litigation as a means of relief. Given that the Supreme Court has held that I/DD individuals have a right to live in the least restrictive settings necessary, it is essential that Illinois take further steps to reduce reliance on the remaining institutional facilities. While Illinois has made significant progress in defining what actions are necessary and formulating goals and plans, more can be done to speed up the implementation process. In doing so, legal aid organizations should continue to use litigation to hold Illinois accountable in reallocating Medicaid resources currently used in large care facilities to the Home and Community Based Services (HCBS) Waiver Program.<sup>55</sup> For example, private operators of nursing homes and adult care homes and institutional lobbies are extremely powerful within many state legislators and will likely continue to hinder any efforts to move Medicaid dollars towards the HCBS.<sup>56</sup> As there are powerful interests that will fight to retain as much government funding as possible within the institutional settings, it is all the more necessary to advocate for class action litigation to force the necessary systemic change.<sup>57</sup>

## VII. CONCLUSION

While Illinois has made some progress in its efforts to deinstitutionalize and provide increased community-based care options, systemic change has been slow, in part due to strong institutional lobbies and foreseeable bureaucratic tangles. To ensure that individuals with I/DD are provided with their right to the least restrictive care settings possible, legal aid agencies, and other private resources must not shy away from utilizing the

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55. See BRADDOCK & HEMP, *supra* note 1, at 41.

56. See BAGENSTOS, *supra* note 3, at 49-50.

57. See BAGENSTOS, *supra* note 3, at 50.

most powerful tool to affect change - litigation.<sup>58</sup> Further, doing so will also force proactive accountability within the Illinois government to fund adequate community-based resources.

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58. ENBAR et al., *supra* note 38, at 3 (stating that “several key advocacy groups are now considering litigation as the only viable remedy to promote community integration for people with developmental disabilities”); *see also* BAGENSTOS, *supra* note 3 at 6 (noting that “[advocates] of deinstitutionalization are employing the most powerful tool they have ever possessed to achieve their goal”).

Deinstitutionalization: How the State Budget Has  
Overshadowed Public Policy in Caring for  
Illinois' Mentally Ill

*Lisa Dannewitz\**

I. INTRODUCTION

The phrase “mentally ill” carries a stigma that negatively influences the treatment and care of a vulnerable group. In the early 1900’s, the public sought to hide this faction away in large, state-run institutions<sup>1</sup> out of fear they were dangerous or incapable of engaging with society at large.<sup>2</sup> Moreover, states established institutions in the least desirable areas where housing was inexpensive, yet unsafe.<sup>3</sup> For years, civil rights groups protested the state action with little result.<sup>4</sup> By the middle of the twentieth century, sociologists conducted studies of such state-run institutions.<sup>5</sup> The results overwhelmingly demonstrated that conditions in the facilities were deplorable<sup>6</sup> and the asylum structure actually perpetuated several of the patients’ conditions.<sup>7</sup>

The term “deinstitutionalization” describes the policy decisions to close

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1. Arlene S. Kanter, *A Home of One's Own: The Fair Housing Amendments Act of 1988 and Housing Discrimination Against People with Disabilities*, 43 AM. U. L. REV. 925, 929 (1994).

2. Meghan K. Moore, *Piecing the Puzzle Together: Post-Olmstead Community-Based Alternatives for Homeless People with Severe Mental Illness*, 16 GEO. J. ON POVERTY L. & POL'Y 249, 251 (2009).

3. Kanter, *supra* note 1.

4. Norman Dain, *Critics and Dissenters: Reflections on "Anti-Psychiatry" in the United States*, 25 J. HIST. BEHAV. SCI. 3, 9 (1989).

5. Nancy K. Rhoden, *The Limits of Liberty: Deinstitutionalization, Homelessness, and Libertarian Theory*, 31 EMORY L.J. 375, 380 (1982).

6. *Id.*

7. *Id.*

state-funded institutions and move mentally ill patients into community-based care facilities.<sup>8</sup> Early advocates of deinstitutionalization focused on the humanitarian concerns of living conditions and embraced an overly optimistic view that patients could seamlessly integrate into the community.<sup>9</sup> The movement gained traction in 1955 with widespread introduction of the first anti-psychotic medication, allowing policymakers to explain the release of patients into the community.<sup>10</sup> Ten years later, the enactment of federal Medicaid and Medicare statutes stimulated deinstitutionalization again.<sup>11</sup> Medicaid did not fund treatment for mental illness in state institutions but reimbursed up to seventy-five percent of the costs if the patient instead received care at a private facility.<sup>12</sup> State politicians endorsed the movement when they realized the opportunity to cut state spending while appeasing the public's desire for more humane treatment of the mentally ill.<sup>13</sup>

This article examines how Illinois has embraced deinstitutionalization and what effects, if any, the deinstitutionalization movement has had on the mentally ill. Section II considers the successes and failures of the deinstitutionalization movement in the twentieth century. Section III discusses how litigation has shaped mental health policy in the last fifteen years. Section IV briefly outlines the current state of mental healthcare in Illinois, including cost concerns of the current system. Finally, Section V discusses why Illinois' shift to a community-based care model will fail due to its shortsighted outlook, budget constraints and judicial pressure.

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8. Moore, *supra* note 2.

9. Rhoden, *supra* note 5, at 377.

10. *Id.* at 379.

11. E. FULLER TORREY, *OUT OF THE SHADOWS: CONFRONTING AMERICA'S MENTAL ILLNESS CRISIS*, (New York: John Wiley & Sons, 1997).

12. Rhoden, *supra* note 5, at 384.

13. Dain, *supra* note 4, at 7.

## II. THE FAILURE OF DEINSTITUTIONALIZATION

To successfully deinstitutionalize its mentally ill, Illinois must not only reduce the number of mentally ill patients in psychiatric hospitals, but also increase the number of smaller, less isolated community-based alternatives.<sup>14</sup> In the twentieth century, the deinstitutionalization movement unevenly placed its focus on reducing the number of institutionalized patients. Across the country, state-run hospitals moved out as many as ninety-two percent of their mentally ill patients.<sup>15</sup> At the peak of institutionalization in 1955, nearly 559,000 people lived in state mental hospitals out of a total population of 165 million.<sup>16</sup> About forty years later, hospitals had reduced that number to 57,151 patients for a population of about 275 million.<sup>17</sup> Thus, institution rates decreased from 339 per 100,000 capita to twenty-one per 100,000 capita, with some states showing even more drastic reductions.<sup>18</sup> In Illinois, the effective deinstitutionalization rate was ninety-four percent.<sup>19</sup>

For good reason, the exodus of the mentally ill has been called a psychiatric “Titanic.”<sup>20</sup> The movement created a mental illness crisis by causing the discharge of patients from public hospitals without providing medication and rehabilitation services in the community.<sup>21</sup> Lawmakers intended supportive services for those living in the community to include a wide range of help including assistance maintaining income, health care, personal hygiene, housekeeping; budgeting; developing job skills; and

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14. H. Richard Lamb & Leona L. Bachrach, *Some Perspectives on Deinstitutionalization*, 52 PSYC. SERVS. 8, 1039 (2001).

15. TORREY, *supra* note 11.

16. Lamb & Bachrach, *supra* note 14.

17. *Id.*

18. *Id.*

19. TORREY, *supra* note 11.

20. *Id.*

21. *Id.*

monitoring medication.<sup>22</sup> Additionally, lawmakers intended treatment providers to engage in ongoing communication.<sup>23</sup> However, due to insufficient preparation and support for this plan, many of the people who moved out of institutions ended up homeless, in ill-equipped nursing homes, or in jail.<sup>24</sup>

Deinstitutionalization transformed into trans-institutionalization, a large shift of people from one state-funded institution (public mental hospitals) to another (jails, nursing homes, etc.).<sup>25</sup> In the 1960 and 1970s, institutions for mental disease (IMDs) emerged in Illinois to house the most severely mentally ill patients.<sup>26</sup> The IMDs were privately run, for-profit nursing homes, often able to house up to 400 people.<sup>27</sup> Critics argued these facilities were nothing but downsized institutions operated under equally deplorable conditions.<sup>28</sup> State efforts to move patients to more integrated settings were piecemeal at best and far short of the large-scale systemic change needed.<sup>29</sup> Before deinstitutionalization could work, Illinois needed a harder push toward community-based facilities.<sup>30</sup>

### III. THE SUPREME COURT TAKES A STAND

Recently, mental health advocates have found support for community-

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22. John Fallon & Corinne Rearer, *The Corrections System Has Become The Nation's Largest Mental Health Provider*, HOMELESS HEADLINES 1 (Feb. 2011), [http://www.law.uchicago.edu/files/file/HOMELESS%20HEADLINES\\_20110303161841%20\(2\)\\_0.pdf](http://www.law.uchicago.edu/files/file/HOMELESS%20HEADLINES_20110303161841%20(2)_0.pdf).

23. *Id.*

24. *Id.*

25. *Id.*

26. Joe Linstroth & Caroline O'Donovan, *Home Sweet Home: Finding Housing For Mentally Ill Adults*, WBEZ 91.5 (May 4, 2012), <http://www.wbez.org/blogs/bez/2012-05/home-sweet-home-finding-housing-mentally-ill-adults-98815>.

27. Carla K. Johnson, *For-Profit Nursing Homes That Care For Mentally Ill Cost State \$122M*, ASSOCIATED PRESS (Feb. 7, 2010), <http://www.sj-r.com/breaking/x503201872/For-profit-mental-institutions-cost-Illinois-122M>.

28. *Id.*

29. Ira A. Burnim & Jennifer Mathis, *The Olmstead Decision at Ten: Directions to Future Advocacy*, 43 CLEARINGHOUSE REV. 386, 387 (2009).

30. *Id.*

based care in the courts.<sup>31</sup> Specifically, in *Olmstead v. L.C. ex rel. Zimring*, two mentally disabled women brought a discrimination suit against the state of Georgia challenging their confinement to a segregated facility under Title II of the Americans with Disabilities Act (ADA).<sup>32</sup> Both women were voluntarily admitted to the psychiatric ward of a public Atlanta hospital.<sup>33</sup> Although physicians eventually cleared them for community-based programs, they both remained institutionalized.<sup>34</sup> The women argued that the State must provide placement in community care.<sup>35</sup>

In affirming the lower court, the United States Supreme Court held that unjustified isolation and segregation of disabled individuals violated the ADA.<sup>36</sup> The Court concluded that states are required to place mentally ill patients, like the plaintiffs, in community care settings when a medical professional determines placement is appropriate, the patient does not oppose the transfer to a less restrictive setting, and the placement can be reasonably accommodated.<sup>37</sup>

Following *Olmstead*, mental health advocates emphasized that the ADA's integration mandate applied to all institutions including: nursing homes, board and care homes, and residential treatment centers.<sup>38</sup> Organizations such as the Bazelon Center for Mental Health Law stressed that public institutional living perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participation in community

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31. Robert Pear, *U.S. Seeks More Care for Disabled Outside Institutions*, N.Y. TIMES (Feb. 13, 2000).

32. *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 581 (1999).

33. *Id.*

34. *Id.*

35. *Id.*

36. *Id.* at 597.

37. *Id.* at 607.

38. BAZELON CENTER, *OLMSTEAD: IMPLEMENTING THE INTEGRATION MANDATE*, <http://www.bazelon.org/Where-We-Stand/Community-Integration/Olmstead-Implementing-the-Integration-Mandate.aspx>.

life.<sup>39</sup> The Bazelon Center explained how institutional life is not conducive to “inclusion in all facets of community life,”<sup>40</sup> and institutional residents suffer regimented lives without opportunities to learn independent living skills.<sup>41</sup> Comparatively, Bazelon argued that community-based living fosters independence by allowing mental health patients to make normal daily decisions about what to eat, when to get up, and how to spend their time.<sup>42</sup>

By 2005, Illinois had largely ignored mental health advocates and made few changes to its community care program.<sup>43</sup> Accordingly, in *Ligas v. Hamos*, a group of institutionalized patients who qualified for community placement filed a class action lawsuit against the Illinois Department of Human Services and the Illinois Department of Healthcare and Family Services.<sup>44</sup> The litigants challenged Illinois’ practice of requiring patients to reside in intermediate care facilities for people with development disabilities (“ICF-DDs”) as a condition precedent for long-term care benefits.<sup>45</sup> Specifically, the litigants in *Ligas v. Hamos* wanted to move out of private state-funded facilities and be placed in community-based services.<sup>46</sup> By 2011, two other disability rights lawsuits had been filed

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39. Statement of Robert Bernstein, President and Director of the Judge David L. Bazelon Center for Mental Health Law (June 22, 2010), <http://www.bazelon.org/LinkClick.aspx?fileticket=qgcUAsuUJsU%3d&tabid=323>.

40. Written Testimony for Olmstead Enforcement Update, BAZELON CENTER (Jul. 6, 2012) <http://www.bazelon.org/LinkClick.aspx?fileticket=E7kUaGesvoU%3d&tabid=533>.

41. *Id.*

42. *Id.*

43. Press Release, Equip for Equal., Ill. Residents Sue State for Violating Ams. with Disabilities Act, Failing to Provide Cmty. Servs. (July 28, 2005).

44. Consent Decree at 1, *Ligas v. Hamas* (N.D. Ill 2011) (No. 05 CC 4331); *see also*, ILL. DEPT. OF HUMAN SERVICES, CLASS MEMBER STATUS, <http://www.dhs.state.il.us/page.aspx?item=58677>.

45. Second Amended Complaint for Declaratory and Injunctive Relief at 1, *Ligas v. Hamas* (N.D. Ill 2009) (No. 05-4331).

46. *Id.*

against the state,<sup>47</sup> and the Chicago Tribune had published an investigation detailing reports of sexual assault, violence, and drug abuse in the state's worst facilities.<sup>48</sup> Governor Quinn worked with state officials to reach a settlement, offering supportive housing and treatment to roughly 5,000 mentally ill adults living in large nursing homes designated as Institutions for Mental Diseases ("IMD").<sup>49</sup> However, the state has made little progress since, falling far short of its first-year move out goal.<sup>50</sup>

#### IV. CURRENT STATE OF MENTAL HEALTH CARE IN ILLINOIS

Illinois' failure to transition from IMDs is draining the state budget and inadequately providing care for the mentally ill.<sup>51</sup> The effects of deinstitutionalization, such as a reduction in the number of state institutions, have a compounding effect in a state already suffering from a deficit of care facilities as new cases of mental illness arise each year.<sup>52</sup> Approximately one in four adults will suffer from a diagnosable mental disorder in a given year,<sup>53</sup> creating an unmet demand for care providers.<sup>54</sup> For example, Illinois closed seven mental hospitals between 1980 and 2010 requiring nursing homes to fill the gap in care.<sup>55</sup> While Illinois manages twenty-six much smaller IMDs,<sup>56</sup> mental health professionals agree IMDs are antiquated,<sup>57</sup>

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47. See *Williams v. Quinn*, 748 F. Supp. 2d 892 (N.D. Ill. 2010); *Colbert v. Blagojevich*, 2008 WL 4442597 (N.D. Ill. 2008).

48. Gary Marx & David Jackson, *Illinois Struggles to Move Mentally Ill Adults Out of Nursing Homes*, CHI. TRIBUNE (July 4, 2012).

49. *Id.*

50. *Id.*

51. Linstroth & O'Donovan, *supra* note 26.

52. TORREY, *supra* note 11.

53. NAT'L INST. MENTAL HEALTH, THE NUMBERS COUNT: MENTAL DISORDERS IN AMERICA (2013), <http://www.nimh.nih.gov/health/publications/the-numbers-count-mental-disorders-in-america/index.shtml#KesslerPrevalence>.

54. *Id.*

55. Johnson, *supra* note 27.

56. *Id.*

57. Linstroth & O'Donovan, *supra* note 26.

and Governor Quinn's settlement promised to provide alternative treatment.<sup>58</sup> Additionally, critics argue such institutions are expensive,<sup>59</sup> specifically pointing to the \$122 million Illinois spent in 2009 to operate these privately run, for-profit nursing homes.<sup>60</sup> The IMD homes only accommodate 5,000 mentally ill people while traditional nursing homes serve at least 13,000.<sup>61</sup> Additionally, Medicaid rules prevent Illinois from claiming federal matching dollars for the care of mentally ill people who live in IMDs.<sup>62</sup> Despite these disadvantages, Illinois continues to rely on IMDs more than any other state and pays twice what it would pay if the patients lived in alternative housing.<sup>63</sup> The IMDs' political action committee contributed \$147,970 from 2007-2009, potentially explaining their entrenchment in the state.<sup>64</sup>

Significant portions of the mentally ill not receiving care in an IMD or nursing home find themselves in jail.<sup>65</sup> Mental health treatment is more prevalent in prisons and jails than in hospitals or treatment centers.<sup>66</sup> Cook County Jail is one of the three largest inpatient psychiatric facilities in the country.<sup>67</sup> Specifically, there were over 1,700 people on daily psychotropic medication, which is approximately twenty percent of the jail population.<sup>68</sup> Moreover, eighty percent of incarcerated women have a chronic mental

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58. Marx & Jackson, *supra* note 48.

59. Linstroth & O'Donovan, *supra* note 26.

60. Johnson, *supra* note 27.

61. *Id.*

62. *Id.*

63. *Id.*

64. *Id.*

65. *All Things Considered: Nation's Jails Struggle With Mentally Ill Prisoners* (NPR radio broadcast Sept. 4, 2011), available at <http://www.npr.org/2011/09/04/140167676/nations-jails-struggle-with-mentally-ill-prisoners>.

66. *Id.*

67. *Id.*

68. David Ormsby, *Illinois Flirts With Its Own Sandy Hook*, HUFFINGTON POST, Dec. 28, 2012, available at [http://www.huffingtonpost.com/david-ormsby/illinois-mental-health-care\\_b\\_2375471.html](http://www.huffingtonpost.com/david-ormsby/illinois-mental-health-care_b_2375471.html).

illness.<sup>69</sup> A 2010 report by the National Sheriffs' Association and the Treatment Advocacy Center found that a seriously mentally ill person is three times more likely to be incarcerated than hospitalized.<sup>70</sup> Bob Bernstein, the Executive Director of the Bazelon Center, believes "[m]ost people [with mental illness] by far are incarcerated because of very minor crimes that are preventable."<sup>71</sup> However, once incarcerated, the mentally ill find it difficult to break out of the cycle,<sup>72</sup> and "[T]hey deteriorate. They can't follow the rules there and so they stay a long time, and they become difficult to release."<sup>73</sup> Few inmates with mental illness receive treatment while in prison because the expense is too high.<sup>74</sup> However, the cost of preventative care before incarceration falls far below prison costs.<sup>75</sup> For example, the Bazelon Center reported a more intensive mental health program in Michigan cost the state \$9,029 per person per year while the average Michigan inmate cost over \$34,000 per year.<sup>76</sup>

Despite the blatant need for community mental health programs across the state, between 2009 and 2012,<sup>77</sup> Illinois continued to cut funding by more than \$187 million, or 31.7% percent.<sup>78</sup> Even before such cuts, the State's per capita spending on mental health was only \$85 compared to the

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69. *Id.*

70. Editorial, *Limit Jail Stays, Add Beds For Mentally Ill*, CHI. SUN TIMES (last updated Sept. 24, 2012), <http://www.suntimes.com/opinions/4722298-474/editorial-limit-jail-stays-add-beds-for-mentally-ill.html>.

71. Alana Horowitz, *Mental Illness Soars in Prisons, Jails While Inmates Suffer*, HUFFINGTON POST, Feb. 4, 2013, available at [http://www.huffingtonpost.com/2013/02/04/mental-illness-prisons-jails-inmates\\_n\\_2610062.html](http://www.huffingtonpost.com/2013/02/04/mental-illness-prisons-jails-inmates_n_2610062.html).

72. *Id.*

73. *Id.*

74. *Id.*

75. *Id.*

76. *Id.*

77. Sara Burnett, *Advocates Warn of 'Broken' Illinois Mental Health System*, ASSOCIATED PRESS (last updated Jan. 28, 2013), available at <http://www.rstar.com/news/x1503808757/Advocates-warn-of-broken-Illinois-mental-health-system>.

78. Ormsby, *supra* note 68.

national average of \$123.<sup>79</sup> Mental health clinics in Lakeview<sup>80</sup>, the South Side, and McHenry County<sup>81</sup> closed in 2012 due to the uncertainty surrounding state funding.<sup>82</sup> Illinois estimated owing at least \$8 billion in unpaid bills to all categories of service providers.<sup>83</sup> Sharon Kayser, long-time executive director of the now-closed Counseling Center of Lakeview, explained the problem to the Associated Press:

“You say, ‘I’m not going to invest in my building this year. I’m not going to replace the systems that are outdated. I’m not going to hire new staff. We’re not going to give cost of living increases. . . You (would) do those things because you think maybe things will change. But it doesn’t change. . . . There is no waiting it out.’”<sup>84</sup>

Sandy Lewis, the Executive Director of McHenry County’s Mental Health Board, said closing mental health facilities costs the state more in the long run because more mentally ill people will end up in courts, jails, and emergency rooms,<sup>85</sup> and “Providing services has been difficult amid Illinois’ severe budget crisis.”<sup>86</sup> Representative David Leitch is co-sponsoring a bill seeking \$12 million of mental health funding that was left out of this year’s appropriation due to a budgeting error.<sup>87</sup> “Leitch describes the current system as ‘sad’ and ‘pathetic.’ What’s needed, he said,

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79. Burnett, *supra* note 77.

80. David Mercer, *Lawmakers Plan \$1.3B Trim to State Bills Backlog*, ASSOCIATED PRESS, June 10, 2012, available at, <http://www.deseretnews.com/article/765581759/Lawmakers-plan-13B-trim-to-state-bills-backlog.html>.

81. Robert McCoppin, *McHenry Center Latest Domino to Fall in Mental Health Services*, CHI. TRIBUNE, June 27, 2012, available at [http://articles.chicagotribune.com/2012-06-27/news/ct-met-mchenry-mental-health-cuts-20120627\\_1\\_family-service-mental-health-services-bipolar-affective-disorder](http://articles.chicagotribune.com/2012-06-27/news/ct-met-mchenry-mental-health-cuts-20120627_1_family-service-mental-health-services-bipolar-affective-disorder).

82. Ormsby, *supra* note 68.

83. McCoppin, *supra* note 81.

84. Mercer, *supra* note 80.

85. McCoppin, *supra* note 81.

86. Burnett, *supra* note 77.

87. *Id.*

isn't just more money but a total overhaul to a less bureaucratic system."<sup>88</sup>

#### V. CONCLUSION

Governor Quinn's approach to a mental health care solution will fail due to its shortsighted outlook, budget constraints, and judicial pressure. Illinois needs a cost effective solution capable of serving the entire mental health community, not just patients living in IMDs. If the State focuses its few resources on the 5,000 mentally ill addressed by Governor Quinn's settlement plan, more than 13,000 patients living in nursing homes and thousands more living in prisons will be left without help.<sup>89</sup>

Even with its reduced focus, the settlement plan has been ineffective and fallen far short of its first-year target of moving at least 256 people.<sup>90</sup> As of June 2012, only forty-five patients had actually moved into community care or signed a lease.<sup>91</sup> Many patients are unwilling to be assessed for community placement and nearly fifty percent were deemed ineligible once assessed.<sup>92</sup> One group home in Centralia, Illinois is struggling with the Governor to keep its doors open.<sup>93</sup> Despite a vote to keep the center open from the Committee on Government Forecasting and Accountability, Governor Quinn insists upon its closure.<sup>94</sup> Ninety-five percent of the guardians at the Murray Center oppose transfer to less restrictive community-based living because they fear it places their loved ones at risk for abuse and neglect.<sup>95</sup>

Illinois is far from a long-term solution. Given Illinois' deep budget

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88. *Id.*

89. Johnson, *supra* note 27.

90. *Id.*

91. *Id.*

92. *Id.*

93. MURRAY PARENTS ASSOCIATION, <http://www.murrayparentsassociation.com/olmstead-information.html>.

94. *Id.*

95. *Id.*

constraints, the state should focus its resources on the mentally ill who are currently without treatment instead of those satisfied and safe in their living arrangement. A piecemeal approach will only drain the State of money while leaving gaps in its treatment coverage. The State can learn from the failures of the deinstitutionalization movement and focus on developing alternative housing before concentrating on moving patients out of their current homes. While Illinois has made steps in the right direction, a focused approach to the mental health system will not only benefit the mentally ill population, but could also bring much needed relief to the failing state budget thereby helping the entire state.

Illinois Nursing Home Care Act: Addressing the  
Needs of the Mentally Ill in Nursing Homes

*Caitlin McNulty\**

I. INTRODUCTION

On May 7, 2010, the Illinois legislature passed Senate Bill 326, the Nursing Home Care Act (“Act”).<sup>1</sup> This Act entails significant changes regarding how Illinois regulates nursing homes.<sup>2</sup> In particular, the Act encompasses several sections that address the quality of care issues relating to nursing home residents with mental health needs. Over the past two decades nursing homes admissions have undergone a transformation, with important changes in the proportions of nursing home residents with mental illnesses being admitted.<sup>3</sup> As a result, this Act aims to address the unique concerns associated with caring for nursing home residents with mental health illnesses.

This article will discuss the recent history of treatment of mentally ill, various attempts to remedy the shortcomings of treatment, the present status of mentally ill patients in Illinois, and the inefficiencies of Illinois’ current legislative attempt. In general, the Act is Illinois’ attempt to undertake many of the issues and shortcomings that currently exist for providing

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1. POLSINELLI SHUGHART, ILLINOIS LEGISLATURE PASSES NURSING HOME CARE ACT REFORM-WHAT PROVIDERS NEED TO KNOW NOW 1 (May 2010), available at <http://www.polsinelli.com/publications/healthcare/resources/ltc0510.pdf>

2. *Id.*

3. Catherine A. Fullerton et al., *Trends in Mental Health Admissions to Nursing Homes, 1999-2005*, 60 PSYCHIATRIC SERVS. 965, 965-966 (July 2009), available at <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2759604/>

adequate care to patients living in nursing homes with mental illness needs.<sup>4</sup>

## II. THE HISTORY OF TREATMENT OF MENTALLY ILL

Large portions of residents in nursing homes have mental illnesses.<sup>5</sup> While different studies using different methods for identifying mental illness make it difficult to ascertain exact numbers by state or nation-wide, it is clear that the number of nursing home residents with mental illnesses has risen.<sup>6</sup> As a result, the quality of mental health care in nursing homes has been a major policy issue.<sup>7</sup> One of the key policy issues for lawmakers is whether nursing homes are the appropriate care facilities for those with mental illness.<sup>8</sup> These residents have unique care needs and unique signs of quality of care.<sup>9</sup> For example, the introduction of new psychiatric drugs in the 1950's changed the way care was administered to mentally ill patients.<sup>10</sup> Psychiatric drugs are prescribed to patients suffering from schizophrenia, Alzheimer's disease and other mental conditions.<sup>11</sup> It was the hope that the psychiatric hospital patients could function in the community if they were

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4. See generally David Jackson & Gary Max, *Quinn Signs New Nursing Home Safety Bill*, CHI. TRIB., (July 29, 2010), available at [http://articles.chicagotribune.com/2010-07-29/news/ct-met-nursing-home-bill-signing-20100729\\_1\\_nursing-home-public-health-dangerous-patients](http://articles.chicagotribune.com/2010-07-29/news/ct-met-nursing-home-bill-signing-20100729_1_nursing-home-public-health-dangerous-patients) (explaining how the Chicago Tribune conducted a series of investigations which exposed numerous issues at facilities that house younger psychiatric patients).

5. David C. Grabowski et al., *Quality of Mental Health Care for Nursing Homes Residents: A Literature Review*, MED. CARE RES. REV. 627, 627-28(2010) [hereinafter *A Literature Review*] available at <http://mcr.sagepub.com/content/67/6/627.short>

6. See Ann D. Bagchi et al., *How Many Nursing Home Residents Live with a Mental Illness?*, 60 PSYCHIATRIC SERV. 958, 958 (2009) available at [http://ps.psychiatryonline.org/article.aspx?articleid=100603&link\\_type=google scholar](http://ps.psychiatryonline.org/article.aspx?articleid=100603&link_type=google scholar)

7. Literature Review, *supra* note 5, at 628.

8. David C. Grabowski et al., *Mental Illness in Nursing Homes: Variations Across States*, 28 HEALTH AFF. 689, 689 (2009) available at <http://content.healthaffairs.org/content/28/3/689.abstract> [hereinafter *Variations Across States*].

9. *Id.* at 689.

10. See Victor A. Molinari et al., *Mental Health Treatment in Nursing Homes*, 12 MARQ. ELDER L. 1, 3 (2011-12).

11. Gavin P. Lentz, *Investigation Finds Nursing Homes Administering Unneeded Psychiatric Drugs to Patients* Mar. 24, 2013, <http://www.eldercareneglect.com/investigation-finds-nursing-homes-administering-unneeded-psychiatric-drugs-to-patients>.

given the necessary medical support.<sup>12</sup> However, nursing homes became the de facto placement for these patients because states were ill equipped to find alternative placements.<sup>13</sup> Unfortunately, the staffs in many nursing homes were inadequately trained and did not know how to address the special needs of the mentally ill.<sup>14</sup>

This issue persists today, and as a result large numbers of mentally ill individuals are placed in nursing homes with psychiatric medications being used as their primary treatment.<sup>15</sup> Prescribing medication in this fashion is not an adequate solution because it inhibits individuals from pursuing an independent lifestyle, which was one of the initial hopes of psychiatric medication.

### III. PREVIOUS ATTEMPTS TO REMEDY

To address issues relating to the standard of care in long-term care facilities, Illinois passed the Nursing Home Care Reform Act of 1979.<sup>16</sup> When this statute was adopted it was considered “probably the most comprehensive in the nation.”<sup>17</sup> The major provisions of the statute included: a right to safety and good care without abuse, the right to participate in one’s own care, the right to privacy, the right to stay in the facility, and general rights as a citizen and facility resident.<sup>18</sup> In 1988, this statute was amended as the Nursing Home Care Act (“NHCA”).<sup>19</sup> The NHCA expanded previous legislation by adding a Resident’s Bill of Rights,

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12. Molinari et al., *supra* note 10, at 3.

13. Variations Across States, *supra* note 8, at 689.

14. Molinari et al., *supra* note 10, at 3.

15. *Id.*

16. Susan J. Hemp, *The Right to a Remedy: When Should an Abused Nursing Home Resident Sue?*, 2 ELDER L.J. 195, 205 (1994).

17. *Id.*

18. *Id.*

19. PETER A. MONOHAN, ET AL., ISSUES IN LONG TERM CARE (ILCS ed.), available at <http://www.illinois-law.com/docs/NursingHomeLit.htm>

expanding the enforcement power of the Illinois Department of Public Health, setting minimum qualifications for skill levels and training for nursing assistants and technicians, and provided policing powers for community groups, relatives, or friends to become involved in monitoring the quality of care provided.<sup>20</sup> Nevertheless, the NHCA did not eliminate quality of care issues in Illinois nursing homes.

#### IV. PRESENT STATUS OF MENTALLY ILL PATIENTS IN ILLINOIS

More than 500,000 people living in nursing homes have a mental illness such as schizophrenia, bipolar disorder, depression, and anxiety disorder.<sup>21</sup> Illinois has one of the highest rates of admission for individuals with mental illnesses into nursing homes.<sup>22</sup> While some mentally ill patients receive quality care and treatment in Illinois nursing homes, others live in institutions that offer limited therapy.<sup>23</sup> This approach fails to provide appropriate individualized care for the mentally ill, and it is fiscally more expensive than community based treatment options.<sup>24</sup> Unfortunately, the push to address this issue comes at a time when the State of Illinois is suffering a severe budget deficit, and many state tax funded programs are being eliminated or scaled back. However, creating more community housing options would not only provide more adequate care to the mentally ill, but it could also save the State millions of dollars.<sup>25</sup>

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20. *Id.*

21. Variations Across States, *supra* note 8, at 689 (defining serious mental illness as schizophrenia and bipolar disorder which are considered the most disabling and most frequently associated with serious mental illness and, consequently, institutionalization among people with mental illness).

22. *Id.* at 691.

23. Gary Marx & David Jackson, *Illinois Struggles to Move Mentally Ill Adults Out of Nursing Homes*, CHI. TRIB., July 4, 2012, available at <http://www.chicagotribune.com/health/ct-met-nursing-home-report-20120704,0,7396495.story> [hereinafter *Illinois Struggles*]

24. Mary Susan Littlepage, *Advocates for the Mentally Ill Criticize Illinois Nursing Homes, Housing Options*, Truthout (2009), <http://archive.truthout.org/1113093>

25. *Id.*

*A. Illinois' Attempt to Improve Care with the  
Nursing Home Safety Task Force*

In 2009 the Illinois government began to consider ways to improve Illinois nursing homes after an investigation revealed numerous reports of sexual assault, violence, and drug abuse in troubled facilities.<sup>26</sup> On October 3, 2009, Illinois Governor Patrick Quinn initiated the Nursing Home Safety Task Force (the “Task Force”), to ensure the safety of Illinois nursing home residents.<sup>27</sup>

The Nursing Home Safety Task Force Report (the “Report”) examined what issues were prevalent in nursing homes and suggested ways improve the safety of residents. The Report stated that almost all of the regulations regarding the state’s nursing homes, as well as the facilities themselves, are intended to provide care for elderly adults who can no longer care for themselves.<sup>28</sup> In addition, the Report stressed that nursing homes are not the appropriate care facility for young individuals with serious mental illnesses.<sup>29</sup> The Task Force found the mixture of vulnerable elderly patients with mentally ill patients, who can often be aggressive, was catastrophic.<sup>30</sup> Rather, a more appropriate setting for young, mentally ill patients would be specially designed and monitored community residential setting.<sup>31</sup>

The Task Force recommended raising the standard of care offered in nursing homes, thus ensuring the availability of appropriate treatment for residents.<sup>32</sup> Additionally, the Report encouraged offering more community-

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26. Illinois Struggles, *supra* note 23.

27. Letter from Michael Gelder, Chair, Governor Pat Quinn’s Nursing Home Task Force, to Governor Quinn, Governor of Illinois, Nursing Home Safety Task Force (Feb. 19, 2010) (on file with Governor Pat Quinn, Nursing Home Safety Task Force).

28. GOVERNOR PAT QUINN, NURSING HOME SAFETY TASK FORCE 1 (State of Illinois, 2010) [hereinafter TASK FORCE].

29. *Id.*

30. *Id.*

31. *Id.*

32. *Id.* at 3.

based residential options for individuals with mental illnesses.<sup>33</sup> The recommendations fit into three categories: “(A) Enhance the Pre-Admissions Screen and Background Check Process, (B) Set and Enforce Higher Standards of Care, and (C) Expand Home and Community-Based Residential and Service Options.”<sup>34</sup> However, the Report failed to address how these changes will be funded. It merely set forth new ideas for legislation without a plausible way to implement them across the state.

### *B. Assessment of Patients with Mental Illnesses*

The Nursing Home Care Act was signed into law, and many of the recommendations set forth by the Task Force are reflected in it. Facilities that offer psychiatric rehabilitation are now required to carry a special certification.<sup>35</sup> If a facility does not obtain this special certification, it cannot admit patients with serious mental illnesses.<sup>36</sup> Prior to being admitted into a nursing home, patients are pre-screened, by a certified professional, to ascertain if they have any mental illnesses.<sup>37</sup> This assessment is meant to provide a clear indication of patients’ needs in order to ensure quality care is being provided. Furthermore, the Department of Human Services reassess all persons diagnosed with having a serious mental illness after the first ninety days, then six months, and yearly

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33. *Id.*

34. *Id.*

35. POLSINELLI SHUGHART, *supra* note 1, at 2. To carry the special certification nursing facilities will have to meet certain staffing requirements. *Id.* These requirements will gradually increase. *Id.* Effective July 1, 2010 facilities will be required to provide 2.5 hours of nursing and personal care for each resident requiring skilled care and 1.7 hours of nursing and personal care for each resident requiring intermediate care. *Id.* By January 1, 2014 the Act states facilities will be required to provide 3.8 hours of nursing and personal care for each resident requiring skilled care and 2.5 hours of nursing and personal care for each resident requiring intermediate care. *Id.* Additionally the Illinois Health Facilities and Services Review Board may deny a permit based upon an applicant’s prior licensure history. *Id.*

36. *Id.*

37. *Id.*

thereinafter.<sup>38</sup> This continual reassessment will be done in order to ensure the individual has a continued need for care.<sup>39</sup> However, there has been no indication if this is being successfully implemented in nursing homes, or more importantly, if it is having the desired effect.

### 1. Psychotropic Drug Administration

Before the 1990's psychotropic drugs were primarily used on adults with severe psychotic disorders.<sup>40</sup> Psychotropic drugs should be prescribed and administered to patients with schizophrenia, Alzheimer's disease, and other conditions, as the physician deems necessary.<sup>41</sup> However, today these drugs are being prescribed to a much larger and diverse clinical population.<sup>42</sup> Investigations revealed that Illinois nursing homes gave these drugs to residents, without cause or proper physician supervision.<sup>43</sup> Improper use of psychiatric drugs can have dire effects ranging from tremors to an increased risk of falls and death.<sup>44</sup> Often, doctors will approve the administration of a psychiatric drug over the phone without ever seeing the patient.<sup>45</sup> Despite the high prevalence of mentally ill residents in nursing homes, most facilities do not have access to mental health provider with proper training in psychiatry and mental health treatment.<sup>46</sup>

The Task Force recognized this issue and called for a policy to assure

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38. *Id.*

39. *Id.*

40. Stephen Crystal et al., *Broadened Use of Atypical Antipsychotics: Safety, Effectiveness, and Policy Challenges*, *HEALTH AFF.*, 770, 770 (2009), available at <http://content.healthaffairs.org/content/28/5/w770.abstract>

41. Lentz, *supra* note 11.

42. Crystal et al., *supra* note 40, at 770-771.

43. Sam Roe, *Psychotropic Drugs Given to Nursing Home Patients Without Cause*, *CHI. TRIB.* (Oct. 27, 2009), available at [http://articles.chicagotribune.com/2009-10-27/health/chi-nursing-home1-psychotropics-oct27\\_1\\_dangerous-lethargy-psychotropic-drugs-nursing-home](http://articles.chicagotribune.com/2009-10-27/health/chi-nursing-home1-psychotropics-oct27_1_dangerous-lethargy-psychotropic-drugs-nursing-home)

44. Lentz, *supra* note 11.

45. *Id.*

46. A Literature Review, *supra* note 5, at 628.

psychotropic drugs were being properly administered for only those with serious mental illness.<sup>47</sup> As a result, Illinois promulgated Sec. 1-120.7 of the Act which requires psychiatric services rehabilitation to be administered by, “an individual employed by a long-term care facility to provide for, mentally ill residents, at a minimum, crisis intervention, rehabilitation, and assistance with activities of daily living.”<sup>48</sup> This section aims to remedy the improper use of psychotropic drugs by ensuring patients are not given unnecessary drugs. If implemented properly and effectively, this section of the Act would improve the overall well-being of many residents as a study has indicated that those on psychotropic drugs were more likely to experience a decline in well-being, and when taken off these drugs, most patients’ well-being improved.<sup>49</sup> However, there has yet to be any serious discussion on the success or failure of this portion of the Act.

## 2. Nursing Staff Issues

Another prevalent issue affecting the quality of care for the mentally ill in nursing homes is staffing. Few homes have full-time mental health professionals on staff, or staff members that specialize in mental health care.<sup>50</sup> The lack of qualified care means most of the mental health needs of

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47. TASK FORCE, *supra*, note 28, at 13. “The task force received many complaints about inappropriate use of psychotropic drugs. *Id.* Family members said relatives were drugged to the point of unresponsiveness. *Id.* Others testified that psychotropic drugs were repeatedly used for unapproved indications. *Id.* Family members specifically complained about the misuse of prescription drugs when orders permitted nursing home staff to administer the medications “as needed. *Id.* Reports show that only a few physicians prescribe the vast majority of psychotropic drugs for people with mental illnesses in nursing homes covered by Medicaid.” *Id.*

48. Nursing Home Care Act, § 210 ILL. COMP. STAT. 45 (2010). *See also*, § 2-104(b) (commands all medical treatment be administered as ordered by a physician), § 2-106(a) (“a resident shall not be given unnecessary drugs”), § 2-106(b) (“psychotropic medication shall not be prescribed without the informed consent of the resident, the resident’s guardian, or other authorized representative”).

49. Roe, *supra* note 43re.

50. Molinari et al., *supra* note 10 at 3-4.

residents are left untreated.<sup>51</sup> The Task Force addressed this issue and called for higher staffing standards, including more nurses and rehabilitation staff, to improve care and treatment in nursing homes.<sup>52</sup> In addition, the Report required a new certification of compliance required for all nursing homes that treat mentally ill patients.<sup>53</sup> This certification requires nursing homes to meet enhanced standards of resident care, staff, training, physical plant, mental health programming, and alcohol and substance abuse treatment, consistent with the mental health code.<sup>54</sup>

The Act addresses staffing issues in Sec. 3-202.05 by increasing necessary staffing ratios.<sup>55</sup> Furthermore, Sec. 3-202.2(b) sets forth new requirements of certification of psychiatric rehabilitation programs.<sup>56</sup> Psychiatric rehabilitations services are mandatory at all licensed long-term care facilities.<sup>57</sup> This Section also requires sufficient staff to be available twenty-four hours a day, to meet the needs of all residents.<sup>58</sup> Nursing homes must train staff shall during orientation and then annually thereafter with the appropriate skills to meet the specific care needs of residents with serious mental illnesses.<sup>59</sup> Since residents with serious mental illnesses have a more difficult time voicing their needs,<sup>60</sup> having properly trained staff is essential in ensuring their needs are being met.

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51. See *id* at 4. see also, *Nursing Home Indicted for Abuse of Mentally Ill Patient*, SLATER & ZURZ LLP (Mar. 20, 2009) <http://slaterzurz.wordpress.com/2011/12/27/nursing-home-indicted-for-abuse-and-neglect-of-mentally-ill-patient/> (last visited March 2, 2013)(explaining how staff did not know how to properly deal with a suicidal patient, and he ended up killing himself under their watch).

52. TASK FORCE, *supra* note 28, at 1.

53. *Id.* at 9.

54. *Id.*

55. Nursing Home Care Act, 210 ILL. COMP. STAT 45 §§3-202 (2010).

56. *Id.*

57. *Id.*

58. *Id.*

59. *Id.*

60. Lentz, *supra* note 11.

Increasing employment standards can lead to creating a better quality of life and care for residents. Additionally, better-educated staff members can reduce cases of neglect and abuse, which were prevalent in Illinois before this Act was adopted. While the headlines reporting nursing home abuse have died down, there is no clear indication that staffing issues have improved or the Act is being implemented.

### 3. Resident Care Plan

Furthermore, the Act also calls for a resident care plan<sup>61</sup> outlined in Sec. 3-202.2(a) as well as Sec. 3-202.2(b).<sup>62</sup> The Act requires facilities, with the participation of the resident and resident's guardian to:

“Develop and implement a comprehensive care plan for each resident that includes measureable objectives and timetables to meet the resident’s medical, nursing, and mental and psychosocial needs that are identified in the resident’s comprehensive assessment, which allow the resident to attain or maintain the highest practicable level of independent functioning, and provide for discharge planning to the least restrictive setting based on the resident’s care needs.”<sup>63</sup>

For residents with mental illnesses this comprehensive plan includes quarterly reviews of residents’ treatment plans, notes the residents’ progress, and analyzes their current needs.<sup>64</sup> This is critical because statistically individuals with mental illnesses are more likely to stay in nursing homes for longer periods of time.<sup>65</sup> This situation is particularly true in Illinois because the State relies heavily on nursing homes to house the mentally ill.<sup>66</sup> As the Act states, monitoring mentally ill residents can

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61. Nursing Home Care Act, 210 ILL. COMP. STAT 45 §§ 202.2 (2010).

62. *Id.*

63. *Id.*

64. *Id.*

65. Variations Across States, *supra* note 8, at 689.

66. Littlepage, *supra* note 24.

better address the residents' needs.<sup>67</sup> The Task Force addressed the desire to make community-based housing arrangements available to qualified individuals, who while mentally ill, do not have complicated medical health care needs requiring them to live in nursing homes.<sup>68</sup> One of the goals of the Act is to provide supportive housing and treatment to the mentally ill.<sup>69</sup> The purpose of the comprehensive care plan is to move qualified mentally ill residents out of nursing homes and into subsidized apartments or group homes where they would receive therapy and other services.<sup>70</sup>

To ensure nursing homes are complying with the Act's new standards, the State periodically inspects the facilities.<sup>71</sup> Sec. 3-212 requires surveyors to be trained about the appropriate assessment, care planning, and care of individuals with mental illnesses.<sup>72</sup> This training is vital as surveyors need to be able to recognize when a facility is correctly complying with requirements of care.<sup>73</sup> Periodic inspection is necessary as the Task Force shed light on the fact that some facilities frequently violate rules, and when caught comply with the rules for a period of time, and then return to violating rules until a complaint or annual review brings the violation to light again.<sup>74</sup> This type of "yo-yo" compliance is handled under Sec. 3-212, which allows surveyors to inspect without prior notice to the facilities.<sup>75</sup> Additionally, the State levies penalties against individuals who pre-notify a facility of an impending inspection.<sup>76</sup> These measures are in place to ensure that the patients' needs are being met, which will improve the quality of

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67. Nursing Home Care Act, 210 ILL. COMP. STAT 45 §§ 202.2 (2010).

68. TASK FORCE, *supra* note 28, at 15.

69. *See* Illinois Struggles, *supra* note 23.

70. *Id.*

71. Nursing Home Care Act, 210 ILL. COMP. STAT 45 §§ 3-212 (2010).

72. *Id.*

73. *Id.*

74. TASK FORCE, *supra*, note 28 at 10.

75. Nursing Home Care Act, 210 ILL. COMP. STAT 45 §§ 4.04 (2010).

76. *Id.*

care being provided by nursing homes.

#### V. INEFFICIENCIES WITH LEGISLATION

However, there is no guarantee the Act is going to solve these problems. Illinois had existing law that dealt with many of the problems addressed, however these laws were not enforced. Without proper funding it is unlikely this Act will compel greater enforcement in nursing homes. While the Task Force did address many shortcomings regarding quality of care issues in Illinois nursing homes,<sup>77</sup> and the Act addresses many of them through new rules and regulations,<sup>78</sup> the impact on care for the mentally ill has not been as great as hoped. As of June 2012 only forty-five mentally ill patients had signed a lease or moved into subsidized apartments or group homes.<sup>79</sup> This is substantially less than the first year goal of 256 people or more.<sup>80</sup> The Act fails to require any increase in spending on community alternatives to nursing homes, which is one of the reasons so few patients have been relocated to outside community alternatives.

#### VI. CONCLUSION

The Illinois legislature demonstrated a clear concern for the quality of care offered to mentally ill residents in nursing homes. The legislature recognized that nursing homes are inappropriate for mentally ill individuals, unless they have some other condition that requires the care of nursing home staff.<sup>81</sup> While the Act has yet to be fully implemented, the early signs are not positive. Without greater resources, or a more efficient reallocation

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77. *See generally*, TASK FORCE, *supra* note 28.

78. *See generally*, 210 ILL. COMP. STAT. 45 (2010).

79. Illinois Struggles, *supra* note 26.

80. *Id.*

81. Comments on Preliminary Recommendations of Governor Quinn's Nursing Home Safety Task Force (March 20, 2013) (statement from Illinois' Mental Health of America), <http://www.law.uchicago.edu/files/file/mhai%20response%20to%20taskforce.pdf>

of sources, it seems unlikely that the Act will be fully implemented and will not have the substantial impact on quality of care amongst the mentally ill in nursing homes for which proponents were hoping.

An Analysis of the Federal Medicaid Statute's  
Spousal Anti-Im impoverishment Provision in Light of  
the Patient Protection and Affordable Care Act's  
Medicaid Expansion and Current Federal Budgetary  
Constraints

*Deborah Moldover\**

I. INTRODUCTION

In 1987, Senators Mikulski, Mitchell and Kennedy introduced the Medicaid Community Spousal Protection Act of 1987, later incorporated as an amendment into the Medicare Catastrophic Illness Coverage Act of 1988.<sup>1</sup> The Senators intended this provision to prevent a spouse from becoming impoverished due to paying for an institutional level of care<sup>2</sup> for the other spouse.<sup>3</sup> As enacted, the provision allows couples to sequester some assets for the community spouse,<sup>4</sup> while still preserving the other spouse's Medicaid benefit eligibility.<sup>5</sup>

The financial impact of this expansion of Medicaid eligibility is felt in the budgets of both state and the federal governments.<sup>6</sup> The federal

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1. 133 CONG. REC. 29353 (1987) (statement of Sen. Barbara Mikulski); Medicare Catastrophic Coverage Act of 1988 § 303, 42 U.S.C. § 1396r-5 (2006 & Supp. 2011).

2. A spouse requiring an institutional level of care generally refers to needing care delivered in a nursing home. This spouse is also referred to as the "institutionalized spouse." Wone, *infra* note 40, at 492.

3. 133 CONG. REC. 29353, *supra* note 1.

4. Community spouse refers to the spouse who does not need an institutional level of care such as a nursing home and continues to reside in the "community," often in the family home. Wone, *infra* note 40, at 492.

5. 42 U.S.C. § 1396r-5(d), *supra* note 1.

6. ELICIA J. HERZ, CONG. RESEARCH SERV., RL 33202, MEDICAID: A PRIMER 1 (July 18, 2012).

government pays for at least half (and generally much more) of the costs associated with care for Medicaid beneficiaries.<sup>7</sup> Additionally, it is the state government that is generally responsible for the remainder of the costs as opposed to the beneficiary.<sup>8</sup> Further, the expansion applies to an otherwise mandatory eligibility category, meaning that states do not have the option of refusing to provide coverage for these individuals.<sup>9</sup> As both state and the federal governments look to reduce their spending, federal elected officials may view modifications to mandatory categories of Medicaid eligibility as an attractive option to counter the rising costs associated with increases in Medicaid enrollment.<sup>10</sup> State governments are seeking to reduce expenditures at the same time as the federal government shifts more and more of the financial burden onto them.<sup>11</sup> Additionally, under health care reform, spousal anti-impoverishment protections will extend to couples where one spouse needs home and community based services, not just institutional care.<sup>12</sup> In the current budgetary climate, the evolution of Medicaid eligibility under spousal anti-impoverishment protections begs the

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7. *Id.* at 9.

8. *Id.*; 75 Fed. Reg. 69083 (Nov. 10, 2010). Federal Medical Assistance Percentage [FMAP] rates for FY 2012 reflect a range of 50 – 74.18 as the percentage of Medicaid expenditures covered by the federal government. *Id.*

9. HERZ, *supra* note 6, at 2.

10. See *Percent Change in Monthly Enrollment of Adults in Medicaid*, STATEHEALTHFACTS.ORG, <http://www.statehealthfacts.org/comparetable.jsp?ind=615&cat=4&sub=52&yr=1&typ=2> (last visited April 27, 2013); *Average Annual Growth in Medicaid Spending, FY1990 - FY2010*, STATEHEALTHFACTS.ORG, <http://www.statehealthfacts.org/comparetable.jsp?ind=181&cat=4> (last visited April 27, 2013)

11. Philip Galewitz & Matthew Fleming, *13 States Cut Medicaid To Balance Budgets*, KAISER HEALTH NEWS, July 24, 2012, <http://www.kaiserhealthnews.org/Stories/2012/July/25/medicaid-cuts.aspx>.

12. Spousal impoverishment protections will also be temporarily extended starting January 1, 2014 to couples where one spouse requires home and community-based services. This expansion is mandatory, as opposed to as an optional expansion for the states. Patient Protection and Affordable Care Act (PPACA), Pub. L. No. 111-148, § 2404, 124 Stat. 119, 305 (2010); *Long-Term Services Health Reform Provisions: Expanded Spousal Impoverishment Protection in Medicaid*, FAMILIES USA: THE VOICE FOR HEALTH CARE CONSUMERS, <http://www.familiesusa.org/issues/long-term-services/health-reform/spousal-impoverishment.html> (last visited April 26, 2013).

question: should spousal anti-impoverishment protections remain part of federal law? This paper will consider the possible policy ramifications of eliminating spousal protections from Medicaid eligibility and will also analyze the impact of the Patient Protection and Affordable Care Act (PPACA) on Medicaid eligibility and budgetary constraints.

## II. HISTORY OF THE SPOUSAL ANTI-IMPOVERISHMENT PROVISION

The federal government requires states to finance nursing home services, allowing Medicaid to be a fall-back option for those who do not purchase long-term care insurance.<sup>13</sup> However, prior to the Mikulski-Mitchell-Kennedy amendment, the income and assets for both spouses were included in calculating Medicaid eligibility.<sup>14</sup> Before Congress adopted the Mikulski-Mitchell-Kennedy amendment, the community spouse had an allowance that was below the federal poverty level.<sup>15</sup> The Senators' intended to reduce the level of poverty among elderly women, especially those who had not worked over the course of their marriage.<sup>16</sup> Therefore, this amendment targeted those asset allocation rules that would impact eligibility and, if not changed, would continue to contribute to the impoverishment of elderly women with no other source of income than their husbands' pension.<sup>17</sup> Prior to the enactment of the Medicare Catastrophic Illness Coverage Act, many couples faced the difficult decision of either joint impoverishment in order to qualify for Medicaid to

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13. HERZ, *supra* note 6, at 6.

14. GEORGETOWN UNIVERSITY LONG-TERM CARE FINANCING PROJECT, MEDICAID'S SPOUSAL IMPOVERISHMENT PROTECTIONS 1 (Feb. 2007), available at <http://ltc.georgetown.edu/pdfs/spousal0207.pdf>.

15. 133 CONG. REC. 29353, *supra* note 1.

16. *Id.*

17. Louis D. Torch, *Spousal Impoverishment or Enrichment? An Assessment of Asset and Income Transfers by Medicaid Applicants*, 4 ELDER L.J. 459, 466 (1996).

finance an institutional level of care for one spouse, or divorce.<sup>18</sup>

Federal Medicaid law has always required that the potential beneficiary be categorically eligible and medically needy in order to receive benefits.<sup>19</sup> Even with the spousal protection provision, a married Medicaid applicant's inventory of resources includes the assets of the spouse needing an institutional level of care and the community spouse.<sup>20</sup> The spousal anti-impoverishment provision, however, allows that while the community spouse's income and assets are considered when determining Medicaid eligibility, there are also certain exclusions.<sup>21</sup> Significantly, the institutionalized spouse can transfer a monthly maintenance allowance as well as specific resources such as the family home to the community spouse without forfeiting Medicaid eligibility.<sup>22</sup> Under the spousal protection provision, there is a federally mandated floor,<sup>23</sup> below which the institutionalized spouse's assets must be used to support the community spouse.<sup>24</sup> Additionally, any income that the community spouse receives in his or her own name may be retained by the community spouse.<sup>25</sup> This

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18. GEORGETOWN UNIVERSITY LONG-TERM CARE FINANCING PROJECT, *supra* note 14, at 1.

19. Torch, *supra* note 17, at 466.

20. *Id.*

21. *See id.* at 467-72.

22. *See id.*

23. The spousal anti-impoverishment provision's requirement on the institutionalized spouse to provide financial support to the community spouse means that the community spouse cannot be forced to live below a set threshold above poverty level. The intent of the provision is to "protect the community spouse[] from 'pauperization' while preventing financially secure couples from obtaining Medicaid assistance," Wone *infra* note 40, at 492.

24. GEORGETOWN UNIVERSITY LONG-TERM CARE FINANCING PROJECT, *supra* note 14, at 1.

25. *Id.* In 2011, the federal government set minimum and maximum amounts that a community spouse could receive as the monthly maintenance allowance at \$1,838.75 and \$2,739.00 respectively, with the individual circumstances of the community spouse determining the final number. In addition, the community spouse may retain resources of up to \$109,560.00 while the institutionalized spouse is eligible for Medicaid. *Spousal Impoverishment*, MEDICAID.GOV, <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Eligibility/Spousal-Impoverishment-Page.html> (last visited Feb. 18, 2013).

greatly expands the possible pool of Medicaid beneficiaries.

### III. THE IMPACT OF MORENZ V. WILSON-COKER ON MEDICAID ELIGIBILITY

In *Morenz v. Wilson-Coker*, the Second Circuit considered the case of a Connecticut couple where the community spouse, the wife, refused to provide spousal support to her husband who needed an institutional level of care.<sup>26</sup> Mr. Morenz assigned his spousal support rights to the state of Connecticut such that any obligation that Mrs. Morenz still held to support her husband would reimburse the state of Connecticut for any funds expended for his care.<sup>27</sup> The Second Circuit held that the community spouse could refuse to provide additional support for the institutionalized spouse by assigning his or her right of support to the state, in order for the institutionalized spouse to become eligible for Medicaid benefits.<sup>28</sup> The court considered whether 42 U.S.C. § 1396r-5 prohibited a state from deeming the community spouses' assets to be available for purposes of supporting the institutionalized spouse when making a determination of Medicaid eligibility.<sup>29</sup> In finding that the statutory language in question was unambiguous, the court held that "[a] community spouse's resources cannot be included in making an institutionalized spouse's initial eligibility determination if the institutionalized spouse has assigned support rights to the state or undue hardship is present."<sup>30</sup> Federal law did not prohibit a community spouse from refusing to provide support to the institutionalized spouse.<sup>31</sup>

The court also examined whether under Connecticut law, as distinct from

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26. *Morenz v. Wilson-Coker*, 415 F.3d 230, 233 (2d. Cir. 2005).

27. *Id.* at 232-3.

28. *Id.* at 234.

29. *Id.*

30. *Id.*

31. *Id.*

federal eligibility requirements, an institutionalized Medicaid applicant could assign spousal support rights to the state only when the Medicaid applicant's spouse is unwilling or unable to provide the financial information needed to determine Medicaid eligibility.<sup>32</sup> If the court had upheld the state limitation, then the holding that federal law allows for an institutionalized spouse to assign their support rights to the state would effectively be irrelevant.<sup>33</sup> Medicaid eligibility could still be restricted because state law could prohibit spousal refusal and assignment of rights of support.<sup>34</sup> However, the court held that the limitation on assignment of spousal support rights only pertained to mandatory assignment of spousal support rights.<sup>35</sup> If a community spouse voluntarily gave up his or her spousal support rights and the institutionalized spouse assigns them to the state, then the institutionalized spouse did not depend upon the community spouse's assets for determining Medicaid eligibility.<sup>36</sup>

The policy impact of the court's holding in *Morenz* is complicated by the fact that the court's decision turns on both federal and state law. The rule protects the community spouse from having to divorce the institutionalized spouse and allows him or her to continue living in the couple's home, as Congress intended with the enactment of 42 U.S.C. § 1396r-5.<sup>37</sup> However, it also creates the possibility that many individuals who would not otherwise receive Medicaid benefits based upon being "categorically

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32. *Morenz*, 415 F.3d at 254

33. *Id.* 235.

34. *Id.* n.4.

35. *Id.* at 236.

36. *Id.* at 234.

37. *Women and Aging: Bearing the Burden of Long-Term Care: Joint Hearing Before the Spec. Comm. on Aging and the Subcomm. on Aging of the Comm. on Health, Educ., Labor and Pensions*, 107th Cong. 3 (2002) (opening statement of Sen. Barbara Mikulski, Chairman, S. Subcomm. on Aging of the Comm. on Health, Educ., Labor and Pensions); 133 CONG. REC 29354 (1987) (statement of Sen. Edward Kennedy).

needy”<sup>38</sup> can receive government-funded care. This possible, unintended, expansion of Medicaid eligibility makes the spousal anti-impovery provision an attractive target for those in Congress who seek to reduce the size and scope of the federal budget.

The vast majority of couples that take advantage of the option of spousal refusal<sup>39</sup> are those in need of nursing home and other long-term care services.<sup>40</sup> Without the option for spousal refusal, many couples would not be able to cover the cost of long-term care for the institutionalized spouse for even one year without depleting the couple’s resources and leaving the community spouse dependent upon Medicaid when he or she also needed care.<sup>41</sup> However, granting the option of spousal refusal also makes reductions in Medicaid long-term care spending difficult to attain.<sup>42</sup> Currently, spousal refusal is not available in every state.<sup>43</sup> When available, it allows couples to plan for Medicaid eligibility, rather than applying for benefits only after all income and assets have been consumed by paying for care.<sup>44</sup> As such, individuals who may become eligible for Medicaid benefits after spending down assets are able to receive benefits sooner through careful estate planning.<sup>45</sup> It therefore becomes a question of policy

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38. “Categorically needy” generally refers to those individuals who are automatically eligible for Medicaid coverage, assuming certain income qualifications are met, with the income qualifications varying somewhat by state. *See* HERZ, *supra* note 6, at 1. Those categories include pregnant women, children, women with breast or cervical cancer, individuals with disabilities, the elderly, and uninsured individuals with tuberculosis. *Id.*

39. For a more in depth discussion of the process of spousal refusal, *see* Wone, *infra* note 40, at 498-99.

40. Andrew D. Wone, *Don’t Want to Pay for Your Institutionalized Spouse? The Role of Spousal Refusal and Medicaid in Funding Long Term Care*, 14 ELDER L.J. 485, 490 (2006).

41. *Id.* at 496.

42. *See id.* at 490. Medicaid pays for approximately half of all long-term care expenses as is. *Id.*

43. For a general discussion for spousal refusal rules in New York, Massachusetts and Florida, *see id.* at 519-27 .

44. *See id.*

45. Torch, *supra* note 17, at 460.

if these beneficiaries should receive Medicaid benefits as opposed to depleting their assets and allowing the program to serve a smaller set of individuals who are deemed especially needy.

#### IV. MEDICAID ELIGIBILITY EXPANSIONS UNDER THE PATIENT PROTECTION AND AFFORDABLE CARE ACT

The state-option Medicaid expansion under the PPACA expanded the ceiling of Medicaid eligibility, and changed the face of Medicaid beneficiaries.<sup>46</sup> Additionally, the PPACA includes an expansion of the spousal protections to include those couples with a spouse in need of home and community based services, not just institutional care.<sup>47</sup> This change may make it more politically and socially acceptable for individuals who consider themselves middle class to receive Medicaid benefits, but it also makes Medicaid much more expensive for the federal government.<sup>48</sup> Both Republican and Democratic governors are announcing their intention to expand Medicaid eligibility in accordance with the PPACA.<sup>49</sup>

The PPACA creates a new category for Medicaid eligibility, in addition to the existing groups that had comprised the traditional “categorically needy.”<sup>50</sup> While the expansion directly affects low-income, childless

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46. KAISER FAMILY FOUND., EXPLAINING HEALTH CARE REFORM: QUESTIONS ABOUT MEDICAID’S ROLE, 2 (April 2010), *available at* <http://www.kff.org/healthreform/upload/7920-02.pdf>.

47. PPACA § 2404.

48. KAISER FAMILY FOUND., *supra* note 46. Even though the Medicaid expansion is done at state option, for those states that participate, it is fully funded by the federal government until 2016 with a phase down to 90% FMAP by 2020 for that and subsequent years. *Id.*

49. Sara Kliff, *Republican Governors Embrace Part of Health-Care Law*, WONKBLOG, WASH. POST (Feb. 7, 2013, 10:16 PM), <http://www.washingtonpost.com/blogs/wonkblog/wp/2013/02/07/republican-governors-embrace-part-of-health-care-law/>. Were the governors to do otherwise, they would be leaving federal funds available for other states to accept, without reducing the tax burden faced by their own citizens. *Id.*

50. John Blum & Gayland O. Hethcoat II, *Medicaid Governance In the Wake of National Federation of Independent Business v. Sebelius: Finding Federalism’s Middle Pathway*, *from Administrative Law to State Compacts*, 45 J. MARSHALL L. REV. 601, 612 (2012).

adults, it will also impact eligibility based upon the spousal anti-improvement provision.<sup>51</sup> Medicaid beneficiaries who are newly eligible because of the category created by the PPACA will receive “essential health benefits” coverage as opposed to standard Medicaid.<sup>52</sup> These “essential health benefits” contain some long-term care benefits but they are not identical to those under traditional Medicaid.<sup>53</sup> As a result, low-income seniors may receive multiple kinds of Medicaid, and may not realize that assets should be shifted in order for the spouse needing an institutional level of care to receive traditional Medicaid benefits.<sup>54</sup> This overlap will likely create additional administrative costs for states, and confusion for seniors who are already vulnerable due to financial constraints and the need for long-term care. While the PPACA does include “rehabilitative and habilitative services and devices” within the essential health benefits that all newly eligible Medicaid beneficiaries must receive, nursing home care may fall outside that definition and the federal government has yet to clarify otherwise.<sup>55</sup> Further modifications, or even elimination, of the spousal

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51. *Id.*

52. Medicaid, Children’s Health Insurance Programs, and Exchanges: Essential Health Benefits in Alternative Benefit Plans, Eligibility Notices, Fair Hearing and Appeal Processes for Medicaid and Exchange Eligibility Appeals and Other Provisions Related to Eligibility and Enrollment for Exchanges, Medicaid and CHIP, and Medicaid Premiums and Cost Sharing, 78 Fed. Reg. 4594, 4629 (proposed Jan. 22, 2013).

53. Blum & Hethcoat, *supra* note 50, at 612; 42 U.S.C. § 18022(b)(1). The PPACA defines “essential health benefits” to include the following items: ambulatory patient services, emergency services, hospitalization, maternity and newborn care, mental health and substance use disorder services including behavioral health treatment, prescription drugs, rehabilitative and habilitative services and devices, laboratory services, preventive and wellness services and chronic disease management, and pediatric services including oral and vision care. 42 U.S.C. § 18022(b)(1).

54. *See* Blum & Hethcoat, *supra* note 50 at 612. Traditional Medicaid benefits include long term care services but the types of coverage vary by state. *See Long-Term Services & Support*, MEDICAID.GOV, <http://medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Support/Long-Term-Services-and-Support.html> (last visited April 26, 2013).

55. 42 U.S.C. § 18022(b)(1). It is up to the states to define what constitutes “habilitative” benefits as part of what qualifies as a qualified health plan within each state’s Health Benefits Exchange. Until the Exchanges are fully established, seniors will continue to

protection provision could lead to still more confusion for seniors and still higher administrative costs for Medicaid programs. These costs would be borne not by the federal government but by the states.<sup>56</sup> This fact may make changes to the spousal anti-impovery provision appealing to federal budget cutters, but their constituents may respond negatively at the ballot box.

#### V. SHIFTING THE FINANCIAL BURDEN: ELIMINATION OF THE SPOUSAL ANTI-IMPOVERISHMENT PROVISION

Medicaid funding has always been split between the federal government and the states.<sup>57</sup> However, the majority of administrative responsibility rests on the state level within federal guidelines.<sup>58</sup> For beneficiaries, the division means that while there is a federally mandated floor for Medicaid eligibility with spousal asset exclusions, there is still considerable state variety in how the provision will be applied.<sup>59</sup> One proposal to make access to Medicaid benefits more equitable across state lines is to raise the federal floor to the maximum allowed monthly maintenance allowance, with the federal government increasing FMAP amounts.<sup>60</sup> This would likely improve the overall quality of care that seniors receive. However, it would simply shift the cost burden to the federal government.

Another possible change to Medicaid that federal budget cutters may

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face uncertainty. *See* Medicaid, Children's Health Insurance Programs, and Exchanges: Essential Health Benefits in Alternative Benefit Plans, Eligibility Notices, Fair Hearing and Appeal Processes for Medicaid and Exchange Eligibility Appeals and Other Provisions Related to Eligibility and Enrollment for Exchanges, Medicaid and CHIP, and Medicaid Premiums and Cost Sharing, *supra* note 52, at 4630.

56. CHRIS L. PETERSON, CONG. RESEARCH SERV., RL 32950, MEDICAID: THE FEDERAL MEDICAL ASSISTANCE PERCENTAGE 1 (April 7, 2010).

57. *Id.*

58. HERZ, *supra* note 6, at 1.

59. GEORGETOWN UNIVERSITY LONG-TERM CARE FINANCING PROJECT, *supra* note 14, at 2.

60. *Id.*

consider is the total elimination of the spousal protection provision.<sup>61</sup> If Congress were to adopt this change and reduce Medicaid eligibility, this could reduce federal and state Medicaid outlays, simply by taking potential beneficiaries out of the program.<sup>62</sup> However, for many individuals without long-term care insurance, another option will be waiting until the need for care is so acute that there is no choice but to go to the hospital – care which is covered by Medicare.<sup>63</sup> While Medicare does have limits on the number of days a patient can stay in an acute care hospital, it does not have caps on the financial outlays per patient and costs can quickly add up.<sup>64</sup>

End-of-life care costs are rising equally dramatically as long-term care costs in an inverse relationship such that avoiding Medicaid funded long-term care does not solve the problem of containing costs.<sup>65</sup> When Medicare is the only payor, the financial burden is borne entirely by the federal government.<sup>66</sup> The high cost of end-of-life care has been examined by Dr. Peter Pronovost, a physician at the Johns Hopkins University Hospital and a

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61. The possibility of completely eliminating the spousal protection provision may seem remote in view that the benefit is expanded in a five year demonstration program under the Patient Protection and Affordable Care Act. PPACA § 2404.

62. The number of Medicaid enrollees has been steadily increasing nationally, coinciding with a growth in the overall amount of Medicaid spending. While the growth has not been linear, it is logical to conclude that reducing the number of potential beneficiaries would lead to some reduction in Medicaid spending. .See *Percent Change in Monthly Enrollment of Adults in Medicaid* , *supra* note 10, *Average Annual Growth in Medicaid Spending, FY1990-FY2010*, *supra* note 10. .

63. Jane Gross, Op-Ed., *How Medicare Fails the Elderly*, N.Y. TIMES, Oct. 16, 2011, at SR8

64. Janet Adamy & Tom McGinty, *The Crushing Cost of Care*, WALL ST. J., July 6, 2012, <http://online.wsj.com/article/SB10001424052702304441404577483050976766184.html>. Dr. Peter Pronovost's discussion of the escalating costs of care for Medicare beneficiaries illustrates how the costs of end of life care can rise due to both physicians and patient's families focus exclusively on sustaining life as opposed to quality of life of the patient and cost concerns. *Id.*

65. Korbin Liu, Joshua M. Wiener & Marlene R. Niefeld, *End of Life Medicare and Medicaid Expenditures for Dually Eligible Beneficiaries*, 27 HEALTH CARE FIN. REV. 95, 97 (2006), available at <http://www.cms.gov/Research-Statistics-Data-and-Systems/Research/HealthCareFinancingReview/Downloads/06Summerpg95.pdf>.

66. PATRICIA A. DAVIS, CONG. RESEARCH. SERV., R40425, MEDICARE PRIMER 1 (2010).

professor at the Johns Hopkins University School of Public Health.<sup>67</sup> Dr. Pronovost's discussion of end-of-life care costs shows how the overall cost can be higher when the care is delivered in an acute care setting.<sup>68</sup> While expenditures for dual eligible beneficiaries tend to be higher than for Medicare only beneficiaries, if enrollment in Medicaid is delayed until the patient has consumed the resources of both spouses, the beneficiary is likely going to be sicker and in need of more expensive care.<sup>69</sup>

The potential loss of Medicaid eligibility for an institutionalized spouse makes the discussion of dual eligibles<sup>70</sup> particularly important. Dual eligible beneficiaries of both Medicare and Medicaid represent the highest expenditures for the federal government, using Medicare for acute care services and Medicaid for long-term care needs.<sup>71</sup> The high cost of care for these patients may be in part due to the reasons Dr. Pronovost highlighted as a partial explanation for the high cost of end of life care in general.<sup>72</sup> However, this cost seems to be shared between Medicare and Medicaid. Long-term care in a nursing facility is often a substitute for acute care in a hospital for older, dual eligible beneficiaries.<sup>73</sup> While this has increased the costs of care overall, splitting of costs between two payors may end up reducing the burden borne by the federal government. Combined spending for dual eligible beneficiaries decreased as beneficiaries age.<sup>74</sup> While the federal government pays for 100% of the costs of dual eligibles, the state

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67. Adamy & McGinty, *supra* note 64.

68. *Id.*

69. Liu, Wiener & Niefeld, *supra* note 65, at 95.

70. State Medicaid programs must pay *Medicare cost-sharing expenses* (e.g., Medicare premiums and, in some cases, deductibles and co-insurance) for certain low-income individuals eligible for both programs, often called "dual eligibles." HERZ, *supra* note 6 at 7 (emphasis in original).

71. Liu, Wiener & Niefeld, *supra* note 65, at 96

72. *Id.* at 97.

73. *Id.*

74. *Id.* at 99.

only receives the standard FMAP amount for traditional Medicaid beneficiaries.<sup>75</sup> However, because the states are administrators of the Medicaid program, states have been using their authority to declare certain transfers of assets ineligible for protection under the federal spousal anti-impoveryishment provision.<sup>76</sup> Allowing states to do this shifts the financial burden back to the federal government, and eventually onto the community spouse, essentially eliminating the intended spousal impoverishment protection.<sup>77</sup> Shifting the burden may save state governments money in the short term, but the care that the spouse needing an institutional level of care receives will likely be more expensive due to delay and the high cost of care associated with dual eligible beneficiaries. By attempting to save money, state governments could end up increasing overall health care spending costs for both the states and the federal government.

#### VI. CONCLUSION

While elimination of the spousal asset and income protections first enacted into Medicaid in 1988 may seem attractive to policy makers looking to reduce federal expenditures, it is unlikely to be successful. *Morenz v. Wilson-Coker* has yet to be challenged. While it is only binding in the Second Circuit, it should be viewed as highly persuasive in other jurisdictions. This means that Medicaid continues to be a viable option for middle class families without long-term care insurance. While some family assets must be consumed in order for the institutionalized spouse's assets to meet eligibility guidelines, couples will not have to file for divorce in order to declare that they were not financially prepared for one spouse's medical needs. The PPACA-created Medicaid expansion is optional for states, and

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75. PETERSON, *supra* note 56, at 1.

76. Torch, *supra* note 17, at 488.

77. *Id.*

while this reduces the dependence on the spousal anti-impoverishment provision for a spouse needing an institutional level of care, it does not eliminate it completely. Additionally, the Medicaid expansion increases federal outlays because the expansion is fully funded by the federal government until 2016 with a phase down to 90% FMAP by 2020 for that and subsequent years.<sup>78</sup> Finally, the expansion creates a different pathway for eligibility that also has different benefits. Because there is no guarantee of coverage for nursing home services in this new pathway, low-income seniors may choose to forgo Medicaid until the traditional eligibility point, and depend upon the spousal anti-impoverishment protections to keep the community spouse in the family home. Therefore, elimination of the spousal protection provision of the Medicaid statute, while attractive on paper, is unlikely to lead to significant savings for the federal government without other changes to federal health care programs.

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78. PETERSON, *supra* note 56, at 14.

Paying for the Long-Term Care of the Elderly:  
Current Sources of Payment, Potential Issues, and a  
Proposal for a New Way to Finance  
Long-Term Care

*Eric S. Kim\**

I. INTRODUCTION

Of the over ten million Americans that received long-term care in 2005, fifty-eight percent were over the age of sixty-five.<sup>1</sup> On average, long-term care provided at nursing homes can cost around \$72,000 per year, while long-term care provided through assisted living facilities can cost around \$38,000 per year.<sup>2</sup> In 2006, the overall expenditure for long-term care in the United States (US) was nearly \$178 billion.<sup>3</sup> An average sixty-five-year-old individual has approximately a thirty-five to fifty percent chance of using long-term care services.<sup>4</sup> Furthermore, the average stay in a long-term care facility is likely to be less than three years. In addition, forty to sixty percent of all stays last less than one year, but eleven to twenty-one percent of stays last five years or longer.<sup>5</sup>

Since the majority of the community-based long-term care population relies on family members, relatives, friends, or volunteers as the primary

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1. Judith Feder et al., LONG-TERM CARE FIN.: POLICY OPTIONS FOR THE FUTURE 7 (Georgetown Univ., Long-Term Care Fin. Proj., ed. 2007). The cited 2005 National Health Interview Survey and 2004 National Nursing Home Survey data could not be substantiated.

2. KAISER COMM'N ON MEDICAID FACTS, MEDICAID AND LONG-TERM CARE SERV. AND SUPPORTS 1 (2011), available at <http://www.kff.org/medicaid/upload/2186-08.pdf>. The cited 2010 CMS National Health Accounts Data could not be substantiated.

3. *Id.*

4. Jeffery R. Brown & Amy Finkelstein, *Private Mkt. for Long-Term Care Ins. in the United States: A Review of the Evidence*, 76 J. OF RISK AND INS. 5, 10 (2009).

5. *Id.*

source of help with daily activities, the true cost of long-term care can be difficult to measure.<sup>6</sup> Approximately four-fifths of the national long-term care spending is on the elderly.<sup>7</sup> Furthermore, a 2011 study by McKinsey & Company has shown that long-term and home care has grown faster than any other segment of the health economy since 2006.<sup>8</sup> As the baby boomer generation ages and reaches retirement, the population making use of long-term and home care can be expected to grow significantly and increase the demand for long-term care.<sup>9</sup> Therefore, overall expenditures on long-term care and health care overall are likely to increase accordingly.

By 2020, over twelve million Americans are expected to need long-term care.<sup>10</sup> The US government expects most people to receive long-term care at home, with family and friends being care providers for seventy percent of the elderly.<sup>11</sup> Most long-term care involves assistance with support services in daily living activities, such as dressing, bathing, and using the restroom.<sup>12</sup> However, Medicare does not pay for long-term care because Medicare does not pay for activities that are considered to be part of daily living.<sup>13</sup> Medicare pays only for medically necessary skilled nursing facilities or home health care.<sup>14</sup>

In addition, the economic recession is projected to have significant effects on the health care system and future health care spending, as the recession influences slower spending growth. The recession is also

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6. H. Stephen Kaye et al., *Long-Term Care: Who Gets It, Who Provides It, Who Pays, And How Much?*, 29 HEALTH AFFAIRS 11, 20 (2010).

7. *Id.* at 19.

8. Jesse W. Bradford et al., ACCOUNTING FOR THE COST OF U.S. HEALTH CARE: PRE-REFORM TRENDS AND THE IMPACT OF THE RECESSION 23 (McKinsey & Co., McKinsey Ctr. for U.S. Health Sys. Reform Proj., ed. 2011).

9. *Id.* at 24.

10. MEDICARE.GOV, *What is Long-Term Care?*, available at <http://www.medicare.gov/longtermcare/static/home.asp>. (last visited Feb. 17, 2013.)

11. *Id.*

12. *Id.*

13. *Id.*

14. *Id.*

assumed to contribute a shift in payment sources, as more individuals are expected to finance long-term care using Medicaid rather than private health insurance and private savings as result of the recession.<sup>15</sup>

Currently, the US health care system lacks a coordinated financing system for long-term care.<sup>16</sup> Medicare provides limited coverage of long-term care, and Medicaid has become the primary funding source for long-term care.<sup>17</sup>

This system of paying for long-term care cannot continue. It seems likely that the future demand for long-term care will rise at a higher rate compared to the current rate of growth due to the aging of the baby-boomer generation. Furthermore, the reliance on Medicaid by the elderly for long-term care also can be expected to increase. Paying for long-term care will be one of the most significant issues in the future of health care, and an alternative way to source long-term care to alleviate current financial problems of paying for long-term care should be explored.

## II. CURRENT LONG-TERM CARE FINANCE OPTIONS

Most of the long-term care of the elderly is provided through personal savings, private insurance, Medicaid, Medicare, and family members. Although each of the major long-term care financing options provides a unique way of providing payment, each financing option presents distinct challenges.

First, approximately twenty-two percent of overall long-term care expenditures is funded through personal savings or out-of-pocket

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15. Christopher J. Truffer et al., *Health Spending Projections Through 2019: The Recession's Impact Continues*, 29 HEALTH AFFAIRS 1, 7-8 (2010).

16. Paul H. Keckly & Barbara Frink, *ISSUE BRIEF: MEDICAID LONG-TERM CARE: THE TICKING TIME BOMB 3* (Deloitte, Ctr. for Health Solutions Proj., ed. 2010).

17. KAISER COMM'N ON MEDICAID AND THE UNINSURED, *MEDICAID'S LONG-TERM CARE USERS: SPENDING PATTERNS ACROSS INSTITUTIONAL AND CMTY.-BASED SETTINGS 1* (2011), available at <http://www.kff.org/medicaid/upload/7576-02.pdf>.

expenses.<sup>18</sup> Due to the high cost of long-term care, paying for long-term care can lead to exhausting one's savings.<sup>19</sup> However, reaching the level of impoverishment has a small benefit, as those individuals who have exhausted their savings are likely to qualify for Medicaid when their income and assets dip to qualifying levels.<sup>20</sup>

Private insurance financing accounts for roughly nine percent of total long-term care expenditures.<sup>21</sup> These insurance plans typically offer limited coverage for long-term care and can be expensive.<sup>22</sup> Also, these private insurance plans usually cover long-term care for only a limited time.<sup>23</sup> The combination of the limited coverage and paying high costs for coverage in a distant future has produced an environment of a low demand for long-term care insurance.

Medicaid accounts for about forty percent of total long-term financing.<sup>24</sup> Those that qualify for Medicaid long-term care services are required to have limited assets.<sup>25</sup> Medicaid pays for nursing home stays and other forms of home and community administered long-term care.<sup>26</sup> Medicaid can also act as a significant deterrent to individuals obtaining private long-term care insurance.<sup>27</sup> Since Medicaid is available to anyone who meets the income and asset threshold, Medicaid can be a safety net source of financing for the necessary long-term care services.<sup>28</sup> Although Medicaid has functioned as a

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18. Judith Feder et al., *supra* note 2, at 1.

19. *Id.*

20. Brown & Finkelstein, *supra* note 4, at 10.

21. Judith Feder et al., *supra* note 2, at 1.

22. Joanne Kenen, *The CLASS Act: The Long-Term Care Insurance Program Created by the Affordable Care Act Will be Reshaped to Address Concerns About Solvency*, HEALTH AFFAIRS, May 12, 2011, at 2.

23. *Id.*

24. Judith Feder et al., *supra* note 2, at 1.

25. *See generally, id.*

26. Kenen, *supra* note 22, at 2.

27. Jeffrey R. Brown & Amy Finkelstein, *The Interaction of Public and Private Ins.: Medicaid and the Long-Term Care Ins. Mkt.*, 98 AM. ECON. REV. 1083, 1096 (2008).

28. *See generally*, Judith Feder et al., *supra* note 2, at 1.

safety net for the most vulnerable members of society, many states are likely to face budgetary issues resulting from rising demand for long-term care financing through Medicaid.<sup>29</sup>

Medicare finances approximately twenty-three percent of total long-term care spending.<sup>30</sup> Medicare usually pays for short-term nursing home stays, health care received in the home after a hospital stay, or for home care if a patient has entered hospice.<sup>31</sup> However, it appears that many people have misperceived Medicare as a potential source for long-term care financing.<sup>32</sup> An AARP survey suggests that many believe Medicare provides more long-term care coverage than the amount of actual long-term care coverage.<sup>33</sup>

The final source of long-term care funding is through informal care by family members. It is common for spouses, children, or other family members of the elderly in need of long-term care to provide the necessary care without receiving any payment. This informal arrangement is often provided without any reporting or acknowledgement. Although informal long-term care is accepted as part of a family life, the hidden costs of informal care do not show up in many studies. The advancements in medicine, shorter hospital stays, reduced discharge planning and transitional care, and improvements in home-based treatments have shifted more treatment outside of health care facilities; as a result, those who provide informal care have faced higher and more complex responsibilities as informal care providers.<sup>34</sup> In 2009, AARP estimated that between 42.1 million and 61.6 million adult caregivers provided informal care at an

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29. Kenen, *supra* note 22, at 2.

30. Judith Feder et al., *supra* note 2, at 1.

31. Kenen, *supra* note 22, at 2.

32. *See generally id.*; AARP, THE COSTS OF LONG-TERM CARE: PUB. PERCEPTIONS VERSUS REALITY IN 2006 30 (GfK NOP Roper Pub. Affairs & Media Proj., ed. 2006).

33. *Id.*

34. Lynn Feinberg et al., *Valuing the Invaluable: 2011 Update The Growing Contributions and Costs of Family Caregiving*, AARP 9 (AARP, Pub. Policy Inst. Proj., ed 2011).

economic value of \$450 billion.<sup>35</sup>

Providing informal care has additional drawbacks for the providers of such care. Informal care providers are likely to experience stress<sup>36</sup> and financial hardships.<sup>37</sup> Providing informal care is also likely to negatively affect the provider's employment performance, as informal care providers sometimes miss work, leave early, or even permanently leave their positions.<sup>38</sup> As the result of combined losses in wages, pension, and Social Security, an average female informal care provider is expected to sacrifice \$274,044 in her lifetime.<sup>39</sup> For males, an average lifetime loss of \$233,716 is expected.<sup>40</sup> When multiplying this estimated average lifetime loss to the 9.7 million people over age of fifty who are providing informal care for their parents, the total loss of wages, pension, and Social Security for the entire population is approximately \$3 trillion.<sup>41</sup> The loss of employment productivity as a result of being an informal care provider, such as employees having to be replaced, absenteeism, work interruptions, unpaid leave, and switching from full-time to part-time employment, is estimated to be between \$17.1 billion and \$33.6 billion.<sup>42</sup>

### III. ALTERNATIVE SOURCE OF LONG-TERM CARE FUNDING

The cost providing long-term care becomes significant after

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35. *Id.* at 1.

36. *See generally* NATIONAL ALLIANCE FOR CAREGIVING IN COLLABORATION WITH AARP, CAREGIVING IN THE U.S. 50 (2009), *available at* [http://www.caregiving.org/data/Caregiving\\_in\\_the\\_US\\_2009\\_full\\_report.pdf](http://www.caregiving.org/data/Caregiving_in_the_US_2009_full_report.pdf).

37. *Id.* at 50-52.

38. *Id.* at 54-55.

39. METLIFE MATURE MARKET INST., METLIFE STUDY OF CAREGIVING COSTS TO WORKING CAREGIVERS: DOUBLE JEOPARDY FOR BABY BOOMERS CARING FOR THEIR PARENTS 14 (2011), *available at* <https://www.metlife.com/assets/cao/mmi/publications/studies/2011/mmi-caregiving-costs-working-caregivers.pdf>.

40. *Id.*

41. *Id.* at 15.

42. METLIFE MATURE MARKET INST. & NATIONAL ALLIANCE FOR CAREGIVING, JULY 2006, THE METLIFE CAREGIVING COST STUDY: PRODUCTIVITY LOSSES TO U.S. BUSINESS 18 (2006), *available at* <https://www.metlife.com/assets/cao/mmi/publications/studies/mmi-care-giver-cost-study-productivity.pdf>.

incorporating the hidden expenses. In addition, an overreliance on Medicaid for long-term care at a time when the need for long-term care is expected to increase while the funding for Medicaid is likely to decrease. The Patient Protection and Affordable Care Act attempted to address the long-term care financing issue through the Community Living Assistance Services and Supports Act.<sup>43</sup> Unfortunately, the Community Living Assistance Services and Supports Act was appealed.<sup>44</sup> Long-term care remains one of the most significant uninsured financial risks for the elderly in the US.<sup>45</sup> The number of elderly will increase, thereby increasing the financial burden on federal and state budgets, and utilizing Medicaid as a source of long-term care funding is likely to further strain the federal and state spending.<sup>46</sup>

Adapting Germany's mandatory, long-term care insurance system could provide significant financial assistance to providing long-term care. In 1995, Germany implemented a national mandatory long-term care system, funded through a 1.7 % payroll tax paid together by both employee and employer.<sup>47</sup> Generally, this payroll tax has allowed Germany's long-term care costs to remain financially sustainable.<sup>48</sup>

Germany has a universal health care system, and the health care system in the US significantly differs from the Germany's system; as a result, implementing an identical payroll tax method in the US could be difficult.<sup>49</sup>

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43. 42 U.S.C.A. § 300ll (2013).

44. Robert Pear, *Health Law to Be Revised by Ending a Program*, N.Y. TIMES, Oct. 14, 2011.

45. Jeffrey R. Brown & Amy Finkelstein, *Why is the Mkt. for Long-Term Care Ins. So Small?* 91 J. OF PUB. ECON., 1968, 1967-91 (2007).

46. U.S. GOV'T ACCOUNTABILITY OFFICE, GAO-05-564T, LONG-TERM CARE FIN. GROWING DEMAND AND COST OF SERV. ARE STRAINING FED. AND STATE BUDGET 11 (2007).

47. Howard Gleckman, *Long-Term Care Fin. Reform: Lessons from the U.S. and Abroad*, COMMONWEALTH FUND 6-7 (, Urban Inst. Proj., ed 2010).

48. *Id.* at 8.

49. Mary J. Gibson & Donald L. Redfoot, *Comparing Long-Term Care in Germany and the United States: What Can We Learn from Each Other?*, AARP 13 (Pub. Policy Inst. Proj.,

However, Medicare appears to be a logical way to create a national long-term care financing system through payroll tax.<sup>50</sup> Currently Medicare already has a system to generate revenue through collecting taxes for future medical treatment<sup>51</sup>, and adding another element to the Medicare system can be a natural and gradual expansion of Medicare coverage.

This expansion will require significant research to determine the appropriate tax increase required to address the current and future issues in financing long-term care. Furthermore, this expansion of Medicare can result in additional taxes, and many people will oppose increased taxation. Although this payroll expansion may be unpopular, it is a valid exercise of Congress' legislative power under the US Constitution.<sup>52</sup> In addition, an administrative agency, such as the Centers for Medicare & Medicaid Services, would be likely to gain the authority to create and manage this expansion through the deference it would receive from the Supreme Court.<sup>53</sup>

Collecting additional payroll tax in order to pay for Medicare to manage long-term care financing may be the only way to generate the necessary funding required to deal with the expected increase in usage of long-term care. Although expanding Medicare and its payroll tax may not be the perfect solution to finance long-term care, this expansion of Medicare could be a logical method to address the significant financial problems that will surface in the near future.<sup>54</sup>

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ed. 2007).

50. See Jacob S. Hacker, *Restoring Retirement Security: The Market Crisis, The "Great Risk Shift," and The Challenge for Our Nation*, 19 *Elder L. J.* 1, 45-6 (2011).

51. Lisa Potetz & Juliette Cubanski, *Medicare: A Primer on Medicare Finance*, HENRY J. KAISER FAMILY FOUN. 2 (2009).

52. U.S. Const. art. I, § 8, cl. 1.

53. See *Chevron, U.S.A., Inc. v. Natural Resources Defense*, 104 S.Ct. 2778, 2793 (1984).

54. See Hacker, *supra* note 50, at 45-6.

## IV. CONCLUSION

Currently long-term care remains one of the most significant uninsured risks for the elderly in the US, as numerous factors have contributed to the current state of long-term care financing. With the expected increase in the retirement of the baby-boomer generation, financing long-term care will remain a significant issue. Expanding Medicare to provide coverage of long-term care and financing may not be a perfect solution, but these changes could be a logical method to address the inevitable financial problems that will surface in the near future.<sup>55</sup>

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55. *Id.*

## Long-Term Care Insurance: An Endangered Species

*Nimmi Cleve\**

### I. INTRODUCTION

In our modern society, people are living longer<sup>1</sup> and the ability to afford long-term health care for this prolonged period has become increasingly difficult.<sup>2</sup> As a result, the issues of long-term care have become more challenging to address. Long-term care insurance (LTCI) was created to help assist with the affordability of long-term care.<sup>3</sup> Despite the intentions of its creators, LTCI has not proven to be a financially viable method of handling long-term care costs and therefore may cease to exist as discussed below.<sup>4</sup>

This article will discuss the extensive nature of long-term care and the magnitude its costs represent. Next, this article will discuss the explosive rise in long-term care costs and affordability. This article will then discuss the role LTCI plays to help mitigate these costs and address the obstacles private insurance companies face in providing LTCI to the marketplace. In addition, this article will discuss the goals and limitations of the government's answer to long-term care affordability: the CLASS Act. In this discussion of both the private and public sectors, this article will highlight how financial viability has proven to be elusive in both models of

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1. See LAURA B. SHRESTHA & ELAYNE J. HEISLER, CONG. RESEARCH SERV., RL32701, THE CHANGING DEMOGRAPHIC PROFILE OF THE UNITED STATES 14 (2011) [hereinafter THE CHANGING DEMOGRAPHIC PROFILE] <http://www.fas.org/spp/crs/misc/RL32701.pdf>.

2. Karin C. Ottens, *Using Tax Incentives to Solve the Long-Term Care Crisis: Ineffective And Inefficient*, 22 VA. TAX REV. 747, 753 (2003).

3. Joshua M. Weiner et al., *Federal and State Initiatives to Jump Start the Market for Private Long-Term Care Insurance*, 8 ELDER L.J. 57, 57-58 (2000).

4. See *infra* Parts IV & V.

LTCL.

## II. THE DEFINITION AND SCOPE OF LONG-TERM CARE

Long-term care constitutes a variety of services that include medical and non-medical care to meet health or personal needs over a long period of time.<sup>5</sup> Non-medical care is assistance with basic personal or household tasks of everyday life.<sup>6</sup> These tasks are called activities of daily living (ADLs) and/or instrumental activities of daily living (IADLs), and include activities such as bathing, dressing, taking medication, preparing meals and eating.<sup>7</sup> Long-term care can be provided in various settings, e.g., in the home, in the community, in assisted living facilities or in nursing homes.<sup>8</sup> Individuals who require long-term care include the elderly, the disabled, and those suffering from chronic debilitating conditions such as Alzheimer's and paralysis.<sup>9</sup>

Of the various populations that require long-term care, the largest group is the elderly (sixty-five and older).<sup>10</sup> With the aging of the seventy-six million Baby Boomers, it is anticipated that the elderly will continue to make up a growing percentage of the U.S. population and the amount of money required to meet their long-term health care needs will increase.<sup>11</sup> In 2012, about nine million men and women over the age of sixty-five needed long-term care.<sup>12</sup> By 2020, twelve million Americans age sixty-five and

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5. KAISER COMM'N ON MEDICAID AND THE UNINSURED, MEDICAID'S ROLE IN MEETING THE LONG-TERM CARE NEEDS OF AMERICA'S SENIORS 1 (Jan. 2013), <http://www.kff.org/medicaid/upload/8403.pdf>.

6. *Id.*

7. *Id.*

8. U.S. Dep't of Health and Human Servs. (HHS), *Long-Term Care*, <http://www.healthcare.gov/using-insurance/medicare-long-term-care/long-term-care/#longterm> (last visited Feb. 18, 2013).

9. Ottens, *supra* note 2, at 748-749.

10. *Id.* at 751-752.

11. *Id.*

12. HHS, *What is Long-Term Care?*, [hereinafter *What Is Long Term Care?*]

older will need long-term care.<sup>13</sup> Of this group, it is expected that approximately 43% will spend some time in a nursing facility.<sup>14</sup> “About 10 percent of the people who enter a nursing home will stay there five years or more.”<sup>15</sup> None of this care is free – it will come at the expense of the individual (private insurance and out-of-pocket expenditures) or the taxpayer (government program).<sup>16</sup>

As a subset of the elderly, those individuals aged eighty-five and older are most likely to need long-term care.<sup>17</sup> This age group is expected to reach seven million by 2020 and to double to fourteen million by 2040.<sup>18</sup> The aging of the Baby Boomer generation, coupled with the increase in life expectancy, creates a need for long-term care that is expected to grow exponentially.<sup>19</sup> Consequently, the costs of long-term care will also grow exponentially. It can be expected that increase in long-term care costs will create a tremendous financial burden on society in the future.

### III. THE RISE AND AFFORDABILITY OF LONG-TERM CARE COSTS

The growing need of long-term care hinges on its affordability. The cost of health care has risen precipitously over the past three decades.<sup>20</sup> “The share of GDP [Gross Domestic Product] devoted to health care spending grew from 9% in 1980 to 16% in 2008.”<sup>21</sup> In 2008, the per capita

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<http://www.medicare.gov/longtermcare/static/home.asp> (last updated Aug. 3, 2012).

13. *Id.*

14. Ottens, *supra* note 2, at 751.

15. What Is Long-Term Care?, *supra* note 12.

16. See HHS, *Paying for Long-Term Care*, <http://www.medicare.gov/longtermcare/static/home.asp> (last updated Aug. 3, 2012).

17. Ottens, *supra* note 2, at 751-52.

18. *Id.*

19. See U.S. Soc. Sec. Admin., *Life Expectancy for Social Security*, <http://www.ssa.gov/history/lifeexpect.html> (last modified Jan. 17, 2013).

20. KAISER FAMILY FOUNDATION, SNAPSHOT: HEALTH CARE COSTS, (April 28, 2011) [hereinafter HEALTH CARE COSTS] <http://www.kff.org/insurance/snapshot/oecd042111.cfm>.

21. *Id.* This means that sixteen cents of every dollar changing hands in the United States is spent on health care.

expenditure in the U.S. was \$7,538; nearly double the average of the top fifteen developed countries.<sup>22</sup> The amount spent on health care is expected to reach nearly \$4 trillion by 2015, or 20% of GDP.<sup>23</sup>

The Department of Health and Human Services (HHS) estimates that about 70% of Americans over age sixty-five will need long-term care support.<sup>24</sup> About one-third of all Americans will spend some time in a nursing home during their lives.<sup>25</sup> The average cost of living in a nursing home is catastrophic for the average middle class American: \$72,000 per year.<sup>26</sup> Assisted living environments that provide long-term care at a less intense level, average \$38,000 per year.<sup>27</sup> Although only 14% of long-term care recipients live in institutions like nursing homes and assisted living facilities, the cost to care for them makes up 70% of all expenditures on long-term care in the United States.<sup>28</sup> The other 86% of long-term care recipients, comprised of disabled children and adults, as well as some elderly persons, receive their care in the home.<sup>29</sup>

Median income may serve as a proxy for assessing affordability.<sup>30</sup>

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22. *Id.* In 2008, the per capita expenditure for the top fifteen developed countries ranged from \$2,729 (Japan) to \$7,538 (U.S.). *Id.* The average per capita expenditure of these fifteen countries is about \$3,922. *Id.*

23. Brendan W. Miller, *Your Money or Your Lifestyle!: Employer's Efforts to Contain Healthcare Costs-Lifestyle Discrimination Against Dependents of Employees?*, 5 *IND. HEALTH L. REV.* 371, 373 (2008).

24. HHS, *Who Needs Care?*, [http://www.longtermcare.gov/LTC/Main\\_Site/Understanding/Definition/Know.aspx](http://www.longtermcare.gov/LTC/Main_Site/Understanding/Definition/Know.aspx) (last visited Mar. 24, 2013).

25. Gary A. Simon, *Can Long-Term Care Insurance Be Fixed?*, 37 *J. HEALTH CARE FIN.* 51, 51 (2010).

26. *See* KAISER COMM'N ON MEDICAID & THE UNINSURED, *MEDICAID AND LONG-TERM CARE SERVICES AND SUPPORTS 1* (Oct. 2010), <http://www.kff.org/medicaid/upload/2186-07.pdf>.

27. *Id.*

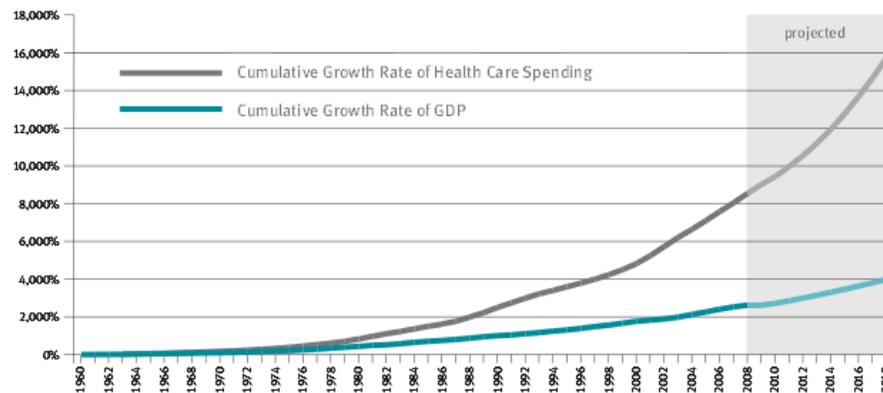
28. *Id.* Total long-term care expenditures total \$177.6 billion. *Id.* Total nursing home care expenditures total \$124.9 billion and that is roughly 70% of total long-term care expenditures. *Id.*

29. *Id.*

30. *See generally* DAVID A. VANDENBROUCKE, U.S. DEPARTMENT OF HOUSING AND URBAN DEVELOPMENT, *HOUSING AFFORDABILITY DATA SYSTEM 7-8* (2011).

Median income grew about 15% between 1980 and 2008.<sup>31</sup> During this same time period, however, the share of GDP spent on health care grew about 78%.<sup>32</sup> This far outstripped the growth rate of median income. If these dual rates of growth persist, health care will become increasingly more unaffordable in the future. To further illustrate, the per capita expenditure on health care during this period grew roughly 900% as seen in the graph below.<sup>33</sup>

Figure 1: Cumulative growth rates of GDP and health care spending: United States, 1960-2007 and projected for 2008-2018



Source: Office of the Actuary, Centers for Medicare and Medicaid Services, 2008<sup>34</sup>

The affordability of long-term care was and continues extending beyond the reach of the average American.<sup>35</sup> This precipitated the creation of LTCL.<sup>36</sup> Its role,

31. U.S. Dep't. of Commerce, *The 2012 Statistical Abstract - Money Income of Households - Median Income by Race and Hispanic Origin in Current and Constant (2009) Dollars*, <http://www.census.gov/compendia/statab/> (last visited Mar. 16, 2013). In 1980, the median income was \$43,892 and in 2008, the median income was \$50,112. This represents an approximate 15% increase. *Id.*

32. HEALTH CARE COSTS, *supra* note 20. In 1980, 9% of GDP was dedicated to health care spending and in 2008, 16% of GDP was dedicated to health care spending. *Id.* This represents a 78% increase. *Id.*

33. SOC. SEC. ADVISORY BD., *THE UNSUSTAINABLE COST OF HEALTH CARE I* (Sep. 2009) [hereinafter UNSUSTAINABLE COST] [http://www.ssab.gov/documents/TheUnsustainableCostofHealthCare\\_graphics.pdf](http://www.ssab.gov/documents/TheUnsustainableCostofHealthCare_graphics.pdf). The cumulative growth rate of health care spending in 1980 was about 1,000%. *Id.* In 2008, the cumulative growth rate of health care spending increased to about 9,000%. *Id.* This represents about a 900% total increase. *Id.*

34. *Id.*

as is true for any insurance product, was to make long-term care affordable and attainable by managing and distributing the costs associated with it.<sup>37</sup> Unfortunately, this task proved to be unrealistic as discussed below.

#### IV. LTCI IN THE PRIVATE SECTOR

Personal financing and Medicaid have historically served to meet the costs of long-term care.<sup>38</sup> Those who could afford it paid for their own long-term care expenses out-of-pocket, while those who could not afford it relied on Medicaid for their long-term care needs.<sup>39</sup> More recently, the rising cost of health care has made it unaffordable for many individuals who do not qualify for Medicaid to personally finance their health care needs.<sup>40</sup>

Insurance companies in the private sector introduced LTCI in an attempt to bridge this growing financial shortfall that individuals faced.<sup>41</sup> This product was meant to enable individuals to afford the growing costs of their health care.<sup>42</sup> Insurance companies modeled LTCI on traditional health insurance metrics such as current health care costs, the anticipated rates of increase in these costs, historical policy lapse rates, historical yield on investments, and other operating expenses.<sup>43</sup>

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35. Weiner et al., *supra* note 3.

36. *Id.* at 58.

37. See Jeffrey R. Brown & Amy Finkelstein, *The Interaction of Public and Private Insurance: Medicaid and the Long-Term Care Insurance Market* 5-6 (Nat'l Bureau of Econ. Research, Working Paper No. 10989, 2004).

38. See Weiner et al., *supra* note 3 at 59.

39. HHS, *Eligibility*, <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Eligibility/Eligibility.html> (last visited Mar. 16, 2013). To be eligible for Medicaid, an individual must have a low income and meet a federal or state recognized eligibility group, such as children, the elderly, or those with disabilities. *Id.*

40. Lawrence A. Frolik, *An Essay on the Need for Subsidized, Mandatory Long-Term Care Insurance*, 21 NOTRE DAME J.L. ETHICS & PUB. POL'Y. 517, 521 (2007).

41. Seth J. Chandler, *Long Term Care: The Next Healthcare Frontier*, 19 ANNALS HEALTH L. 19, 19-20 (2010). LTCI was introduced as early as the 1970's. *Id.*

42. *Id.*

43. Comment, *Cost and Coverage of Industrial Life Insurance*, 61 YALE L.J. 46, 50 (1952). Policy lapse rate refers to the rate at which insurance policy holders stop paying their premiums thereby allowing their policy to lapse. *Id.* at 54. Once this occurs, an insurance company is released from any payment obligations and retains all premiums paid to date. Sharo M. Atmeh, *Regulation Not Prohibition: The Comparative Case Against the Insurable Interest Doctrine*, 32 NW. J. INT'L L. AND BUS. 93, 134 (2011).

In addition to the aforementioned criteria, insurance companies accounted for circumstances like the present and future cognitive capacity of the insured.<sup>44</sup> These capacities may be compromised, for example, in people suffering from Alzheimer's and dementia.<sup>45</sup>

The private LTCI market initially grew slowly due to low participation and high premiums.<sup>46</sup> Eventually, some insurance companies felt it was not possible to offer LTCI and remain profitable owing to an increase in anticipated costs, a decrease in policy lapse rates, and a decrease in rates of return.<sup>47</sup> It is important to remember that in addition to accomplishing the beneficial outcomes that LTCI affords, the underlying goal of insurance companies is profitability.<sup>48</sup> As a result, ten out of the top twenty insurance companies exited the LTCI market.<sup>49</sup> Other companies that chose to continue to offer LTCI have made continuous changes to their policies by decreasing discounts and increasing premiums.<sup>50</sup> The likelihood of private insurance companies to continue selling LTCI is questionable in a world where the ability to offer LTCI and remain profitable is diminishing.

#### V. LTCI IN THE PUBLIC SECTOR

Given the growing elderly population and rising costs of health care, Medicaid faces its own fiscal predicament as these factors compromise the government's ability to maintain the current level of benefits.<sup>51</sup> As many elderly persons cannot afford private long-term care insurance and also cannot afford to pay the high costs

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44. Ottens, *supra* note 2, at 749.

45. *Id.*

46. Simon, *supra* note 25.

47. Howard Gleckman, *What's Killing the Long-Term Care Insurance Industry*, FORBES, Aug. 29, 2012. In 2010, Met Life, one of the biggest players in the LTCI market, decided to no longer offer the product. Ron Lieber, *When A Safety Net Is Yanked Away*, N. Y. TIMES, Nov. 12, 2010. In 2012, Unum discontinued selling LTCI and was soon followed by Prudential Insurance. Gleckman, *supra* note 47.

48. Whitney R. Maudlin, *Good Business/Bad Faith: Why the Insurance Industry Should Adopt a Good Faith Model*, 44 TORT TRIAL & INS. PRAC. L.J. 151, 151 (2008).

49. Kelly Greene, *Long-Term Care: What Now?*, WALL ST. J., Mar. 9, 2012.

50. Gleckman, *supra* note 47.

51. Diane L. Dick, *Tax and Economic Policy Responses to the Medicaid Long-Term Care Financing Crisis: A Behavioral Economics Approach*, 5 CARDOZO PUB. L. POL'Y & ETHICS J. 379, 383 (2007).

of long-term care, they turn to Medicaid.<sup>52</sup> It is true, however, one cannot be a Medicaid beneficiary without meeting certain low-income and asset criteria.<sup>53</sup> Thus, many people, including the elderly, make gifts of property to others and voluntarily impoverish themselves in order to meet these criteria.<sup>54</sup> The elderly make up a considerable portion of Medicaid's beneficiaries.<sup>55</sup> In 2004, more than one-third of total Medicaid dollars were spent on long-term care for the elderly.<sup>56</sup> The number of elderly persons will only drastically increase as the Baby Boomers continue to age and this demographic change jeopardizes the ability of Medicaid to remain financially solvent.<sup>57</sup> As more elderly people become Medicaid eligible, unfortunately, the available funds will be severely inadequate.<sup>58</sup>

The federal government decided to introduce its own version of LTCI as a vehicle to work in conjunction with Medicaid to help meet the rising costs of long-term care.<sup>59</sup> On March 23, 2010, President Barack Obama signed the Community Living Assistance Services and Supports Act (CLASS Act) into law as part of the Patient Protection and Affordable Care Act.<sup>60</sup> The federal government intended the CLASS Act to be a voluntary, national long-term care insurance option for employees via their employer.<sup>61</sup>

The CLASS Act was designed to provide a cash benefit to individuals with functional limitations for the purchase of non-medical services and supports<sup>62</sup>

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52. *Id.* at 382.

53. *Id.*

54. *Id.*

55. *Id.* at 383.

56. *Id.*

57. *Id.*; See generally Symposium, *Market Principles: The Right Prescription for Medicaid*, 17 STAN. L. & POL'Y. REV. 33, 34 (2006). (This article references the state of Florida, however, the Medicaid situation in Florida can be extrapolated to the Medicaid situation across the nation.)

58. Joshua Tenzer, *Reaching the Final Frontiers in Medicaid Managed Care*, 62 N.Y.U. ANN. SURV. AM. L. 329, 345 (2006).

59. KAISER FAMILY FOUNDATION ON HEALTH REFORM, HEALTH CARE REFORM AND THE CLASS ACT 1 (Apr. 2010), [hereinafter CLASS ACT] <http://www.kff.org/healthreform/upload/8069.pdf>.

60. *Id.*

61. 42 U.S.C. § 3201 (2010); 42 U.S.C. § 3204(a)(1) (2010).

62. Examples of community living services and supports include housing modification,

necessary to maintain community residence.<sup>63</sup> The goal of the legislation was to provide workers with a financing alternative for long-term care that supports community living and does not require people to turn to Medicaid, an option that would only drive Medicaid costs up.<sup>64</sup>

The program was financed through monthly premiums paid by voluntary contributions of working individuals.<sup>65</sup> An individual's monetary benefit was not subject to any lifetime or aggregate limit.<sup>66</sup> Equally important to note is that only the payer was eligible for benefits.<sup>67</sup> This was in contrast to many employer-offered, traditional health insurance plans that may include spouses and dependents as beneficiaries.<sup>68</sup> The CLASS Act mandated that the program be self-funded over a seventy-five year period and not require any monies from taxes.<sup>69</sup>

One of the privileges that private insurance companies enjoy is to decide who they want to insure, and to impose limits on which conditions would be covered, for what period of time, and the maximum amount they are willing to pay in benefits.<sup>70</sup> The CLASS Act, while having some latitude in setting its own parameters, differed in one significant aspect: it could not turn anyone away that met the minimum qualifications of eligibility, i.e., being a working individual.<sup>71</sup>

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assistive technologies, personal assistance services and transportation. CLASS ACT, *supra* note 59, at 2.

63. *Id.* at 1; 42 U.S.C. § 3201(1) (2010).

64. *See* 42 U.S.C. § 3201.

65. CLASS ACT, *supra* note 59, at 2. To qualify for benefits, individuals had to be at least eighteen-years-old and have contributed monthly premiums to the program for at least five years. Additionally, individuals must have been unable to perform multiple ADLs or had a cognitive disability that required supervision to perform daily tasks, e.g. Alzheimer's. Eligible individuals would receive a cash benefit based on the degree of their disability or impairment and averaging no less than \$50 a day. The Secretary of Health and Human Services set the benefit amount relative to the functional limitation. *Id.*

66. 42 U.S.C. § 3203(a)(1)(D)(iv).

67. CLASS ACT, *supra* note 59, at 2.

68. Nat'l Ass'n of Ins. Commissioners, *Health Insurance Open Enrollment: Choosing the Best Option for You and Your Family* (Oct. 2008), [http://www.naic.org/documents/consumer\\_alert\\_health\\_insurance\\_open\\_enrollment.htm](http://www.naic.org/documents/consumer_alert_health_insurance_open_enrollment.htm).

69. 42 U.S.C. § 3208(a)-(b) (2010).

70. *See* Nat'l Ass'n of Health Underwriters, *Consumer Guide to Individual Health Insurance* (2013) <http://www.nahu.org/consumer/IndividualInsurance.cfm>.

71. Morris Klein, *The New Class Act*, 7 NAELA J. 35, 37-38 (2011).

As a result, workers that could not obtain or afford LTCI in the private sector would choose the public option.<sup>72</sup> More importantly, because participation in the CLASS program was voluntary, it was likely that younger, healthier workers would opt out of paying the premium.<sup>73</sup> Therefore, those workers most likely to need the CLASS program would be its sole enrollees representing the most risk and requiring a greater amount of paid benefits.<sup>74</sup>

Congress legislated two criteria for the CLASS Act: voluntary participation by working individuals and a self-funded program for seventy-five years without any tax dollars.<sup>75</sup> These mandates created a challenging environment within which the program had to operate and remain viable.<sup>76</sup> Consequently, nineteen months after the passage of the CLASS Act, HHS concluded that the CLASS Act was not financially sustainable.<sup>77</sup> On January 2, 2013, Congress repealed the CLASS Act.<sup>78</sup> The federal government clearly recognized that this version of LTCI was not a financially viable solution to address the nation's long-term care needs.

## VI. LTCI AND ITS INHERENT PROBLEMS

LTCI began as a promising means to contain escalating long-term care costs, but has not met with the success that was originally anticipated.<sup>79</sup> LTCI may not be a bad product by nature, however, two main factors are leading to its eventual demise. First, the limitations of the structures of both private and public LTCI and, second, the escalating long-term care costs.<sup>80</sup>

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72. Alexander N. Daskalakis, *Public Options: The Need for Long-Term Care, Its Costs, and Government's Attempts to Address Them*, 5 ST. LOUIS U. J. HEALTH L. & POL'Y 181, 201 (2011).

73. *Id.* at 203.

74. *Id.*

75. CLASS ACT, *supra* note 59, at 2.

76. Memorandum from Kathy Greenlee, *CLASS Adm'r to Kathleen Sebelius, Sec'y Health and Human Serv.* (Oct. 14, 2011), available at <http://aspe.hhs.gov/daltcp/reports/2011/class/CLASSmemo.shtml>.

77. *Id.*

78. American Taxpayer Relief Act of 2012, Pub. L. No. 112-240, § 642 (2013).

79. Gleckman, *supra* note 47.

80. *See supra* Parts III, IV & V.

One way to help understand this dichotomy is to envision a swimming pool as representative of an LTCI instrument. The pool has one intake pipe, and two outlet pipes to regulate the water level. The purpose of these three pipes is to maintain an adequate water level within the pool so that it does not run dry. The intake pipe represents funding for the LTCI instrument. The first outlet pipe, and by far the larger of the two, represents the instrument's financial obligations. The second outlet pipe represents the cost associated with administering the LTCI instrument. If the drainage rate exceeds the fill rate, the pool will eventually run dry. The current problem that the LTCI universe faces is precisely this: expenditures are far exceeding funding. Therefore, the LTCI model is not financially viable in its current avatar. In an effort to remedy the situation, the funding needs to increase, expenditures need to decrease, or a combination of both needs to occur.

## VII. CONCLUSION

On a macro level, the issue of long-term care should be addressed with regard to both its cost and the ability of individuals to cover that cost. The exponential growth in the cost of health care severely handicaps the individual and overburdens the system.<sup>81</sup> At no other time since the inception of Medicaid, have health care costs escalated as fast as they have today.<sup>82</sup> LTCI was a measure introduced to help mitigate the high costs of long-term care.<sup>83</sup> Perhaps some consideration should be paid to the task of containing the elevated costs of health care versus solely trying to pay for them. The eventual and necessary goal is to ensure that the "LTCI pool" does not run dry. By entertaining *both* sides of the problem, it may afford a solution that is more attainable. Unfortunately, LTCI has not yet proven itself to be the panacea that it was originally touted to be.

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81. Weiner et al., *supra* note 3, at 58.

82. See UNSUSTAINABLE COST, *supra* note 33.

83. Chandler, *supra* note 41.

The Role of Patient-Centered Medical Homes In  
Reducing State Medicaid Programs' Long-Term  
Care Costs

*Serj Mooradian\**

I. INTRODUCTION

As Americans live longer, the country's long-term care needs are increasing.<sup>1</sup> Approximately twelve million people in the United States need long-term care; this number is expected to increase to twenty-seven million by 2050.<sup>2</sup> The cost associated with this dramatic rise is unsustainable, particularly by Medicaid, which pays for forty-three percent of the country's long-term care.<sup>3</sup> In 2009, this amount was \$171.8 billion or 47.8% of Medicaid's total cost.<sup>4</sup> Between retiring baby boomers and the Medicaid expansion under the Patient Protection and Affordable Care Act ("PPACA"), the Congressional Budget Office predicts that Medicaid long-term care costs will increase by an average of 7% per year over the next ten years<sup>5</sup> - more than doubling over this timeframe.<sup>6</sup> This highlights the

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1. *See generally* ROBERT WOOD JOHNSON FOUND., CAN CULTURE CHANGE OFFER VIABLE SOLUTIONS TO MEET INCREASED DEMANDS FOR LONG-TERM CARE? 1 (2012) [hereinafter CULTURE CHANGE], available at [http://rwjf.org/content/dam/farm/reports/issue\\_briefs/2012/rwjf401182](http://rwjf.org/content/dam/farm/reports/issue_briefs/2012/rwjf401182). Seventy percent of American adults alive today will need long-term care in their lives. *Id.* This will increase as the proportion of the population over sixty-five rises. *Id.* In the next twenty years, the percentage of Americans over sixty-five years old will increase from roughly 13% to 19% of the population, an increase from over forty million to approximately seventy million people. *Id.*

2. *Id.* This dramatic increase is likely to be partly due to an increase in the prevalence of Alzheimer's disease. *See id.*

3. *Id.*

4. MEDICAID & CHIP PAYMENT & ACCESS COMM'N, REPORT TO THE CONGRESS ON MEDICAID AND CHIP 114 (2012) [hereinafter MACPAC REPORT], available at [http://www.macpac.gov/reports/2012-06-15\\_MACPAC\\_Report.pdf](http://www.macpac.gov/reports/2012-06-15_MACPAC_Report.pdf).

5. CONG. BUDGET OFFICE, SPENDING AND ENROLLMENT DETAIL FOR CBO'S FEBRUARY

urgency with which long-term care costs within Medicaid must be contained.

The federal government and states have a shared interest in Medicaid cost containment. Medicaid is a federal-state program,<sup>7</sup> in which the federal government funds 57% of its entire cost.<sup>8</sup> The specific percentage varies from state to state, as the states can increase their share of specific parts of the program by offering additional services.<sup>9</sup> One of the specific parts that some states supplement is long-term care.<sup>10</sup> In 2010, the states paid for fifty-three percent of total Medicaid long-term care costs.<sup>11</sup>

Despite predictions that state budgets will improve in 2013,<sup>12</sup> containing Medicaid expenses should remain a top priority to the states. Medicaid consumes twenty-four percent of the states' combined budgets.<sup>13</sup> Controlling the cost of long-term delivery can therefore help improve the states' budgets generally. Feasibly, the states have two approaches to reducing their long-term-care-related Medicaid costs: they can shift the cost

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2013 BASELINE: MEDICAID (2013), *available at* <http://www.cbo.gov/sites/default/files/cbofiles/attachments/43885-Medicaid.pdf>.

6. The author calculated that a 7% increase over ten years results in a total 197% increase. Based on the MEDPAC Report numbers, this would lead to a total long-term care costs of \$338.5 billion by 2019. *See* MACPAC REPORT, *supra* note 4.

7. *See* Ctrs. for Medicare & Medicaid Servs., *Financing and Reimbursement*, MEDICAID.GOV, <http://medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Financing-and-Reimbursement/Financing-and-Reimbursement.html> (last visited Apr. 28, 2013).

8. *Id.*

9. *Id.*

10. *See* Kaiser Family Found., *Distribution of Medicaid Spending on Long Term Care, FY2010*, STATE HEALTH FACTS, <http://www.statehealthfacts.org/comparetable.jsp?typ=4&ind=180&cat=4&sub=47> (last visited Apr. 28, 2013).

11. *See id.* Please note that author added the totals spent by each individual state and compared the sum to the amount spent by the federal government.

12. Pamela M. Prah, *States' Fragile Recovery at Risk*, STATELINE (Jan. 23, 2013), <http://www.pewstates.org/projects/stateline/headlines/states-fragile-recovery-at-risk-85899444612>.

13. *Id.*

of long-term care to consumers<sup>14</sup> or, alternatively, they could reduce the overall cost of long-term care delivery.<sup>15</sup> Both methods would reduce the states' share of long-term care cost. The former is traditionally done through financial incentives, but this option does not solve the rising costs issue.<sup>16</sup> Lowering the cost of long-term care delivery is the most viable way forward. Primary-care reform, through the implementation of Patient-Centered Medical Homes ("PCMHs"), is a better solution. Community Care of North Carolina is an example of a state Medicaid program that has successfully curbed long-term care costs through the implementation of a PCMH model in its Medicaid delivery.<sup>17</sup>

## II. FAILURE OF STATE ATTEMPTS TO SHIFT THE COSTS OF LONG-TERM CARE TO CONSUMERS

Traditionally, some states have tried to ease their long-term care financing burden by shifting the cost to consumers.<sup>18</sup> States have done so in two ways: through tax incentives for purchasing long-term care insurance<sup>19</sup> and with Long-Term Care Partnership Programs ("partnership programs").<sup>20</sup> Twenty-eight states and the District of Columbia offer tax deductions for individuals and/or employers who purchase long-term care insurance.<sup>21</sup> However, tax deductions have been ineffective at incentivizing consumers to buy long-term care insurance, primarily because the deductions are so small that they do not function as enough of an

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14. *See infra* Part II.

15. *See infra* Parts III-V.

16. *See infra* Part II.

17. *See infra* Part V.

18. *See infra* notes 21-29 and accompanying text.

19. *See infra* notes 21-25 and accompanying text

20. *See infra* notes 26-29 and accompanying text.

21. *Long-Term Care Insurance Tax-Deductibility Rules*, AM. ASS'N FOR LONG-TERM CARE INS., <http://www.aaltci.org/long-term-care-insurance/learning-center/tax-for-business.php> (last visited Apr. 28, 2013).

incentive.<sup>22</sup> Instead, they merely reward those consumers who would otherwise be purchasing the insurance.<sup>23</sup> Further complicating the problem, individuals who know that Medicaid will cover the cost of their long-term care expenses have little incentive to incur the cost of the insurance, even with a tax break.<sup>24</sup> Long-term care insurance is just “too expensive, especially for older individuals who need it the most.”<sup>25</sup>

Second, many states attempt to incentivize the purchase of long-term care insurance through partnership programs, in which the states relax Medicaid eligibility requirements for individuals who have purchased long-term care insurance policies.<sup>26</sup> All but six states and the District of Columbia have partnership programs in place.<sup>27</sup> However, the same problems arise with these programs as with tax incentives – long-term care insurances policies are expensive. Partnership programs are “ideally suited [to encourage] *middle-income* Americans” to buy long-term care insurance.<sup>28</sup> However, many middle-income Americans would otherwise not be eligible for Medicaid.<sup>29</sup> Therefore, while partnership programs do

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22. See Karin C. Ottens, *Using Tax Incentives to Solve the Long-Term Care Crisis: Ineffective and Inefficient*, 22 VA. TAX REV. 747, 764 (2003). Although Ottens’s article discusses federal tax deductions, the author applies the premise to state tax deductions.

23. *Id.*

24. *Id.* at 764.

25. *Id.* at 765.

26. See generally Dep’t of Health & Human Servs., *State Partnership Programs*, LONGTERMCARE.GOV, [http://www.longtermcare.gov/LTC/Main\\_Site/Paying/Private\\_Financing/LTC\\_Insurance/State\\_Partnership.aspx](http://www.longtermcare.gov/LTC/Main_Site/Paying/Private_Financing/LTC_Insurance/State_Partnership.aspx) (last visited Apr. 28, 2013) (giving an overview of the program).

27. *Long Term Care Insurance Partnership Plans*, AM. ASS’N FOR LONG-TERM CARE INS., <http://www.aaltci.org/long-term-care-insurance/learning-center/long-term-care-insurance-partnership-plans.php#approved> (last visited Apr. 28, 2013).

28. *Id.* (emphasis added).

29. See KAISER FAMILY FOUND., *WHERE ARE STATES TODAY? MEDICAID AND CHIP ELIGIBILITY LEVELS FOR CHILDREN AND NON-DISABLED ADULTS 3* (2013), available at <http://www.kff.org/medicaid/upload/7993-03.pdf>. In 2013, the upper income limits for Medicaid eligibility among the states range from 160%-400% of the Federal Poverty Line. *Id.* This upper limit is \$37,680-\$94,200 for a family of four. See DEP’T HEALTH & HUMAN SERVS., *2013 POVERTY GUIDELINES 1* (2013), available at

encourage more individuals to buy long-term care insurance generally, they do not comprehensively confront the problem of rising long-term care costs by the people that Medicaid is supposed to cover: those who cannot afford long-term care insurance in the first place.

To address the cost problem associated with long-term care delivery by Medicaid programs, the states need to reform the way they deliver primary care to their Medicaid populations. Long-term care costs are rising too quickly for consumers to be able to absorb them, even with long-term care insurance.<sup>30</sup> The states need to disrupt the current model of long-term care delivery in order to effectuate meaningful cost savings. Primary care reform through the implementation of PCMHs will be such a disruption.

### III. OVERVIEW OF PATIENT-CENTERED MEDICAL HOMES

PCMHs deliver primary-care through multidisciplinary teams that provide “accessible, comprehensive, coordinated, and continuous patient-centered care.”<sup>31</sup> In addition to the traditional, fee-for-service type reimbursements, PCMHs receive a capitated monthly management fee from payors, to coordinate patients’ care.<sup>32</sup> PCMHs typically have a dedicated care coordinator to work with clinicians and other providers.<sup>33</sup> The extra coordination helps PCMHs optimize their patients’ health outcomes by intervening with preventive measures before the medical issues become more complex.<sup>34</sup>

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Poverty-level-charts.pdf.

30. *See supra* Part I.

31. Mary Takach, *About Half of the States are Implementing Patient-Centered Medical Homes For Their Medicaid Populations*, 31 HEALTH AFF. 2432, 2432 (2012) [hereinafter Takach].

32. *See id.* at 2433-34.

33. *Id.* at 2434.

34. Daniel D. Meang et al., *Reducing Long-Term Cost by Transforming Primary Care: Evidence from Geisinger’s Medical Home Model*, 18 AM. J. MANAGED CARE 149, 154 (2012).

Twenty-five states have incorporated PCMHs into their Medicaid programs,<sup>35</sup> which is due, in part, to federal funding made available under the PPACA.<sup>36</sup> The PPACA funding is specifically for states that designate health teams who operate as health homes for individuals with chronic conditions.<sup>37</sup> This suggests that Congress viewed PCMHs as a feasible option for reducing the cost of chronic care.

PPACA does not define PCMH.<sup>38</sup> However, the Agency for Healthcare Research and Quality, part of the Department of Health and Human Services, defines it as encompassing five functions and attributes:

- (1) Comprehensive care by a group of multidisciplinary providers to meet the large majority of its patients' physical and mental health needs, including prevention and chronic care;
- (2) Patient-centered orientation, in which providers understand and respect their patients' unique needs, culture, values, and preferences;
- (3) Coordinated care between the providers in all settings, including specialty care, hospitals, home health care, community services, and supports, especially during transitions between sites of care;
- (4) Accessible services with shorter waiting times for urgent needs, enhanced in-person hours, around the clock telephone or electronic access to a member of the care team; and
- (5) A demonstrated commitment to quality and quality improvement by ongoing engagement in activities such as using evidence-based medicine and clinical decision-support tools.<sup>39</sup>

These attributes create the ideal conditions for reducing the incidence of chronic disease. As discussed below, the reduction of chronic disease will,

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35. *Medical Home & Patient Centered Care*, NAT'L ACAD. FOR ST. HEALTH POL'Y, <http://www.nashp.org/med-home-map> (last visited Apr. 28, 2013).

36. 42 U.S.C. § 1396w-4(c)(1) (2010); *see also* Takach, *supra* note 31.

37. 42 U.S.C. § 1396w-4(c)(1).

38. *See id.*

39. *Defining the PCMH*, AGENCY FOR HEALTHCARE RES. & QUALITY, [http://pcmh.ahrq.gov/portal/server.pt/community/pcmh\\_\\_home/1483/PCMH\\_Defining%20the%20PCMH\\_v2](http://pcmh.ahrq.gov/portal/server.pt/community/pcmh__home/1483/PCMH_Defining%20the%20PCMH_v2) (last visited Apr. 28, 2013).

in turn, contribute to significantly containing the costs long-term care among Medicaid beneficiaries.

#### IV. LINKING PATIENT-CENTERED MEDICAL HOMES WITH DECREASING MEDICAID LONG-TERM CARE COSTS

PCMHs do not offer a silver bullet for Medicaid's long-term care cost crisis. Rather, they offer a way of transforming Medicaid primary-care delivery that specifically targets the population that is susceptible to needing long-term care services.<sup>40</sup> Implementing PCMH models reduces medical costs in medically complex patients,<sup>41</sup> all while also increasing medical outcomes in this population.<sup>42</sup>

The states should find it appealing to implement a system of health care delivery that targets vulnerable patients and coordinates these patients' care in a way that reduces their medical costs and their health outcomes.<sup>43</sup> If the model works, it will contain the long-term care problem before it is gets worse.

#### V. COMMUNITY CARE NORTH CAROLINA: A MODEL OF USING PATIENT- CENTERED MEDICAL HOMES TO COMBAT THE COST TO MEDICAID OF LONG-TERM CARE

Since 1998, Community Care North Carolina ("CCNC") has provided some evidence that states who adopt a PCMH model for their Medicaid

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40. T.J. Flottemesch et al., *Patient-Centered Medical Home Cost Reductions Limited to Complex Patients*, 18 AM. J. MANAGED CARE 677, 685 (2012).

41. *Id.* ("[A]mong the sickest and most costly patients, improved PMCH related systems appear to have been associated with reduced costs and utilization across multiple categories . . .").

42. See DOUGLAS MCCARTHY & KIMBERLY MUELLER, COMMUNITY CARE OF NORTH CAROLINA: BUILDING COMMUNITY SYSTEMS OF CARE THROUGH STATE AND LOCAL PARTNERSHIPS, 7-8 (2008) [hereinafter MCCARTHY & MUELLER], available at [http://www.commonwealthfund.org/~media/Files/Publications/Case%20Study/2009/Jun/1219\\_McCarthy\\_CCNC\\_case\\_study\\_624\\_update.pdf](http://www.commonwealthfund.org/~media/Files/Publications/Case%20Study/2009/Jun/1219_McCarthy_CCNC_case_study_624_update.pdf).

43. Vulnerable patients may include those with disabilities, mental illness, and chronic issues. See generally *id.*

programs can lower their long-term care costs in this way.<sup>44</sup> CCNC is a private-public partnership that brings together regional networks of healthcare delivery professionals to provide cooperative, coordinated care through the PCMH model.<sup>45</sup> The program is comprised of fourteen networks,<sup>46</sup> made up of physicians, hospitals, social service agencies, and county health departments.<sup>47</sup> Each network manages the care of its enrollees<sup>48</sup> and covers approximately 90% of its region's Medicaid enrollees.<sup>49</sup> Each covered enrollee is linked to a PCMH, which provides acute, chronic, and preventative care services, and coordinates secondary care on behalf of its patients.<sup>50</sup>

Instrumental in the coordination of care are CCNC's case managers, who identify specific patients who could benefit most from care coordination.<sup>51</sup> Such patients include those who make repeated emergency room visits; patients with asthma, diabetes, or heart failure; and patients with chronic conditions and high service use or complex care needs, including those with mental health conditions.<sup>52</sup> Case managers ensure continuity of care by working directly with patients to educate them about treatments and ensure that they stay compliant with the treatments.<sup>53</sup> The case managers also help

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44. *See generally id.*

45. *The Community Care Story: Why a Community-Based System Really Works*, CMTY. CARE OF N.C., <http://www.communitycarenc.org/about-us> (last visited Apr. 28, 2013).

46. *Working Together*, CMTY. CARE OF N.C., <http://www.communitycarenc.org/our-networks> (last visited Apr. 28, 2013).

47. KAISER COMM'N ON MEDICAID & THE UNINSURED, COMMUNITY CARE OF NORTH CAROLINA: PUTTING HEALTH REFORM IDEAS INTO PRACTICE IN MEDICAID 3 (2009) [hereinafter KAISER], available at <http://www.kff.org/Medicaid/upload/7899.pdf>.

48. *Id.*

49. *See* N.C. DEP'T OF HEALTH & HUMAN SERVS., NORTH CAROLINA MEDICAID CCNC/CA MONTHLY ENROLLMENT REPORT (2012), available at <http://www.ncdhhs.gov/dma/ca/enroll/caenr12.pdf>.

50. KAISER, *supra* note 47.

51. MCCARTHY & MUELLER, *supra* note 42.

52. *Id.*

53. *Id.*

clinical care providers assess the patients' care needs and work with the providers to ensure that the patients' needs are met.<sup>54</sup>

CCNC and the individual networks then use data gathered by the case managers to create evidence-based programs that aim to improve health outcomes either statewide (through CCNC) or locally (through the individual networks).<sup>55</sup> Statewide initiatives have targeted asthma, diabetes, efficient prescribing and use of drugs, and prescription drug management in nursing home patients.<sup>56</sup> Local initiatives include efforts to improve assessment and treatment of mental health patients and to coordinate care with local safety-net providers and indigent care programs to provide continuity of care to patients who move between Medicaid and being uninsured.<sup>57</sup> In these initiatives, the state has targeted inefficient parts of the Medicaid population and addressed them in order to prevent costs from spiraling out of control.

Using the PCMH model, CCNC has saved North Carolina at least \$700 million in Medicaid expenditures since 2006.<sup>58</sup> More aggressive estimates place savings at almost \$1 billion during 2007 to 2010.<sup>59</sup> While cutting costs, North Carolina has also improved quality outcomes for CCNC patients, as measured by national standards.<sup>60</sup> By targeting patients that are likely to need long-term care in the future, CCNC has lowered the cost of its future long-term care costs. While the amount has not been quantified, it is likely to be significant. The aggregate effect of such savings between

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54. *Id.*

55. *Id.* at 8.

56. *Id.* at 8-9.

57. *Id.* at 9.

58. Powerpoint Presentation, Cmty. Care of N.C., Community Care of North Carolina: 2012 Overview 23 (2012), <https://www.communitycarenc.org/about-us/> (last visited Feb. 17, 2013). The PowerPoint may be found at the bottom right of the webpage.

59. *Id.* at 17.

60. MCCARTHY & MUELLER, *supra* note 42, at 7-8 (discussing improved outcomes in emergency room admissions, asthma and diabetes outcomes, and lower drug expenditures).

several states would make a significant impact on Medicaid's long-term care costs nationwide.

Therefore, CCNC can serve as a model for the other twenty-four states that have committed to incorporating the PCMH model into their Medicaid programs.<sup>61</sup> The model is gaining acceptance across the clinical disciplines: among the many groups that have accepted the PCMH model as a viable way forward are the American Medical Association,<sup>62</sup> American Hospital Association,<sup>63</sup> hospitals and insurance companies,<sup>64</sup> and safety-net providers.<sup>65</sup> Many of these organizations are developing their own PCMH programs to take advantage of the potential cost savings they bring.<sup>66</sup> The general PCHM model is considered by some, including insurance companies, to be the engine that produces cost savings under the Accountable Care Organizations promulgated under the PPACA.<sup>67</sup> On paper, at least, the goodwill to implement PCMHs exists.

All these stakeholders need to work together to realize the potential savings that exist. By coordinating care, providers can work together to identify and effectively treat patients with both physical and mental health disabilities, avoid negative outcomes associated with transfers in care

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61. *See supra* note 35 and accompanying text.

62. AM. MED. ASS'N, REPORT OF THE COUNCIL ON MEDICAL SERVICE 6 (2009), available at <http://www.ama-assn.org/resources/doc/cms/a09-cms-rpt-8.pdf> (last visited Feb. 17, 2013).

63. AM. HOSP. ASS'N, PATIENT-CENTERED MEDICAL HOME: AHA RESEARCH SYNTHESIS REPORT 2 (2012), available at <http://www.aha.org/research/cor/patient-centered/index.shtml>.

64. *E.g.*, BCBSNC and UNC Health Care Open Carolina Advanced Health, BLUECROSS BLUESHIELD OF N.C. (Dec. 7, 2011), <http://www.bcbsnc.com/content/providers/news-and-information/news/dec7a-2011.htm>.

65. *E.g.*, Peter Cunningham et al., *Safety-Net Providers in Some US Communities Have Increasingly Embraced Coordinated Care Models*, 31 HEALTH AFF. 1698, 1698 (2012).

66. DELOITTE CTR. FOR HEALTH SOLUTIONS, MEDICAL HOME 2.0: THE PRESENT, THE FUTURE 6-7 (2010), [http://www.deloitte.com/assets/Dcom-UnitedStates/Local%20Assets/Documents/US\\_CHS\\_MedicalHome2\\_092210.pdf](http://www.deloitte.com/assets/Dcom-UnitedStates/Local%20Assets/Documents/US_CHS_MedicalHome2_092210.pdf).

67. Lola Butcher, *Medical Homes Prepare the Way For Accountable Care Organizations*, MANAGED CARE (October 2011), <http://www.managedcaremag.com/content/medical-homes-prepare-way-accountable-care-organizations>.

settings, such as discharge from hospitals and lapses in Medicaid coverage. By ensuring that both providers and patients follow through with the best practices, care delivery can become more efficient. As CCNC has shown, addressing factors that lead to long-term care being needed can have a great impact on costs savings.

#### VI. CONCLUSION

The emergence of PCMHs offers an opportunity for meaningful primary-care reform that could help bring down the quickly rising costs of long-term care. By implementing PCMHs into their Medicaid programs, the states can derive significant savings that will ease what has already become a large burden on their budgets. With the federal government providing funding to implement such changes and an eagerness on the part of all of Medicaid stakeholders to participate, the timing is right for the transition to a PCMH model. The savings that North Carolina has made as a result of implementing CCNC can serve as a model for the states to work toward tackling the issues that lead to significant long-term care costs. If the states are successful in doing so, it will benefit not only Medicaid funding or their general state budgets, but to society as a whole.