
THE CONSEQUENCES OF CHOICE: DOES CALIFORNIA ADEQUATELY PROTECT CHOICE OF RESIDENCE FOR INDIVIDUALS WITH ALZHEIMER'S?

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I. INTRODUCTION

Where should an elderly individual with Alzheimer's disease reside? Who should decide? These two questions concern not only those individuals suffering from Alzheimer's, but also their families and friends. This is partly because where an individual with Alzheimer's resides largely determines who will serve as the individual's personal and financial caregiver.² These questions also concern family members on another level because the individual's children and grandchildren may eventually suffer from the disease themselves.³

When posed to both caregivers and individuals suffering from the disease in its early stages, these questions elicit varied responses. A 2008 MSNBC news story on Alzheimer's, which profiled the disease's victims

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² See JoNel Aleccia, *Alzheimer's Offspring Confront Their Own Risk*, MSNBC.COM (Oct. 13, 2008, 9:25:24 AM), <http://www.msnbc.msn.com/id/27107645> (profiling Alzheimer's patients and their caretakers).

³ *Id.* ("In the study of 111 families in which two parents were diagnosed with Alzheimer's, more than 22 percent of the adult children also developed the disease. That compares to about 13 percent expected in the general population, according to the national Alzheimer's Association. The risk rose with age, affecting 30 percent of children older than 60 and nearly 42 percent of those older than 70."). Also, children with a parent who has Alzheimer's and carries a particular gene (the ApoE4 gene) demonstrate deteriorating brain function before clinical symptoms can be detected. *Id.*

and those who care for them, demonstrates this point.⁴ Francis was interviewed shortly after he began to notice symptoms characteristic of Alzheimer's disease.⁵ He explained that he did not want to burden his family emotionally or financially; for that reason, he did not tell his family about his symptoms, and he planned to divorce his wife, become indigent, and rely on government assistance as his disease worsened.⁶ Francis's care-giving preference dictated his rather extreme plan of action: out of fear of being a burden, he dismissed the possibility of in-home care and intended to separate himself from his family.⁷ On the other hand, Julie, who was caring for her father with Alzheimer's, insisted that she would stay at home if she developed symptoms of the disease.⁸ Her attitude may reflect a distaste for the housing options outside of her home, or it could reflect a desire to remain with her family and community as long as possible.

While Francis's and Julie's stories illustrate the gamut of preferences regarding choice of residence and care-giving arrangements, they also point to deeper issues within the choice-of-residence decision. In an ideal world, all persons with Alzheimer's disease would express a preference for where they would like to live and how they would like to be cared for, and their families, the relevant public health agencies, and judges would respect those preferences.⁹ As the two examples above illustrate, however, these preferences can be both varied and complex. Francis was concerned with the emotional and financial consequences of his disease, and he expected the government to support him in a care-giving role and his family to support his care-giving preference.¹⁰ Julie's situation was entirely different. She admitted that she provided in-home care for her father because that was her own preference, which she imposed upon his choice of residence.¹¹ Julie's actions demonstrate how others, even if they have the best of intentions, can affect where an individual with Alzheimer's ultimately resides.

Given the myriad variables and outside pressures involved in choice-of-residence decisions, social policies and legal protections are necessary to preserve the integrity of the decision-making process for individuals with

⁴ *See id.*

⁵ *Id.*

⁶ *Id.*

⁷ *Id.*

⁸ *Id.*

⁹ *See* Lawrence A. Frolik, *Promoting Judicial Acceptance and Use of Limited Guardianship*, 31 STETSON L. REV. 735, 741 (2002) [hereinafter Frolik, *Acceptance*].

¹⁰ Aleccia, *supra* note 3.

¹¹ *Id.*

Alzheimer's. California's substantial Alzheimer's population¹² poses a challenge to the state, but it also provides an opportunity for California to substantially impact the way the United States treats the choice of residence. This Note examines current policies and contemporary scholarship regarding individuals with Alzheimer's, and proposes several possible paths that California can take to better preserve the liberties of these individuals.

This Note proceeds as follows: Section II addresses Alzheimer's disease generally and introduces guardianships, the legal system's primary vehicle for managing individuals with diminished decision-making capacity.¹³ Sections III and IV analyze the consequences of different residential and care-giving scenarios and examine the justifications—both legal and ethical—behind regulating individuals with Alzheimer's. Sections V and VI examine the methods by which the legal system and medical professionals evaluate capacity; these sections then suggest how to best adapt these methods to choice of residence. Sections VII and VIII focus on California's recent efforts to protect the preferences and welfare of those with Alzheimer's. This Note concludes by suggesting further protections that build upon the state's efforts.

II. ALZHEIMER'S DISEASE: PATHOLOGY AND PRAGMATISM

Alzheimer's disease is the most common form of dementia,¹⁴ which is caused by damage to brain cells and which is characterized by “the loss of or decline in memory and other cognitive abilities.”¹⁵ As with other forms of dementia, Alzheimer's affects the synapses of the brain, which become unable to transfer information.¹⁶ The “hallmark” symptom of the disease, unique to Alzheimer's, is the collection of plaque deposits in the brain.¹⁷ The disease was first discovered only at the beginning of the twentieth century, when an autopsy discovered these plaques and a loss of nerve cells in the brain.¹⁸ Contemporary treatments demonstrate that the question of

¹² See ALZHEIMER'S ASS'N, 2010 ALZHEIMER'S DISEASE FACTS AND FIGURES 15 tbl.2 (2010), http://www.alz.org/documents_custom/report_alzfactsfigures2010.pdf.

¹³ See Jennifer Moye, *Guardianship and Conservatorship*, in *EVALUATING COMPETENCIES: FORENSIC ASSESSMENTS AND INSTRUMENTS* 309, 309 (Thomas Grisso ed., 2d ed., Kluwer Academic/Plenum Publishers 2003).

¹⁴ ALZHEIMER'S ASS'N, *supra* note 11, at 5 tbl.1.

¹⁵ *Id.* at 5.

¹⁶ *Id.* at 7.

¹⁷ *Id.* at 5 tbl.1.

¹⁸ See Peter V. Rabins, *Dementia and Alzheimer's Disease: An Overview*, 35 GA. L. REV. 451, 452–53 (2001).

what causes this brain damage has not been comprehensively answered¹⁹: drugs can temporarily mitigate symptoms,²⁰ but “[n]o treatment is available to slow or stop the deterioration of brain cells in Alzheimer’s disease.”²¹

Although estimates vary, there is no doubt that Alzheimer’s disease affects millions of Americans.²² According to the Alzheimer’s Association, Alzheimer’s disease affects as many as 5.3 million people in the United States,²³ and that number appears to be growing. In 2000, California was home to an estimated 440,000 senior citizens with Alzheimer’s²⁴; in 2010, estimates of the same population approach 480,000.²⁵ Nationwide, the number of people aged sixty-five years and over with the disease is expected increase more than 50% by 2030.²⁶ Without medical advances in the prevention or treatment of Alzheimer’s, as many as sixteen million elderly individuals nationwide could suffer from the disease by 2050.²⁷

A. COGNITIVE AND NON-COGNITIVE SYMPTOMS

Alzheimer’s disease involves both cognitive and non-cognitive symptoms. The earliest cognitive symptom of Alzheimer’s disease is memory impairment,²⁸ which is evidenced by deterioration in short-term memory²⁹ and difficulty remembering new information.³⁰ During later stages of the disease, individuals experience more noticeable impairment as the disease begins to affect speech; everyday learned activities; and “executive function,” which includes “the abilities to initiate, sustain[,] and stop activities, to be mentally flexible[,] and to abstract.”³¹ These symptoms can impair thinking, self-expression, decision making, and judgment.³² Disorientation, which leads to “unsafe wandering,” can also occur.³³

¹⁹ See ALZHEIMER’S ASS’N, *supra* note 11, at 8.

²⁰ *See id.*

²¹ *Id.*

²² THE PRESIDENT’S COUNCIL ON BIOETHICS, TAKING CARE: ETHICAL CAREGIVING IN OUR AGING SOCIETY 36 (2005) [hereinafter TAKING CARE], available at http://bioethics.georgetown.edu/pcbe/reports/taking_care/taking_care.pdf.

²³ ALZHEIMER’S ASS’N, *supra* note 11, at 10.

²⁴ *Id.* at 15.

²⁵ *Id.*

²⁶ *Id.* at 14.

²⁷ *See id.* More conservative estimates place the number around eleven million. *Id.*

²⁸ *See* Rabins, *supra* note 17, at 455.

²⁹ *See* Bruce Jennings, *Freedom Fading: On Dementia, Best Interests, and Public Safety*, 35 GA. L. REV. 593, 595 (2001).

³⁰ ALZHEIMER’S ASS’N, *supra* note 11, at 7.

³¹ Rabins, *supra* note 17, at 455.

³² ALZHEIMER’S ASS’N, *supra* note 11, at 7; Rabins, *supra* note 17, at 455–56.

³³ ALZHEIMER’S ASS’N, *supra* note 11, at 7.

The behaviors associated with non-cognitive symptoms place stress on caregivers and make it more likely that the individual will be institutionalized.³⁴ Non-cognitive symptoms include behavioral, emotional, psychological, and psychiatric symptoms,³⁵ of which apathy and depression are the most common.³⁶ Other symptoms include psychotic manifestations, such as delirium and hallucinations, which “can result in aggressive behavior and consequently affect the emotional state of the family and relatives, who often find it difficult to tolerate the persistence of such behavior.”³⁷ Additionally, individuals with Alzheimer’s frequently develop sleep disorders,³⁸ which can negatively affect the sleep patterns of their caregivers, who need to monitor the individuals’ behavior.³⁹

In the final stages of the disease, the individual is confined to his or her bed,⁴⁰ unable to communicate or recognize loved ones,⁴¹ and has difficulty swallowing.⁴² Alzheimer’s disease eventually leads to death, often from infections caused by immobility, like pneumonia.⁴³ The individual’s decision-making ability diminishes as the disease becomes more advanced,⁴⁴ but Alzheimer’s progresses unpredictably: some patients die just three years after experiencing their first symptom, while others live more than twenty-two years after diagnosis.⁴⁵

The rising number of people with Alzheimer’s, along with the unpredictable and debilitating nature of the disease, presents a serious challenge to society and the legal system: how does the United States protect individuals with Alzheimer’s disease, the families of those individuals, and the public, in the face of a disease that erodes capacity at an uneven and unpredictable rate?

³⁴ *See id.*

³⁵ *See* Rabins, *supra* note 17, at 456.

³⁶ *See* Fatemeh Nourhashémi et al., *Clinical Aspects of Alzheimer’s Disease*, in 2 PRINCIPLES AND PRACTICE OF GERIATRIC MEDICINE 1083, 1087 (M.S. John Pathy et al. eds., 4th ed. 2006).

³⁷ *Id.*

³⁸ *See id.*

³⁹ *See id.*

⁴⁰ ALZHEIMER’S ASS’N, *supra* note 11, at 7; Rabins, *supra* note 17, at 456.

⁴¹ ALZHEIMER’S ASS’N, *supra* note 11, at 7.

⁴² *See* Rabins, *supra* note 17, at 456.

⁴³ ALZHEIMER’S ASS’N, *supra* note 11, at 7.

⁴⁴ *See id.*

⁴⁵ *See* Rabins, *supra* note 17, at 454.

B. LEGAL TREATMENT OF ALZHEIMER'S: THE GUARDIANSHIP AND CONSERVATORSHIP SYSTEMS

The United States legal system provides assistance to individuals with diminished functional or decision-making capacity primarily through guardianships.⁴⁶ The guardianship system generally involves a court-appointed individual or agency that serves as a supervisor and surrogate decision-maker for the patient,⁴⁷ who becomes the guardian's "ward."⁴⁸ The guardian's decision-making authority is broad and covers the ward's residence and finances as well as the ward's healthcare and other basic needs.⁴⁹

The conservatorship system closely resembles the guardianship system, but a court-appointed conservator typically serves as a surrogate decision-maker only on financial matters related to the ward's estate.⁵⁰ Though a conservator's role is relatively limited, conservatorships and guardianships are both subject to abuse: conservators may misuse a patient's finances, while guardians could do the same and also unnecessarily place the ward in an institution or a substandard residence.⁵¹ Because of their potential for abuse and their constraints on a ward's autonomy, conservatorships and guardianships often represent the "most restrictive alternative" and the last resort for individuals with Alzheimer's.⁵²

III. CHOICE OF RESIDENCE: CHOICES, RISKS, AND CONSEQUENCES

When choosing a residence, long-term care must be at the forefront of an individual's considerations because, as Francis and Julie demonstrated, the patient's residence determines the type of care he or she will receive.⁵³ Choice of residence comprises two critical components: (1) the decision-making process of the individual and (2) the actual change (or lack thereof) in residence.⁵⁴ When an individual with diminished capacity is prevented from participating in the decision-making process, that individual suffers

⁴⁶ Moye, *supra* note 12, at 309.

⁴⁷ *Id.*

⁴⁸ BLACK'S LAW DICTIONARY (9th ed. 2009) (Westlaw) ("A person, usu. a minor, who is under a guardian's charge or protection."). Though sometimes referred to as a "conservatee" in conservatorship proceedings, this Note uses the general term "ward" for the sake of clarity.

⁴⁹ *Id.*

⁵⁰ *Id.*

⁵¹ *See id.* at 312–13.

⁵² *Id.* at 312.

⁵³ *See supra* Part I.

⁵⁴ *See generally In re M.R.*, 638 A.2d 1274 (1994) (examining whether developmentally disable woman had the specific capacity to express which of her two divorced parents she preferred to live with).

negative consequences from this characterization of incompetence, but the individual also potentially suffers negative consequences resulting from the actual residence decision.⁵⁵ This latter type of consequence is independent of and in addition to the consequences that result from not participating in the decision.⁵⁶ Thus each component can produce positive or negative consequences, and each component is a necessary, independent aspect of the choice-of-residence process.

A. PARTICIPATION IN THE DECISION-MAKING PROCESS

In the United States, individuals have the right to make their own decisions and control their own lives.⁵⁷ Guardianship, however, signals the loss of many rights for a ward; “appointment of a guardian results in loss of the right to make choices about residency, health care, medication, relationships, marriage, contracts, voting, driving, use of leisure time, and spending.”⁵⁸ Thus, the construct of legal competency first recognizes that individuals have particular rights, and then provides that those rights can be limited if an individual’s ability to make decisions is so impaired that the individual falls short of a particular threshold.⁵⁹ Although losing legal rights, such as the right to choose one’s residence, is a negative consequence in itself, this loss can also produce psychological issues for the deprived individual.⁶⁰

Inability to participate in the decisionmaking process in the choice of one’s residence can also signal the end of an individual’s autonomy.⁶¹ Individuals are assumed to be autonomous until proven otherwise,⁶² when the individual can no longer determine where he or she will live, the individual

⁵⁵ See Moye, *supra* note 13, at 309 (explaining that restricting an individual’s autonomy has “great significance for the individual”); see also Shauna-Vi Harlton et al., *Defining Eldercare for Policy and Practice: Perspectives Matter*, 47 FAM. REL. 281, 285–286 (1998) (describing the importance of the choice of residence and differing views as to who should make decisions regarding eldercare services).

⁵⁶ See Charles W. Lidz & Robert M. Arnold, *Rethinking Autonomy in Long Term Care*, 47 U. MIAMI L. REV. 603, 605–06 (1993).

⁵⁷ See Moye, *supra* note 13, at 310 (“All adults are presumed to be legally competent to make decisions regarding self and estate unless determined in a court of law to be otherwise.”); THOMAS GRISSO, *EVALUATING COMPETENCIES: FORENSIC ASSESSMENTS AND INSTRUMENTS 2* (2d ed., Kluwer Academic/Plenum Publishers 2003).

⁵⁸ Moye, *supra* note 13, at 313.

⁵⁹ See Moye, *supra* note 12, at 310; GRISSO, *supra* note 56, at 2.

⁶⁰ Moye, *supra* note 12, at 313.

⁶¹ See Robert P. Roca, *Determining Decisional Capacity: a Medical Perspective*, 62 FORDHAM L. REV. 1177, 1191 (1994).

⁶² *Id.* at 310; GRISSO, *supra* note 56, at 2.

likely feels a substantial loss of autonomy.⁶³ This loss is not recoverable⁶⁴: the nature of progressive dementia essentially assures that once an individual loses his or her right to autonomy, the individual will never enjoy that right again.⁶⁵

Without autonomy, the individual may feel his or her “moral personhood” has been degraded⁶⁶ as the surrounding community begins to treat the individual as an object rather than a person.⁶⁷ The individual may also suffer a loss of identity and self-esteem⁶⁸: individuals with progressive dementia often link their identities to certain activities, such as driving,⁶⁹ so one’s living situation is likely to be similarly linked to one’s identity.⁷⁰ In other words, although Alzheimer’s may progress to the point where the capacity for certain activities no longer exists, the individual may still recognize that the activity has been taken away and may feel as if he or she has lost an aspect of identity.⁷¹

Depriving an individual of his or her autonomy also undermines the concept of consumer direction,⁷² which is grounded in positive autonomy, or the power to make affirmative choices rather than simply refuse an option.⁷³ According to this concept, individuals who require long-term care should have control over their living situations, including who takes care of them and when that care is administered.⁷⁴ Although applying consumer direction to those with Alzheimer’s may present complications, the concept should not be regarded as impossible or inappropriate in this context.⁷⁵

⁶³ See Moye, *supra* note 12, at 313.

⁶⁴ Jennings, *supra* note 28, at 610 (“When freedom is curtailed in early dementia it is final chances that are being forgone, not first changes with plenty of second chances yet to come.”).

⁶⁵ See *id.* at 609–10.

⁶⁶ See *id.* at 614. Jennings defines “moral personhood” as the condition in which an individual is viewed by his or her community as a person, rather than as an object. *Id.*

⁶⁷ *Id.*

⁶⁸ *Id.* at 595–96.

⁶⁹ *Id.*

⁷⁰ *Cf. id.* (“The individual wants to continue to act as she always has, but has lost the clairvoyance about her own abilities necessary to understand that such behavior is now inappropriate.”)

⁷¹ See *id.* at 595–96; see also *supra* note 67 and accompanying text.

⁷² See Andrew I. Batavia, *The Growing Prominence of Independent Living and Consumer Direction as Principles in Long-term Care: A Content Analysis and Implications for Elderly People with Disabilities*, 10 ELDER L.J. 263, 286 (2002).

⁷³ See *id.* at 264–65.

⁷⁴ *Id.* at 266.

⁷⁵ See *id.* at 280; see also Julie L. Master, *The Benefits of Consumer-Directed Services for Caregivers of Persons with Alzheimer’s Disease*, 87 FAMS. IN SOC’Y 583, 587–89 (2006), available at http://www.alz.org/national/documents/aoagrant_tools_services.pdf (studying a system of vouchers to the family caregivers instead of decisions by the professional care manager).

B. THE CHOSEN RESIDENCE

Regardless of who makes the decision, choosing a long-term care residence is both important and difficult. Professor Peter Rabins of the Johns Hopkins Bioethics Institute describes the ideal healthcare system for individuals with Alzheimer's as one that offers a variety of options that can adapt to the individual patient's needs:

A health care system that meets the needs of people with Alzheimer's disease will make available a variety of environments (in-home care, day care, assisted living care, nursing home care), provide a range of social and medical supports, address the changing needs of the patient and family caregiver over time and preserve the dignity of each individual.⁷⁶

Professor Rabins's ideal system raises a number of important questions: Would each option be available to every individual? How would these options be financed and regulated, and how much of the financial burden would fall on the individual? How will these options "preserve the dignity of each individual"? While this Note reserves the last question for a later section, the first three questions are examined below.

1. Aging in Place: Long-Term In-Home Care

A change in residence may negatively affect the individual regardless of whether he or she participated in the decision. For an individual with diminished capacity, moving residences can cause stress, confusion, and can feel like a "physical manifestation of the loss of independence and physical well-being."⁷⁷ Moving can also cause depression and "a passive, defeatist attitude" towards life,⁷⁸ which may harm the individual's self-identity and self-esteem.⁷⁹ Though some of these negative psychological symptoms may be short-lived consequences of relocation, changing residence also negatively impacts the individual more concretely by imposing high monetary costs and occasionally causing physical weakness.⁸⁰

Declining to move and remaining in one's residence and community—known as "aging in place"—allows individuals to maintain their routines and social networks.⁸¹ Aging in place still poses a number of challenges, however. It may be difficult for an individual to maintain his or her

⁷⁶ Rabins, *supra* note 17, at 464.

⁷⁷ LAWRENCE A. FROLIK, THE LAW OF LATER-LIFE HEALTH CARE AND DECISION MAKING 43 (2006) [hereinafter FROLIK, LATER-LIFE].

⁷⁸ *Id.*

⁷⁹ See Jennings, *supra* note 28 at 603 (discussing the effects of losing the ability to drive).

⁸⁰ FROLIK, LATER-LIFE, *supra* note 75, at 43–44.

⁸¹ FROLIK, LATER-LIFE, *supra* note 75, at 43.

residence, for example, and ensuring the individual's personal health and safety may require family, community, or even government support.⁸² "Social support" from family and community members often mitigates the workload associated with aging in place, but as Francis's situation demonstrates, this sort of willing and able community support is not always present or welcomed.⁸³

Securing the necessary financing to provide in-home care is perhaps the greatest challenge of aging in place.⁸⁴ Alzheimer's is incurable and its path is unpredictable, so in-home care requires vigilance and extensive planning.⁸⁵ Government programs, such as Medicare and Medicaid, may appear as tempting options, but these programs generally provide either limited or no support.

Medicare covers only limited care for individuals after they have been released from hospitalization; Medicare does not cover long-term care.⁸⁶ Medicaid can assist low-income elderly individuals or elderly individual who have exhausted their finances on long-term care.⁸⁷ Medicaid currently covers almost half of all long-term care in the United States,⁸⁸ and long-term care for the elderly currently accounts for a third of Medicaid's total funding.⁸⁹ However, Medicaid requires a waiver for long-term in-home care,⁹⁰ and in many states these waivers are limited and provide less compensation than the program provides for nursing home care.⁹¹ If the waiver program cannot fully cover an individual's health care, the individual can utilize other state and local programs, such as adult day care, in conjunction with their waiver care.⁹²

i. Aging in Place in California

California's approach to choice of residence for those with Alzheimer's disease largely depends the ability of Medi-Cal, California's Medicaid program, to provide care-taking funding to the state's growing Alzhei-

⁸² See *id.* at 44.

⁸³ See Moyer, *supra* note 12, at 325.

⁸⁴ See generally Richard L. Kaplan, *Retirement Planning's Greatest Gap: Funding Long-Term Care*, 11 LEWIS & CLARK L. REV. 407, 410-16 (2007) (discussing the challenges to individuals incorporating long-term care into their retirement planning).

⁸⁵ See *supra* notes 21 and 45 and accompanying text.

⁸⁶ FROLIK, LATER-LIFE, *supra* note 75, at 127.

⁸⁷ See *id.* at 128.

⁸⁸ See *id.*

⁸⁹ See *id.*

⁹⁰ *Id.* at 129.

⁹¹ *Id.*

⁹² See FROLIK, LATER-LIFE, *supra* note 75, at 47-49.

mer's population.⁹³ Medi-Cal is the nation's largest Medicaid program.⁹⁴ In the fiscal year ending May 2009, the federal government paid for 57% of California's \$46.6 billion Medi-Cal budget.⁹⁵ California's portion of that \$46.6 billion comprised 19% of the state's general fund—the second largest share after K-12 education.⁹⁶ Furthermore, Medi-Cal spending has doubled over the last decade, and Medi-Cal's share of general-fund expenditures increased by 2% from 2007 to 2009. Though this increase is partly due to decreases in state revenue and rising costs of healthcare,⁹⁷ given the current economic conditions, Medi-Cal funding could face serious problems in the future.

Elderly individuals—and in-home care programs—will be particularly vulnerable to funding cuts if any are made. The elderly population in California plays a dichotomous role in the Medi-Cal budget: elderly individuals make up only 13% of Medi-Cal's beneficiaries but require 26% of the program's expenditures.⁹⁸ A significant portion of those expenditures go to community-based long-term care,⁹⁹ which now receives more Medi-Cal funding than nursing care facilities.¹⁰⁰ California's numerous Medi-Cal waiver programs likely contribute to the amount of funds allotted to elderly individuals generally,¹⁰¹ but among the categories of funding provided to disabled adults, community-based long-term care has seen the sharpest spending increase.¹⁰² These numbers are encouraging in one sense, as they demonstrate California's commitment to caring for its elderly population; however, these numbers are also troubling because they indicate that community-based long-term care may be one of the first areas targeted by any future budget cuts.

In 2008 and 2009, in the face of a \$41 billion state budget deficit, the California legislature cut funding throughout the state's healthcare system,

⁹³ See *supra* notes 21–26 and accompanying text.

⁹⁴ CAL. HEALTHCARE FOUND., *MEDI-CAL FACTS AND FIGURES: A LOOK AT CALIFORNIA'S MEDICAID PROGRAM 4* (2009), <http://www.chcf.org/publications/2009/09/medical-facts-and-figures> [hereinafter *FACTS AND FIGURES*] (follow "Medi-Cal Facts and Figures, 2009" hyperlink).

⁹⁵ *Id.* at 9.

⁹⁶ *Id.* at 8.

⁹⁷ *Id.*

⁹⁸ *Id.* at 36.

⁹⁹ *Id.* at 55.

¹⁰⁰ *Id.* at 34.

¹⁰¹ CAL. ASS'N FOR HEALTH SERVS. AT HOME, *An Overview of California Waiver & Non-Waiver Programs*, CAHSAH.COM, <http://www.cahsah.org/statebudget/waiveroverview.pdf> [hereinafter *California Waiver*] (last visited Nov. 14, 2010).

¹⁰² *FACTS AND FIGURES*, *supra* note 93, at 60.

including cuts to Medi-Cal.¹⁰³ These cuts reduced funding for Adult Day Care¹⁰⁴ and discontinued a service that helped seniors live independently or in their homes with assistance.¹⁰⁵ The federal government responded to the state's budget crisis and its requests for assistance by earmarking \$10 billion for Medi-Cal under the 2009 Federal Stimulus Package.¹⁰⁶ Nonetheless, California's budgetary problems have not disappeared and the state continues to press the federal government to contribute more funding to Medi-Cal and play a larger role in ensuring the program's vitality.¹⁰⁷

2. Supportive Housing

Supportive housing provides assistance to individuals with diminished capacity who need help in their daily lives and who may not be capable of living on their own.¹⁰⁸ The most common form of supportive housing is assisted living, which is a less expensive residential option than nursing homes.¹⁰⁹ Many assisted living facilities are prepared to accept those in the early stages of Alzheimer's, and some offer specialized wings or floors for individuals with more severe dementia who may require greater security to address symptoms like wandering.¹¹⁰

Supportive housing options cater to individuals of nearly every income level, so finances, rather than sheer preference, may dictate the type of supportive housing facility an individual chooses.¹¹¹ Certain assisted liv-

¹⁰³ Anthony Wright, *Will Further Severe Spending Cuts be Needed*, CALIFORNIA PROGRESS REPORT, Feb. 24, 2009, <http://www.californiaprogressreport.com/site/?q=node/814> [hereinafter Wright, *Cuts*] (questioning whether further cuts would be needed, and noting that California again made major spending cuts in July of 2009); Jennifer Steinhauer, *California Budget Trimmed Further*, N.Y. TIMES, July 28, 2009, http://www.nytimes.com/2009/07/29/us/29calif.html?_r=1. Less than six months later, Governor Schwarzenegger threatened even more cuts to Medi-Cal and related services, such as adult day care and In-Home Supportive Services, which are depended upon by individuals with Alzheimer's and their caregivers. Anthony Wright, *You've Got to Be Kidding*, CALIFORNIA PROGRESS REPORT, Jan. 11, 2010, <http://www.californiaprogressreport.com/site/?q=node/7327> [hereinafter Wright, *Kidding*]. The severity of these cuts could vary depending on the amount of funds provided by the federal government in connection with any federal healthcare legislation. *Id.*

¹⁰⁴ Marty D. Omoto, *Budget Update #4—Medi-Cal, Other Health Services, & Mental Health Services*, CALIFORNIA PROGRESS REPORT.COM, Feb. 27, 2009, <http://www.californiaprogressreport.com/site/?q=node/801>.

¹⁰⁵ See *infra* note 102 and accompanying text.

¹⁰⁶ See FACTS & FIGURES, *supra* note 93 at 10; John Howard, *Medi-Cal Funding Targeted in New Bills*, CAPITOL WKLY., Mar. 6, 2009, <http://www.capitolweekly.net/article.php?xid=xtduo6stblhx6t>.

¹⁰⁷ See Wright, *Kidding*, *supra* note 102; see also, *Meeting Medi-Cal's Long-Term Demands*, OFFICE OF THE GOVERNOR (July 1, 2009), <http://gov.ca.gov/index.php?/fact-sheet/12835/>.

¹⁰⁸ FROLIK, LATER-LIFE, *supra* note 77, at 63–70.

¹⁰⁹ *Id.* at 64.

¹¹⁰ *Id.* at 65.

¹¹¹ See *id.*

ing facilities, such as those associated with a Continuing Care Retirement Community (“CCRC”), offer more personalized care depending on an individual’s cultural or social preferences, but generally exceed the financial means of individuals who are not in the middle or upper class.¹¹² Board-and-care homes offer custodial care with fewer amenities and a lower price, and provide a viable option for lower income individuals.¹¹³ While board-and-care homes may allow individuals to stay closer to their communities, they may also provide less oversight than other forms of supportive housing.¹¹⁴

California regulates supportive housing that fits the definition of a “Residential care facility for the elderly” (“RCFE”)¹¹⁵ by issuing licenses¹¹⁶ that require the RCFE to comply with specified standards.¹¹⁷ RCFEs provide “care and supervision,”¹¹⁸ defined as “ongoing assistance with activities of daily living without which the resident’s physical health, mental health, safety or welfare would be endangered.”¹¹⁹ RCFEs are not intended for those who have a serious chronic illness that causes the individual to be bedridden¹²⁰ or requires “24-hour, skilled nursing, or intermediate care,”¹²¹ but such individuals who already reside in an RCFE may remain there if the facility meets certain safety requirements.¹²² In-home care is not regulated as an RCFE.¹²³

i. Supportive Housing in California

California hopes to clarify the large class of RCFEs by dividing RCFEs into three smaller levels based on the care they provide.¹²⁴ Under this system, the first level, “base care and supervision,” would be intended for individuals who “are able to maintain a higher degree of independence and need only minimum care and supervision.”¹²⁵ The second level, “non-medical personal care,” would be intended for individuals who have “func-

¹¹² *Id.* at 68–69.

¹¹³ *Id.* at 67.

¹¹⁴ *Id.* at 67–68.

¹¹⁵ CAL. HEALTH & SAFETY CODE §§ 1569.2, .312 (Deering 2009).

¹¹⁶ *Id.* §§ 1569.10, .45.

¹¹⁷ *Id.* § 1569.50(a).

¹¹⁸ *Id.* § 1569.2(b).

¹¹⁹ *Id.*

¹²⁰ *Id.* § 1569.72(a)(2).

¹²¹ *Id.* § 1569.72(a)(1).

¹²² *See id.* § 1569.72(c), (e). These requirements primarily concern procedures that would ensure the safety of bedridden individuals in case of a fire. *Id.*

¹²³ *See id.* § 1569.145(f).

¹²⁴ *Id.* § 1569.70.

¹²⁵ *Id.* § 1569.70(a)(1).

tional limitations and psychosocial needs requiring not only care and supervision but frequent assistance with personal activities of daily living and active intervention to help them maintain their potential for independent living.”¹²⁶ The third level, “health related assistance,” would be intended for individuals who need “extensive assistance with personal activities of daily living” and may need “the occasional services of an appropriate skilled professional due to chronic health problems.”¹²⁷

This proposed plan to split the RCFE classification into three levels could assist individuals choosing a residence. If codified into law, these levels may allow California’s legislature to assign different regulations for each level of care, which would provide those choosing between residence options a clearer understanding of what each level entails. Additionally, if the plan requires facilities to follow prescribed procedures to assess the appropriate level of care for each resident,¹²⁸ then residents at facilities with more than one level of care will not unnecessarily move from one level to another, and will not unnecessarily forfeit their independence. Indeed, the first two levels of care emphasize independence to an extent that may ease concerns of individuals who want to maintain as much independence as possible, but who decide that in-home care is not right for them.¹²⁹

The state legislature has expressed its intent to implement this plan.¹³⁰ Californians with Alzheimer’s disease facing a choice of residence and health care could benefit from the plan, and the could encourage the legislature to update RCFE regulations even further, but as of 2010 the plan has not been enacted.

3. Nursing Homes

Nursing homes “provid[e] skilled nursing care or rehabilitation services for [individuals who are] injured, disabled, or sick,”¹³¹ and whose acute or chronic care needs would likely make them ineligible for California’s RCFEs.¹³² In all, the 17,000 nursing homes nationwide are home to approximately 1.6 million individuals. Much of that population is temporary, however.¹³³ The average stay in a nursing home is less than one year, and

¹²⁶ *Id.* § 1569.70(a)(2).

¹²⁷ *Id.* § 1569.70(a)(3).

¹²⁸ *See id.* § 1569.70(b)(2).

¹²⁹ *See id.* § 1569.70(a)(1)–(2).

¹³⁰ *Id.* § 1569.70.

¹³¹ FROLIK, LATER-LIFE, *supra* note 77, at 72.

¹³² *See* HEALTH & SAFETY § 1569.72.

¹³³ FROLIK, LATER-LIFE, *supra* note 77, at 72.

one-third of the population stays for less than one month.¹³⁴ Individuals with severe dementia are among those who stay the longest.¹³⁵ For individuals with acute or chronic needs, nursing homes are cheaper and more efficient than hospitalization or in-home nursing care.¹³⁶ Medicare covers skilled nursing care provided in a nursing home, while Medicaid covers both nursing and custodial care.¹³⁷

Like supportive housing, nursing homes are subject to state regulation.¹³⁸ Unlike supportive housing, nursing homes are also subject to federal regulation by virtue of their dependence upon Medicare and Medicaid for reimbursement.¹³⁹ If a nursing home does not abide by regulations such as those contained in the Federal Nursing Home Reform Act, it will not qualify for Medicare and Medicaid reimbursement.¹⁴⁰ This would be a significant loss for almost any nursing home,¹⁴¹ particularly in California, where Medi-Cal and Medicare together pay for approximately 75% of all nursing home care.¹⁴²

Although nursing homes may provide efficient protections for their residents through federal regulation, they may not be an attractive option for an individual with Alzheimer's disease, particularly if that individual is still high-functioning and values his or her independence. Compared to in-home living and supportive housing, nursing homes represent a more restrictive living arrangement.¹⁴³ Thus, it seems unlikely that an individual who participates in the choice-of-residence decision would choose a nursing home for long-term care; the individual with the capacity to make that choice likely recognizes that the nursing home environment would diminish his or her remaining autonomy and privacy.

¹³⁴ *Id.*

¹³⁵ *Id.*

¹³⁶ *See id.*

¹³⁷ *See id.* at 74.

¹³⁸ *See e.g.*, CAL. HEALTH & SAFETY CODE § 12638(c) (Deering 2009) ("Any certified nursing assistant employed by a skilled nursing facility or intermediate care facility shall participate in a minimum of five hours of dementia-specific in-service training per year, as part of the facility's in-service training.").

¹³⁹ *See* FROLIK, LATER-LIFE, *supra* note 77, at 74–75.

¹⁴⁰ *See id.* at 80.

¹⁴¹ *See id.* at 75 (noting that only a minority of nursing homes do not rely upon Medicaid, with even fewer not relying upon Medicare).

¹⁴² FACTS & FIGURES, *supra* note 93, at 42.

¹⁴³ *See* FROLIK, LATER-LIFE, *supra* note 77, at 72 ("[No] one moves into a nursing home unless compelled to, because a nursing home is an institution that degrades individual autonomy, privacy, and independence.").

Nevertheless, the financial aspect of nursing home care makes nursing homes a reasonable choice for individuals with Alzheimer's who are concerned about funding their care. Medicare may cover limited nursing home stays following hospitalization, and Medicaid generally covers nursing home expenses for individuals with limited finances.¹⁴⁴ In California, nursing home patients pay only about 15% of their nursing home expenses.¹⁴⁵ It seems that nursing home care would appeal to Francis, the man who expected to leave his family and rely on government funding, because it would obviate his fear of becoming a financial burden. Again, Francis's perspective cautions against imposing one's preferences upon another individual: a nursing home may appear to be the least attractive residential option from the perspective of friends and family, but it can still be a legitimate choice for individuals with certain preferences.

IV. JUSTIFICATIONS FOR REGULATING INDIVIDUALS WITH ALZHEIMER'S

As previously discussed, the legislature and legal system regulate individuals with Alzheimer's through the guardianship system, which requires a determination of legal competency.¹⁴⁶ The justifications behind the laws that allow courts to intervene in the lives of those with Alzheimer's provide invaluable insight into how these laws are created and how they can be reshaped. Logically, proposed changes that are coherent with the premises underlying existing laws are more likely to become incorporated into the legal framework. At the same time, proposed changes must not lose sight of the treasured values that regulations risk; laws governing decision-making capacity and the choice of residence curtail individuals' rights and liberties, restrict personal autonomy, and define how a community views the individual and how the individual views him or herself.¹⁴⁷

Bruce Jennings, a Senior Research Scholar at The Hastings Center,¹⁴⁸ has formulated three models of justifications for regulating individuals with

¹⁴⁴ *Nursing Homes*, MEDICARE.GOV, <http://www.medicare.gov/nursing/payment.asp> (last updated May 8, 2009).

¹⁴⁵ FACTS & FIGURES, *supra* note 93, at 46; FROLIK, LATER-LIFE, *supra* note 75, at 74.

¹⁴⁶ See *supra* notes 45–51 and accompanying text outlining the nature of the guardianship system in the United States.

¹⁴⁷ See generally *supra* Part III (describing potential negative consequences of competency adjudications and guardianship proceedings); see also Moye, *supra* note 12, at 309 (explaining that guardianships and conservatorships are often viewed as a last resort because they irrevocably deprive a ward of the autonomy he or she has previously enjoyed).

¹⁴⁸ The Hastings Center is a bioethics institute dedicated to “address[ing] fundamental ethical issues in the areas of health, medicine, and the environment as they affect individuals, communities, and

Alzheimer's disease.¹⁴⁹ The first model, the public health model, justifies regulation when the risk an individual poses to public welfare outweighs the burden of regulation on the individual.¹⁵⁰ The second model, the guardian model, paternalistically regulates based on what third parties determine is in the "best interest" of the individual concerned.¹⁵¹ Jennings supports the third model, the conservator model, which emphasizes an individualized approach to regulation by determining how to maximize the individual's functional and decision-making capacities.¹⁵² These three models cover the spectrum of potential justifications for governmental and legal regulations and reveal that the best approach abandons broad categorical determinations in favor of individualized treatment.

A. PUBLIC HEALTH MODEL

The public health model focuses on the welfare of society at large.¹⁵³ According to this model, regulation is justified when the potential harm that an unrestrained individual poses to others outweighs the harm the regulation inflicts upon the individual's rights and liberties.¹⁵⁴ A state's police power is a well-known example of this model of justification.¹⁵⁵ The state justifies regulation on the basis of its moral duty to protect the rights of innocent third parties: ordinary citizens expect "that the state will intervene to keep the background level of risk under control,"¹⁵⁶ and the state operates in a way that promotes a "notion of reasonable expectations and rational life-planning."¹⁵⁷

Though the utilitarian emphasis of this model may seem appealing at first blush, the model is problematic when applied to individuals with Alzheimer's for two reasons: first, regulations are not supported by compelling empirical evidence that suggests significant potential harm; second, the

societies." *About Us*, THE HASTINGS CENTER, <http://www.thehastingscenter.org/About/Default.aspx> (last visited Nov. 14, 2010).

¹⁴⁹ See Jennings, *supra* note 28, at 598–99.

¹⁵⁰ *Id.* at 596.

¹⁵¹ *Id.* at 605.

¹⁵² *Id.* at 598 (distinguishing the first two models from the third by noting that the former are premised upon a "duty to protect," while the latter is premised upon a "duty to preserve and sustain.")

¹⁵³ *Id.* at 598–99. Jennings explains the public health model by quoting John Stuart Mill: "[T]he only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others." *Id.* at 599 (quoting JOHN STUART MILL, ON LIBERTY 13 (Curran V. Shields ed., Liberal Arts Press 1956) (1859)).

¹⁵⁴ *Id.* at 599.

¹⁵⁵ See *id.*

¹⁵⁶ *Id.* at 604.

¹⁵⁷ *Id.*

model adopts a categorical approach that assumes all Alzheimer's patients are the same. Before the state acts to curtail the liberties of a group of individuals for the sake of protecting third parties, the state should conduct empirical studies to determine the quantity and severity of risks posed by these individuals.¹⁵⁸ Though any risk is likely to grow along with the Alzheimer's population,¹⁵⁹ the actual risk could actually be quite low, even for activities such as driving.¹⁶⁰ More importantly, the burden of proof should be on the regulator; in other words, absent any relatively strong data that suggests that unrestrained individuals with Alzheimer's pose a serious risk, these individuals should have full access to their ordinary rights and liberties.

The public health model's categorical approach only exacerbates the absence of empirical support for regulating individuals with Alzheimer's. Rather than narrowly tailoring regulations to address specific problems, the model functions on categorizations that assume the individuals being regulated have uniform characteristics and capacities.¹⁶¹ Individuals with Alzheimer's are a poor fit for this categorical approach because the disease's progressive nature means that these individuals fall within a wide range of capacity and impairment levels.¹⁶² Regulations that assume that all individuals with the disease cannot perform a specific activity are arbitrary and unreasonable.¹⁶³

¹⁵⁸ This conclusion finds support in the notion, stated by Grisso and reiterated by Moye, that an individual is considered competent and autonomous until proven to be otherwise. GRISSE, *supra* note 56, at 2; Moye, *supra* note 12, at 310. *Contra* Jennings, *supra* note 28, at 604 (“[E]ven though the number of persons put at risk or harmed by Alzheimer's disease behavior may be relatively small, this consideration should not be decisive from an ethical or legal point of view because each individual so harmed has a right to protection, and did not voluntarily consent to be exposed to this risk. The problem, in other words, with drunken driving is not the sheer number of persons injured or killed, although that number is very large; it is the fact that the state has failed in its duty to protect innocent drivers against this risk of harm in a diligent fashion. Similarly, with risky behavior associated with Alzheimer's disease, even though the number of those harmed is not large, their moral claim to protection, to the peaceful enjoyment of public roadways and other spaces in safety and security, is forceful.” (citation omitted)).

¹⁵⁹ As previously mentioned, current estimates place the number of individuals aged sixty-five years or more with Alzheimer's around 480,000; that number could potentially reach sixteen million by 2050. *See supra* notes 21–26 and accompanying text.

¹⁶⁰ *But see* Jennings, *supra* note 28, at 604. Jennings acknowledges that the risk posed by individuals with Alzheimer's who continue to drive when they are no longer capable of doing so safely may actually be very small, but the public health model considers *any* risk to be unwarranted. *Id.*; *see also supra* note 157.

¹⁶¹ *See id.* at 602–03 (calling the public health model “both over- and under-inclusive”).

¹⁶² *See* Rabins, *supra* note 17, at 454; *see also supra* Part II-A (discussing the disease's symptoms and unpredictable course).

¹⁶³ Jennings, *supra* note 28, at 602–03 (claiming that such regulations would fail a strict scrutiny analysis).

The public health model's inadequate risk assessment and categorical approach could have devastating effects on choice of residence. Broad regulations that presume a homogenous group of similarly incapacitated individuals would prevent countless high-capacity individuals from living independently and enjoying their last months, or even years,¹⁶⁴ of the freedom, liberty, and autonomy that they will eventually lose. This approach is untenable in its current form, but could at least be improved by considering certain "situational" aspects. For instance, this model could better preserve an individual's independence and liberty by creating categories that account for features of in-home care that promote safety of both the public and the individual. Adult day care,¹⁶⁵ in-home custodial care, and technological monitoring devices¹⁶⁶ may help decrease the risks posed by independent living. Acknowledging different categories of risk, while not fixing the public health model, would at least obviate regulation as to some high-capacity individuals with Alzheimer's.

B. GUARDIAN MODEL

Under the guardian model, the individual with Alzheimer's is regulated for paternalistic reasons, with an eye towards what the regulator considers to be in the "best interests" of the individual.¹⁶⁷ The guardian model mandates regulation by way of an appointed surrogate, or guardian,¹⁶⁸ when the individual with Alzheimer's "demonstrate[s] [an] inability . . . to

¹⁶⁴ Though eventually fatal, the life expectancy after the first symptoms appear varies from patient to patient. See Rabins, *supra* note 17, at 454; see also *supra* Part II-A (providing an anecdotal range of life expectancies for Alzheimer's patients).

¹⁶⁵ Adult day care centers generally operate during daytime hours and offer a variety of activities. The centers effectively address the solitude elderly individuals often experience, but they do not provide full-time care. Richard L. Kaplan, *Cracking the Conundrum: Toward a Rational Financing of Long-Term Care*, 2004 U. Ill. L. Rev. 47, 51 (2004); see also FROLIK, LATER-LIFE, *supra* note 77, at 49.

¹⁶⁶ See e.g., John Leland, *Sensors Help Keep the Elderly Safe, and at Home*, N.Y. TIMES, Feb. 12, 2009, at A1 (profiling a technological monitoring device called "eNeighbor," which uses sensors and motion detectors to track elderly individuals as they move throughout their homes).

¹⁶⁷ See *id.* at 605 ("The principal difference between the public health and the guardian frameworks is that, while the goal of protection that public health serves is authoritative, done for and on behalf of the entire polity, the protection offered under a guardian arrangement is paternalistic, done for and on behalf of the best interests of the individual whose behavior is being controlled and whose will is being overridden."); see also *id.* at 608–09 (discussing perspectives on whether paternalism is justified as preventing "harm to the self").

¹⁶⁸ Though Jennings refers to the outside decision-maker as a "guardian," see *id.* at 605–06, the justifications underlying the guardian model should not be restricted to court-appointed guardianships. Rather, if the guardian model has merit, then such intervention would be warranted any time the necessary elements are present, whether within or without the formal legal process. Thus, this section uses the general term "surrogate" in an effort to expand the scope of this model's application.

care for his own interests and affairs.”¹⁶⁹ Unlike the public health model, the guardian model is primarily concerned with protecting the individual; thus, unlike the public health model, the guardian model protects third parties only indirectly.¹⁷⁰ Additionally, the guardian model adopts a more “situational” approach that considers an individual’s particular set of circumstances.¹⁷¹ The model’s relatively personalized approach benefits individuals with Alzheimer’s disease who face a choice-of-residence decision; those with only mild impairment to their mental and physical capacities would likely retain the participation rights that may be denied to those in the later stages of the disease who suffer from more severe impairment.¹⁷²

While the guardian model improves upon certain shortcomings of the public health model, it still contains flaws that endanger the rights of individuals with Alzheimer’s making a choice-of-residence decision. Although the guardian model examines decision-making capacity on an individual basis, the individual is measured against a threshold of capacity, which may still assess capacity too generally.¹⁷³ This creates a strict binary standard of either “capable” or “incapacitated,” which does not adequately account for the spectrum of capacities experienced by Alzheimer’s patients or the capacity required for particular decision. The capacity to make a particular decision depends on the decision itself and the individual’s capacity at the very instant the decision is made¹⁷⁴; it follows, then, that a threshold determination of capacity for all activities may needlessly exclude individuals from important decisions. For instance, an individual who is incapable of managing his or her finances may nonetheless be capable of making a choice concerning his or her preferred form of care and residence.

Furthermore, the guardian model is flawed to the extent that it relies upon “best interests” thinking.¹⁷⁵ The story of Julie, who provided in-home

¹⁶⁹ *Id.* at 605.

¹⁷⁰ *See id.* at 606.

¹⁷¹ *Id.* at 605–06 (“The state entrusts the guardian with the task of carrying out the state’s duty to protect the interests of this individual by honoring the express wishes of the individual if they are known, or, failing that, by pursuing the best interests of the individual as a reasonable person would define them.”).

¹⁷² *See id.* at 607 (noting parallels between the guardian model’s more situational approach and the care provided by nursing homes).

¹⁷³ *See id.*

¹⁷⁴ *See Rabins, supra* note 17, at 458.

¹⁷⁵ Jennings, *supra* note 28, at 605–06 (“The state entrusts the guardian with the task of carrying out the state’s duty to protect the interests of this individual by honoring the express wishes of the individual if they are known, or, failing that, by pursuing the best interests of the individual as a reasonable person would define them.”).

care for her father,¹⁷⁶ demonstrates that best interest thinking often allows third parties to impose their preferences upon the individual to be cared for.¹⁷⁷ Much like the public health model approach, this best interests thinking often exaggerates the potential risks to the individual with Alzheimer's and leads to excessively cautious treatment.¹⁷⁸ Unlike the public health model, however, the guardian model's conservative approach attempts to minimize risks to the individual's future interests rather than risks to the general public.¹⁷⁹ Though this seems a reasonable objective, the "otherwise powerful notion that it makes sense to curtail freedom now for the sake of greater freedom later" does not apply to Alzheimer's disease.¹⁸⁰ Once an individual with Alzheimer's loses independence, autonomy, and legal rights, those things are lost forever.¹⁸¹ Choice of residence illustrates this point. An individual who moves from a less restrictive to more restrictive residence seems unlikely to return again to a less restrictive residence; restrictive environments can create dependence on the more restrictive level of care,¹⁸² and may further diminish the capacity that caused the move to a more restricted environment in the first instance.¹⁸³

C. CONSERVATION MODEL¹⁸⁴

The conservation model "has three basic elements: preserving the integrity of the demented person, sustaining functional capacity, and relieving suffering."¹⁸⁵ The conservation model prioritizes moral concerns over physical comfort and other hedonistic considerations.¹⁸⁶ Rather than acting in the "best interests" of the individual, the conservation model focuses on the present condition of the individual, accepting the changes that have oc-

¹⁷⁶ See Aleccia, *supra* note 3.

¹⁷⁷ *Id.*; see also Jennings, *supra* note 28, at 605-06.

¹⁷⁸ Jennings, *supra* note 28, at 609.

¹⁷⁹ See *id.* at 608-09.

¹⁸⁰ *Id.* at 610.

¹⁸¹ See *id.*

¹⁸² See Patrick T. Murphy, *Keeping Public Wards in the Community and out of Nursing Homes*, 4 ELDER L.J. 499, 502 (1996); see also Erias A. Hyman, *The Nursing Home and Community Residence Facility Residents' Protections Act of 1985 -- Boon Or Bane?*, 32 How. L.J. 39, 40 (1989) (describing it as "transfer trauma").

¹⁸³ The disease, though unpredictable in the short-term, is unfortunately predictable in this regard. See ALZHEIMER'S ASS'N, *supra* note 11, at 8. The disease is ultimately fatal, *id.* at 7, and no treatment has proven effective in slowing or stopping the disease, *id.* at 8.

¹⁸⁴ Jennings refers to this model as the "conservator model," see Jennings, *supra* note 28, at 610, but in order to avoid confusion with the form of a conservatorship, the name has been changed to "conservation" in this Note.

¹⁸⁵ *Id.* at 611.

¹⁸⁶ *Id.* at 613.

curred and maximizing the value and meaning of the individual as he or she currently is.¹⁸⁷ The conservation model strives to protect the moral personhood of the individual with Alzheimer's disease for as long as possible by maintaining connections and relationships with the human moral community and by preventing the individual from being seen as a non-human object rather than a human being.¹⁸⁸

Jennings suggests that the conservation model could influence how Alzheimer's patients receive care and select housing. Jennings believes that individuals with Alzheimer's should be given "an environment (both physical and human) that provides them with alternative ways of sustaining their sense of self other than those past activities that have now become inappropriate or dangerous."¹⁸⁹ This suggested environment seems best accommodated by in-home housing; remaining in one's home could help maintain an individual's identity while also maintaining adequate safety in a familiar environment with familiar routines.¹⁹⁰

Jennings supports the conservation model for the personalized legal treatment it provides individuals with Alzheimer's; however, the model is susceptible to criticisms that it is too idealistic. The conservation model is premised on ethical rather than legal arguments,¹⁹¹ which makes it difficult to apply in statutory form. Jennings provides little guidance on this front: though he endorses incorporating this model into law,¹⁹² he nonetheless fails to provide any explanation as to how this could or should be done.¹⁹³

Nonetheless, the conservation model produces an important indirect effect just by being considered in the legislative and legal decision-making processes: it "increases our awareness of the moral dilemmas involved in

¹⁸⁷ See *id.* at 612.

¹⁸⁸ Jennings describes this process as "keep[ing] the person with dementia inside the human moral community as a subject, a person, for as long as possible, before his or her death or before he or she becomes a human object, a non-person." *Id.* at 614.

¹⁸⁹ *Id.* at 617.

¹⁹⁰ For a discussion of the benefits of in-home care, see FROLIK, *LATER-LIVING*, *supra* note 77, at 43.

¹⁹¹ See Jennings, *supra* note 28, at 610.

¹⁹² See *id.* at 618–19.

¹⁹³ Jennings acknowledges that the conservation model has limited application in statutory law, but he suggests that the model has greater appeal in its ability to influence the way we, as a society, approach Alzheimer's care:

This model will not solve the moral tensions inherent in the fact that the progressive course of Alzheimer's disease carries with it a moral requirement to curtail the affected person's freedom, both for the sake of others and for his or her own sake. However, in this model the justification of limiting freedom will turn on the following argument: Most of the inappropriate or dangerous behavior that early Alzheimer's disease patients wish to engage in grows out of their desire to sustain some part of themselves that they, perhaps inchoately, feel is being lost.

Id. at 616–17.

early dementia care and opens us to new possibilities for family and community support for Alzheimer's disease individuals."¹⁹⁴ Thus, even without incorporating the model directly into law, its ideals can shape the way our society approaches some of the difficult questions that arise when caring for an individual with Alzheimer's.

V. EVALUATION OF CAPABILITIES AND CAPACITY

The methods currently used to assess the capabilities and capacities of individuals with Alzheimer's disease play a critical role in how the legal system impacts the choice-of-residence decision. The guardianship framework seeks to measure an individual's capacity to perform certain functions, which includes the capacity to choose an appropriate residence.¹⁹⁵ While judges determine an individual's legal capacity, their determinations are largely based on the information they receive from the health professionals who evaluate the individual.¹⁹⁶

The current law is concerned with an individual's functional capacity, which healthcare professionals approximate by evaluating the individual's everyday behaviors and cognitive abilities.¹⁹⁷ These competency evaluations have been criticized because they do not have standardized quality controls.¹⁹⁸ Critics claim that examiners lack sufficient guidance to properly evaluate individuals,¹⁹⁹ and as a result, evaluations often generate information that courts neither want nor need.²⁰⁰ The combined efforts of Thomas Grisso and Jennifer Moye address some of the concerns associated with legal competency determinations. Grisso created a conceptual model designed to "structure and organize our thinking about legal competencies,"²⁰¹ and Moye has applied this model to guardianships and conservatorships for the elderly.²⁰²

¹⁹⁴ *Id.* at 618.

¹⁹⁵ *See supra* note 46 and accompanying text.

¹⁹⁶ *See* GRISSE, *supra* note 56, at 2.

¹⁹⁷ *See* Moye, *supra* note 12, at 322.

¹⁹⁸ *See* GRISSE, *supra* note 56, at 17–18.

¹⁹⁹ *See id.* at 11–12.

²⁰⁰ *Id.* at 12–13.

²⁰¹ *Id.* at 23.

²⁰² *See* Moye, *supra* note 12, at 322–89. Moye examined the clinical efficacy of various "forensic assessment instruments," which included psychological tests and capacity scales, *id.* at 331, and concluded that these instruments "cannot define legal competence or incompetence, because these determinations require moral and social judgments about justice that are not empirical in nature," *id.* at 388. *See also* Moye & Marson, *Assessment of Decision-Making Capacity in Older Adults: An Emerging Area of Practice and Research*, 62 (PSYCHOL. SCI.) J. GERONTOLOGY no.1, 2007 at P3, P3 *reprinted in* 7 FOCUS: J. LIFELONG LEARNING & PSYCHIATRY 88 (2009), *available at* <http://focus.psychiatryonline.org/cgi/reprint/7/1/88>.

A. GRISSO'S MODEL AND THE CAPACITY TO CHOOSE RESIDENCE

Grisso's conceptual model for assessments has five primary components: functional, causal, interactive, judgmental, and dispositional.²⁰³ The goal of Grisso's conceptual model is to "guide [competency] assessments toward objectives that are consistent with the legal criteria and process in competence cases."²⁰⁴

1. Functional Component

The functional component focuses on the functions required by one or more of eight major capacity domains: independent living, financial management, treatment consent, testamentary capacity, research consent, sexual consent, voting, and driving.²⁰⁵ Choice-of-residence capacity is not an independent domain, but it is closely related to the independent living domain.²⁰⁶

The independent living capacity domain involves its own functional element as well as a cognitive element,²⁰⁷ both of which may be relevant to a choice-of-residence capacity domain. For the functional element, independent living evaluations ask whether an individual, "with social support . . . can manage the safety and well-being of [his or her] home and person."²⁰⁸ These evaluations also assume "that some degree of risk is reasonable for all adults."²⁰⁹ The functional element of independent living capacity essentially creates a catalog of viable living situations for an individual; for instance, the functional element of independent living capacity would adequately measure whether an individual would be a good fit for in-home care and determine what other assistance, such as community care programs, may be needed. Although it is useful for determining what residence option is appropriate for an individual, the functional element does not provide insight into the capacity to make the choice-of-residence decision.

The cognitive element of independent living capacity more accurately addresses the decision-making capabilities necessary for the choice of resi-

²⁰³ See GRISSO, *supra* note 56, at 23.

²⁰⁴ *Id.*

²⁰⁵ See Moye & Marson, *supra* note 201, at P3-P4.

²⁰⁶ See *id.* at P4. The creation of additional particular capacities such as a choice of residence capacity would be welcome under a "behavioral-ecological approach," which "would seek several domains of functioning that may be salient for various, specific environmental settings, rather than assuming one set of domains could serve to describe essential functions across all settings and circumstances." Moye, *supra* note 13, at 380.

²⁰⁷ Moye & Marson, *supra* note 201, at P3-P4.

²⁰⁸ Moye, *supra* note 12, at 325.

²⁰⁹ *Id.*

dence. Four “core abilities” of consent capacity inform the cognitive element of independent living.²¹⁰ Constructed from case law, consent capacity is the “cornerstone of the medical-legal doctrine of informed consent,” which requires that consent to medical treatment be “informed, voluntary, and competent.”²¹¹

The first of the four core abilities is the ability to express a consistent choice.²¹² This ability is particularly relevant for the choice-of-residence decision because an individual who cannot express consistent preferences would likely be excluded from the process. Among individuals with dementia, however, this ability is usually the least impaired of the four core abilities.²¹³ The second ability is understanding, or an ability to comprehend the risks and benefits of an action.²¹⁴ For individuals with dementia, such understanding is typically the most severely impaired ability.²¹⁵ The third ability is appreciation, which resembles understanding to some degree: appreciation measures the individual’s ability to relate information and consequences to his or her situation.²¹⁶ The last ability is reasoning, which is the ability to evaluate and compare available choices.²¹⁷ Although the risks associated with the choice of residence may frequently be less severe than those associated with the medical care contemplated under the doctrine of informed consent, the risks are still significant as too much independence could potentially result in household accidents or insufficient treatment. Even so, the high standard that underlies the cognitive element could probably be relaxed when applied to choice of residence.

2. Causal Component

The causal component of Grisso’s conceptual model seeks to explain an individual’s functional limitations by identifying the symptoms that affect decision-making capabilities.²¹⁸ Like the functional component, the causal component prevents categorical treatments that assume group homogeneity. The component allows a court to make a more informed deci-

²¹⁰ See Moye & Marson, *supra* note 201, at P5.

²¹¹ *Id.*

²¹² *Id.*

²¹³ *Id.*

²¹⁴ *Id.*

²¹⁵ *Id.*

²¹⁶ *Id.*

²¹⁷ *Id.*

²¹⁸ See Robert P. Roca, *Determining Decisional Capacity: A Medical Perspective*, 62 FORDHAM L. REV. 1177, 1182–83 (1994). A clinical psychiatric diagnosis can protect the integrity of the causal component by defending against ageism and other “inappropriate influences” on capacity judgment. See *id.* at 1195.

sion, but it also safeguards the individual from “inappropriate influences,” such as the individual’s age or the disease or impairment involved.²¹⁹

3. Interactive Component

Grisso’s third component, the interactive component, further emphasizes a situational approach to individuals with Alzheimer’s who face a choice of residence. The interactive component suggests that capacities should be “described and considered in relation to several contextual factors, including the situational demands (e.g., living arrangements or financial assets) and social supports or stressors.”²²⁰ The interactive component endorses a “least restrictive alternative” approach, whereby the individual may operate to the fullest extent practicable given his or her particular context and capacities.²²¹ For instance, rather than declaring incompetence or requiring guardianship, the interactive component proposes alternatives such as assisted decision-making, which would allow the individual to participate in decisions, but to a more limited extent.²²²

4. Judgmental and Dispositional Components

The final two components of Grisso’s conceptual model—the judgmental and dispositional components—highlight the extent to which an individual depends upon the discretion and decision-making powers of judges and medical evaluators.²²³ Legal capacity determinations often do not fall within clear bright-line rules; judges balance myriad factors to assess when the benefits of a restrictive arrangement, such as guardianship or housing in a facility, outweigh the costs the arrangement levies on an individual’s liberty.²²⁴ The judgmental and dispositional components suggest that decision-makers should focus on the practical consequences of their decisions, particularly the serious, potentially irrevocable consequences the

²¹⁹ *Id.* at 1195; see Moyer, *supra* note 12, at 326 (explaining that states that have undertaken guardianship reform have removed prejudicial language from their guardianship statutes, including terms like “advanced age,” which alone has no causal connection to the need for guardianship services).

²²⁰ Moyer, *supra* note 12, at 328.

²²¹ *Id.* at 330.

²²² See *id.* The primary focus of the interactive component is finding a workable solution given the individual’s capacity. Assisted decision-making is just one example of a solution that would relatively incapacitated individuals to “participate as fully as possible in decisions affecting them.” *Id.*

²²³ See *id.* at 330 (“The law describes no absolute degree of functional deficiency or person-situation incongruence that defines when an individual should be declared incompetent and in need of a guardian. Statutes frequently employ terms like *sufficient*, *grave*, or *substantial* to refer broadly to the necessary degree of deficit, yet these are little more than markers signifying that a *highly discretionary judgment* must be made.” (final emphasis added)).

²²⁴ See *id.* at 330–31.

decision will have on that specific individual's life.²²⁵ This type of humanizing empathy would make restrictive arrangements a last resort, and would work well with the interactive component's least restrictive alternative approach.

5. Competency for Choice of Residence

Applying Grisso's conceptual model to individuals with Alzheimer's who face a choice-of-residence decision provides guidance for defining the required capacity. The functional component suggests that this capacity should consider both the individual's ability to live in his or her desired environment, and the individual's ability to make an informed decision under the four core abilities of consent. This capacity should reflect the causal component by requiring causal support for any alleged functional deficiencies. Incorporating the interactive component requires that this capacity be tailored to the individual's particular circumstances, including social support and financial means. The judgmental and dispositional components indicate that such a definition of capacity should not ignore the practical and profound consequences of a capacity determination.

B. PRACTICAL LIMITATIONS OF GRISSO'S MODEL

While Grisso's conceptual model may provide guidance for healthcare professionals and judges, most capacity determinations are made by families, outside of the legal system.²²⁶ Families control whether the legal system ever gets involved, and generally prefer to use less expensive and less restrictive forms of management.²²⁷ An unobstructed path to the legal system is critical to individuals who want to participate in the choice-of-residence decision. These individuals need a way for their wishes to be heard if their families seek to restrict their input, but it may be difficult for them to initiate a complaint without help. California has made efforts to assist elders who find themselves in this situation through media campaigns that increase awareness of elder and dependent-adults abuse,²²⁸ and through local Adult Protective Services agencies that offer twenty-four-hour hotlines for reports of abuse.²²⁹ Continuing these efforts and improving know-

²²⁵ See *id.*

²²⁶ See Moye & Marson, *supra* note 201, at P3.

²²⁷ See *id.*

²²⁸ Press Release, Office of the Cal. State Att'y Gen., *California Attorney General's Office Launches Statewide Elder and Dependent Adult Abuse Media Campaign*, (Apr. 25, 2003), <http://caag.state.ca.us/newsalerts/release.php?id=903&year=2003>.

²²⁹ See CAL. DEP'T OF JUST., A CITIZEN'S GUIDE TO PREVENTING & REPORTING ELDER ABUSE (2002), available at http://ag.ca.gov/bmfea/pdfs/citizens_guide.pdf.

ledge of and access to such reporting services should help elders retain their roles in the decision-making process.

It is worth reemphasizing that any conceptual model must be applied to all participants in the decision-making process, including healthcare professionals. Although standardized tests may be more objective and reliable than general clinical evaluations,²³⁰ they may lack the specificity required to determine which functional abilities affect which decisions.²³¹ Standardized tests frequently do not account for the interactive component, which may provide insight into which environments maximize the individual's capacity.²³² Psychiatric examinations should determine specific causal relationships between symptoms and their effects (the causal component),²³³ and should consider the four core abilities of consent when determining an individual's decision-making capacity.²³⁴ Finally, one must keep in mind that "[c]apacity assessments are ultimately human judgments occurring in a social context"²³⁵; thus, capacity determinations should be well documented and subject to peer review in order to ensure that evaluators use appropriate methods to reach reasonable decisions.²³⁶

VI. GUARDIANSHIP REFORM AND THE LEAST RESTRICTIVE ALTERNATIVE

Historically, the guardianship process has suffered from many flaws²³⁷: for much of the twentieth century, courts and evaluators operated on vague definitions of competency,²³⁸ and proposed wards were frequently subjected to procedural disadvantages that included being denied counsel and adequate notice, and being excluded from hearings.²³⁹ Furthermore, guardians were not monitored to ensure that they fulfilled their guardianship duties.²⁴⁰ At the end of the twentieth century, nationwide guardianship

²³⁰ See Moye & Marson, *supra* note 201, at P4–P5.

²³¹ See Roca, *supra* note 218, at 1182–83 (describing “false positives” from people with limited education).

²³² See Moye, *supra* note 12, at 327.

²³³ Roca, *supra* note 218, at 1182–83.

²³⁴ Moye & Marson, *supra* note 201, at P5; *see also* Roca, *supra* note 218, at 1194–95 (describing a case where headphones proved to be the needed solution for a man who appeared incompetent).

²³⁵ Moye & Marson, *supra* note 218, at P8.

²³⁶ *See id.*

²³⁷ See Moye, *supra* note 12, at 313–14.

²³⁸ *Id.* at 314.

²³⁹ *Id.*

²⁴⁰ *Id.*

reforms established a uniform legal standard of incompetence,²⁴¹ which sought to (1) protect individuals from having a guardian just because of a mental disorder, (2) require a guardian only when functional consequences are extreme, and (3) require evaluations to provide enough functional data for courts to create specialized guardianships.²⁴²

The concept of the least restrictive alternative was one of the sources that inspired reform.²⁴³ The United States Supreme Court adopted this concept into law in *Shelton v. Tucker*,²⁴⁴ a decision that has been described as “a directive to states that in achieving their legitimate goals, they must choose methods least intrusive on the fundamental rights of the people involved.”²⁴⁵ In some situations the least restrictive alternative concept would avoid appointing a guardian altogether; however, the concept can also be applied to guardianships by restricting the guardian’s influence to particular areas where an individual has functional deficiencies and allowing the individual to retain control of the areas where he or she still has the capacity to do so.²⁴⁶

VII. GUARDIANSHIP IN CALIFORNIA: “CONSERVATORSHIP OF THE PERSON”

California’s legal system provides multiple forms of “conservatorships of the person”—the state’s term for guardianships²⁴⁷—as well as opportunities to modify conservatorships. Section 1801 of California’s probate code authorizes a court to appoint a conservator for an individual who has dementia,²⁴⁸ qualifies as a “developmentally disabled adult,”²⁴⁹ or otherwise “is unable to provide properly for his or her personal needs for physical health, food, clothing, or shelter.”²⁵⁰ Even so, the Supreme Court’s decision in *Shelton v. Tucker* still guides California courts to choose the least restric-

²⁴¹ *Id.* (reporting that “[f]rom 1988–2000 a total of 302 guardianship bills were passed in the United States”).

²⁴² *Id.* at 316–17.

²⁴³ Norman Fell, *Guardianship and the Elderly: Oversight not Overlooked*, 25 U. Tol. L. Rev. 189, 201 (1994).

²⁴⁴ *Shelton v. Tucker*, 364 U.S. 479, 488 (1960); Fell, *supra* note 243, at 201.

²⁴⁵ Fell, *supra* note 243, at 201.

²⁴⁶ *Id.*

²⁴⁷ CAL. PROB. CODE § 1801(a) (Deering 2009). This is not to be confused with the term “conservator” introduced earlier in the Note. A conservator is a guardian whose authority is restricted to an individual’s estate only. In California, conservators are called “conservators of the estate.” *Id.* § 1801(b).

²⁴⁸ *Id.* § 2356.5(a).

²⁴⁹ *Id.* § 1801(d).

²⁵⁰ *Id.* § 1801(a).

tive alternative needed to protect the individual.²⁵¹ One example of a common alternative in the state is a “limited conservatorship,” which reserves more rights for the ward than traditional conservatorships.²⁵² These conservatorships may not apply to individuals with Alzheimer’s: it is unclear whether the statute includes individuals with dementia, especially given that the statute dedicated to dementia, § 2356.5, does not refer to limited conservatorships.²⁵³

A. LIMITED CONSERVATORSHIPS AND THE IMPORTANCE OF DEFAULT RULES

Under California’s statutory scheme, the default rule for conservatorship proceedings grants a conservator full authority to make decisions for the ward, including decisions regarding where the ward will live. The consequence of this default rule is that the ward loses the ability to choose his or her residence, unless the ward can convince the court that a full-on, traditional conservatorship is unnecessary.²⁵⁴ This, however, is not the case with a limited conservatorship default rule. Under a limited conservatorship default rule, a court can increase a limited conservator’s authority to include decisions such as those regarding the ward’s residence, but the court may do this only after making adequate findings to support such increased authority.²⁵⁵

The default rules in California imply a presumption of complete incapacity, which is a presumption against allowing an individual with Alzheimer’s to retain his or her rights. This is incompatible with the notion that individuals’ rights and liberties should not be curtailed without reason.²⁵⁶ Furthermore, because a court’s findings are dependent upon examinations by medical professionals, the adequacy of which many scholars question,²⁵⁷ the presumption of incapacity underlying California’s current default rule unfairly burdens potential wards.

A limited conservatorship default rule would better serve the goals of conservatorship proceedings: balancing the individual’s rights with his or her welfare and the welfare of society. Limited guardianship accounts for

²⁵¹ *Id.* § 1800.3(b).

²⁵² *Id.* § 1801(d); *see id.* § 2351.5 (listing the powers of a limited conservator).

²⁵³ *See id.* § 2356.5.

²⁵⁴ *Id.* § 2352.

²⁵⁵ *Id.* § 2351.5(b)(1).

²⁵⁶ *See id.* § 1800(d).

²⁵⁷ *See supra* part V, discussing criticisms of examination procedures and introducing Grisso’s model.

capacity as a continuum rather than a binary, and would require a causal component to disqualify the individual for exercising a specific power.²⁵⁸ Additionally, limited guardianship comes without the stigma of being deemed “incompetent” and better acknowledges and preserves an individual’s remaining capacities in accordance with Jennings’s conservation model.

B. CALIFORNIA PROBATE CODE § 2356.5: CONSERVATORSHIPS FOR INDIVIDUALS WITH DEMENTIA

Section 2356.5 of the California Probate Code specifically addresses conservatorship for individuals with dementia, and has implications for the choice-of-residence decision.²⁵⁹ The statute permits a conservator of an individual with dementia to place that individual in either of two specified types of facilities: a “secured” RCFE or a similarly secure nursing facility.²⁶⁰ Placement in these facilities must satisfy several statutory requirements, including a requirement that the facility be the least restrictive residence possible given the ward’s needs.²⁶¹ The individual must also be deemed impaired and unable to give informed consent or “understand and appreciate the consequences of his or her actions,”²⁶² and a medical professional must find that a restricted, secure environment will benefit the ward.²⁶³

These prerequisites to placement in a restrictive facility provide a model that should apply to all choice-of-residence options. The non-exhaustive list of relevant impairments that the statute references includes several conditions connected with Alzheimer’s, but statute protects individuals from arbitrary determinations by requiring a close connection between the deficit and the decision.²⁶⁴ This requirement effectively incorporates the causal component of Grisso’s model. The statute’s language focuses on an individual’s ability to understand and appreciate—the two cognitive abilities most affected by Alzheimer’s²⁶⁵—and by doing so may prevent courts from wandering into other irrelevant inquiries.²⁶⁶

²⁵⁸ FROLIK, LATER-LIFE, *supra* note 77, at 177.

²⁵⁹ See PROB. § 2356.5(a) (barring placement of a ward or conservatee in a mental health treatment facility against his or her will).

²⁶⁰ *Id.* § 2356.5(b); CAL. HEALTH & SAFETY CODE §§ 1569.698, .691 (Deering 2009).

²⁶¹ PROB. § 2356.5(b)(4).

²⁶² *Id.* § 2356.5(b)(2).

²⁶³ *Id.* § 2356.5(b)(3).

²⁶⁴ *Id.* § 811(a).

²⁶⁵ See *supra* notes 213–214 and accompanying text.

²⁶⁶ See PROB. § 2356.5(b)(2).

The protection § 2356.5 provides is limited, however, because it applies only to the relatively narrow circumstances of a conservator placing a ward in a secured facility.²⁶⁷ The legislature could expand the statutory procedures included in § 2356.5 to apply to all choice-of-residence decisions for individuals with alleged mental deficits, whether the individual is in a conservatorship, a limited conservatorship, or is under some other form of care. At the very least, this procedure should apply to choice-of-residence decisions for anyone who is non-consensually moved from his or her home, which is presumed to be the least restrictive residence.²⁶⁸

The legislature could also expand the qualifications of the medical professional that determines whether a restrictive setting would benefit a ward. Section 2356.5 currently requires that the medical professional be either a physician or a psychologist, and have at least two years of experience diagnosing dementia.²⁶⁹ Although this requirement may help protect individuals, it could be interpreted as asking only for a diagnosis of dementia, not any evaluation of capacity or fit for certain residential environments. California should require more than experience diagnosing dementia: medical professionals should have experience with California's conservatorship system and with legal competency evaluations of diminished capacity individuals so that the medical professional fully understands the environment and consequences of more restrictive residences. Additionally, the legislature should require courts to consult such a qualified medical professional for all capacity and choice-of-residence decisions.

C. FINANCIAL COSTS AND INEFFICIENCIES OF LIMITED CONSERVATORSHIPS

Though individuals with Alzheimer's may be ineligible for limited conservatorships,²⁷⁰ eligibility would probably have few practical consequences for those individuals. Nationwide, only a small percentage of guardianships are limited.²⁷¹ This is likely due in part to the legal expenses associated with guardianship proceedings, which make the court a last resort for many individuals and their families²⁷²; plausibly, high function-

²⁶⁷ See *id.* § 2356.5(b).

²⁶⁸ See *id.* § 2352.5(a).

²⁶⁹ *Id.* § 2356.5(f)(3).

²⁷⁰ See *supra* note 253 and accompanying text.

²⁷¹ See Moye, *supra* note 12, at 317; see also FROLIK, LATER-LIFE, *supra* note 77, at 180.

²⁷² See FROLIK, LATER-LIFE, *supra* note 77, at 180.

ing individuals who would make the best candidates for limited guardianships avoid the judicial system until their dementia advances.

The judiciary's role in guardianship proceedings likely contributes to the infrequency of limited guardianships as well.²⁷³ A perfect guardianship system might consider only the needs of the proposed ward, but the judges who control the guardianship system position themselves as problem-solvers who must weigh the interests of all the affected parties.²⁷⁴ Alzheimer's is a progressive illness, which essentially guarantees that the afflicted individual's capacity will diminish over time.²⁷⁵ Thus, a limited guardian would eventually have to return to court to expand the scope of his or her powers over the impaired individual.²⁷⁶ Full guardianships, on the other hand, almost ensure that the parties will not come before the court a second time because full guardians can do almost anything without the court's approval.²⁷⁷ A judge who considers these options likely balances the temporary freedom of a limited guardianship against the judicial inefficiency and financial burdens it entails, and concludes that the latter carries more weight.

Despite the inefficiencies and expenses arguably inherent in limited guardianships for Alzheimer's patients, it is still important for judges to consider the potential benefits of postponing a fully restrictive guardianship. If California were to change its default rules to grant limited guardianships, then judges would be required to engage in this balancing test before determining that a full guardianship is appropriate. Requiring this level of consideration could reveal possible benefits that were not immediately apparent; for instance, limited conservatorships may reduce the number of unmerited conservatorships proceedings because full legal authority over impaired individuals will be more difficult to obtain. Additionally, requiring a conservator to return to court in order to broaden the scope of his or her control over the impaired individual makes it more likely that the conservator will not attempt to gain or exercise expanded control until the situation demands it.

D. CONSERVATORSHIP REFORM IN CALIFORNIA

As previously mentioned, early versions of guardianship procedures sometimes denied alleged wards the procedural safeguards guaranteed in

²⁷³ See Frolik, *Acceptance*, *supra* note 8, at 741.

²⁷⁴ See *id.*

²⁷⁵ See *supra* note 182.

²⁷⁶ See Frolik, *Acceptance*, *supra* note 8, at 743.

²⁷⁷ See *id.* at 742–43.

other areas of law.²⁷⁸ Due process rights were particularly impacted: early guardianship procedures affected could leave the individuals involved without counsel or adequate notice, and could even leave the individual out of the proceedings.²⁷⁹ Current California law corrects these deficiencies by ensuring that individuals subject to conservatorship proceedings receive adequate notice and information explaining the nature of conservatorship proceedings,²⁸⁰ by requiring that the individual be present at the proceedings absent some extenuating circumstances,²⁸¹ and by providing such individuals with the right to a jury trial.²⁸² California will also appoint counsel at the individual's request,²⁸³ or if the court determines that counsel would be "helpful to the resolution of the matter or . . . necessary to protect the interests" of the individual.²⁸⁴

These provisions certainly remedy many of the glaring shortcomings of earlier guardianship systems, but California should continue to improve upon its current laws. Individuals who are represented by counsel during conservatorship proceedings are more likely to secure a limited conservatorship, generally a favorable outcome, than individuals without representation.²⁸⁵ California should acknowledge this link between representation and favorable outcomes by requiring that counsel represent, or at a minimum advise, individuals involved in choice-of-residence proceedings. Additionally, most of the due process protections of proposed wards depend upon the services that a court investigator provides. For example, the court investigator provides the individual with notice and information regarding the proceedings, and the court investigator interviews the individual and his or her family,²⁸⁶ reviews the petition,²⁸⁷ determines whether the individual is impaired under the relevant statute,²⁸⁸ and recommends whether the individual requires counsel.²⁸⁹ California already requires that court investiga-

²⁷⁸ See *supra* Part VI.

²⁷⁹ See *supra* Part VI.

²⁸⁰ CAL. PROB. CODE § 1821 (Deering 2009) (detailing a list of items that must be included in supplemental forms accompanying notice to a proposed ward).

²⁸¹ *Id.* § 1825(a)(3).

²⁸² *Id.* § 1828(a)(6).

²⁸³ *Id.* § 1471(a)(1).

²⁸⁴ *Id.* § 1471(b). For example, if the court investigator finds that the individual does not want to attend or does not wish to contest the conservatorship and particular conservator, *id.*, or if the individual has a medical excuse, *id.* § 1826(b)(1).

²⁸⁵ See, e.g., Moyer, *supra* note 12, at 319 (stating that the presence of counsel leads to a higher-than-average percentage of limited guardianships).

²⁸⁶ PROB. § 1826(a).

²⁸⁷ *Id.* § 1826(d).

²⁸⁸ *Id.* § 1826(d)(2).

²⁸⁹ *Id.* § 1826(j).

tors have knowledge of the relevant law²⁹⁰ and the ability to communicate with proposed wards,²⁹¹ but the state should also require court investigators to have sufficient education and experience regarding Alzheimer's and other forms of dementia to adequately make these important factual findings.²⁹²

VIII. POSSIBLE ADDITIONAL MEASURES TO PROTECT INTEGRITY OF CHOICE OF RESIDENCE

While the aforementioned improvements to California's conservatorship system would help limit unnecessary restrictions on individuals with diminished capacity, additional measures within and outside of the system could provide useful tools for preserving the rights of these individuals, particularly their right to participate in the choice-of-residence decision. This section discusses three possible additional measures that could serve the interests of individuals with diminished capacity: a three-person expert panel for conservatorship hearings; government compensation for family members to take care of elderly individuals; and advance directives that preserve an individual's wishes as his or her dementia advances.

A. FLORIDA'S THREE-PERSON PANEL FOR GUARDIANSHIP HEARINGS

California could improve its conservatorship system by adopting a three-person panel system similar to what Florida uses in its guardianship proceedings. Florida requires that courts in guardianship hearings appoint an "examining committee,"²⁹³ which must consist of one psychiatrist or other physician, and two experienced, trained individuals capable of formulating an expert opinion.²⁹⁴ One member of the panel "must have knowledge of the type of incapacity alleged in the [guardianship] petition."²⁹⁵ This statutory requirement mandates greater expert participation in guardianship proceedings than California's statutes, which require only that a guardianship petition be supported by a psychologist or physician who has two years of experience diagnosing dementia.²⁹⁶ Florida's system allows input from individuals with extensive knowledge of residence options and the consequences of diagnoses, such as gerontologists and social work-

²⁹⁰ *Id.* § 1454(b)(2).

²⁹¹ *Id.* § 1454(b)(1)(ii).

²⁹² *See id.* § 1454(b)(1)(ii).

²⁹³ FLA. STAT. ANN. § 744.331(3)(a) (LexisNexis 2009).

²⁹⁴ *See id.*

²⁹⁵ *Id.*

²⁹⁶ *See* CAL. PROB. CODE § 2356.5(f)(3) (Deering 2009).

ers²⁹⁷; on the other hand, California's system does not require physicians to have any knowledge of non-medical issues.²⁹⁸ Though Florida's system provides judges with critical insight, increased medical input may be more costly in terms of both money and time.²⁹⁹ If California cannot afford to adopt Florida's model, California can at least follow Florida's example by educating judges and court investigators in the areas in which gerontologists, social workers, and others may have superior knowledge.

B. FINANCIAL SUPPORT FOR CAREGIVERS

Outside of the conservatorship system, California could keep more diminished-capacity elderly individuals in their homes and communities by providing financial assistance to their familial caretakers in the form of a stipend or tax credit.³⁰⁰ This financial assistance could lessen a family's incentives to file a conservatorship petition because it would ease the financial burden of in-home care and would reduce the need to take over the individual's finances in order to pay for such care.

Despite the potential upside of financial assistance, this program would have a significant and problematic downside. Paying families to provide in-home care to their impaired elderly family members could spawn cases of elder abuse if the individual does not receive the necessary level of care. A financial assistance program would lack the monitoring that the conservatorship system requires, and thus would be at greater risk for abuse.³⁰¹ Such a program would be further complicated by the progressive nature of Alzheimer's disease: program administrators would have to determine the appropriate level of compensation as the disease advances, without over- or under-compensating the caretakers—a serious administrative hurdle.

C. ADVANCE DIRECTIVES

Advance directives could aid the conservatorship system and judicial decisions regarding diminished-capacity individuals in general. Typically used in "living wills" and end-of-life medical decisions, advance directives preserve an individual's clear and competent wishes regarding potential fu-

²⁹⁷ See FLORIDA STAT. ANN. § 744.331(3)(a).

²⁹⁸ See *supra* Part VII-B discussing relevant provisions of California's Probate Code.

²⁹⁹ See FROLIK, *LATER-LIFE*, *supra* note 77, at 180.

³⁰⁰ See Murphy, *supra* note 181, at 505.

³⁰¹ See CAL. PROB. CODE § 1850 (Deering 2009) (requiring the court investigator to visit the guardian and issue reports on a semi-annual basis for the first year then an annual or bi-annual basis thereafter); *id.* § 1513.2 (making it a misdemeanor for a guardian to knowingly submit a report that contains falsified information).

ture events.³⁰² This concept could also apply to choice-of-residence decisions: an individual's clear and competent choice of residence, in writing, could guide conservators and judges and could prevent others from imposing their preferences upon the individual as his or her capacity declines.

Critics of advance directives claim that a conflict exists "between the interests of the competent person as they are expressed in the advance directive and the incompetent person at the time the directive would be followed."³⁰³ Critics may level the same criticisms at advance directives that address choice of residence. On one hand, this criticism applies the same paternalistic "best interests" thinking that is so common throughout the conservatorship system. As Jennings recognizes in his conservation model, this type of thinking harms the individual and diminishes the individual's moral personhood.³⁰⁴ On the other hand, this criticism raises important questions regarding the viability of advance directives for future possibilities: can an individual truly express his or her choice-of-residence preference for all possible situations?³⁰⁵ Is there a capacity requirement for individuals who choose to express their preferences in an advance directive? While the first question does not have a clear answer, the second question probably requires a response in the affirmative. After all, if there is a capacity requirement for individuals who wish to participate in the choice-of-residence decision at the time of a possible move, it follows that there should probably be a similar requirement for individuals who wish to make choice-of-residence decisions before any move is proposed.

A surrogate or proxy system could address the uncertainties that riddle advance directives while also allowing an individual to exercise a certain degree of decision-making autonomy throughout the course of his or her disease.³⁰⁶ This system would work by allowing an individual to choose a trusted friend or family member to make decisions for the individual if the individual loses the capacity to do so on his or her own behalf.³⁰⁷ This surrogate decision-maker, as someone close to the incapacitated individual, would consider the individual's best interests while adjusting for any unaddressed, unforeseen contingencies.

³⁰² See Ben A. Rich, *Advance Directive Instruments for End-of-Life and Health Care Decision Making: Personhood, Patienthood, and Clinical Practice: Reassessing Advance Directives*, 4 PSYCHOL. PUB. POL'Y, & L. 610, 610-11 (1998).

³⁰³ *Id.* at 612.

³⁰⁴ See *supra* note 63 and accompanying text.

³⁰⁵ See TAKING CARE, *supra* note 21, at 214.

³⁰⁶ See *id.*

³⁰⁷ See *id.* at 215.

Still, the surrogate system raises a familiar capacity question: At what point does an individual lack the capacity to appoint a surrogate?³⁰⁸ The exact “point” is not important as that point’s position relative to the point at which an individual lacks the capacity to choose his or her residence. Appointing a surrogate to a general decision-maker position likely requires less capacity than weighing the costs, benefits, and potential consequences of various residence options.³⁰⁹ This means that individuals who lack the capacity to choose their residence may still be able to participate indirectly by appointing a surrogate to make the decision for them.

Advance directives and surrogates systems are two effective means of preserving an incapacitated individual’s rightful participation in choice-of-residence decisions. The public has been slow to adopt these measures, however.³¹⁰ California could encourage these advance planning measures by imposing statutory requirements for physicians to inform individuals of these options before their decision-making capacity has diminished.

IX. CONCLUSION

Despite rising numbers of individuals with Alzheimer’s,³¹¹ California has recently cut many senior-focused programs that addressed the challenges these individuals and their families face.³¹² Cuts to services such as home meal deliveries and Alzheimer’s Day Care Resource Centers threaten make it more difficult for individuals with Alzheimer’s to live in their homes and for caregivers to honor residence preferences, whether the individual is mostly self-sufficient or under the care of family or community members.³¹³ Other cuts have weakened protections against elder abuse: both the state’s Long-Term Care Ombudsman and Senior Legal Hotline programs have lost funding.³¹⁴

While cuts to senior programs are surely harmful to the integrity of the choice-of-residence process, protecting California’s substantial and ex-

³⁰⁸ See Scott Y.H. Kim, *The Capacity to Appoint a Proxy and the Possibility of Concurrent Proxy Directives*, 24 BEHAV. SCI. & L. 469, 470 (2006).

³⁰⁹ See *id.*

³¹⁰ Rich, *supra* note 304, at 610. This is true despite government efforts to encourage advance directives. *Id.*

³¹¹ See *supra* notes 21–26 and accompanying text.

³¹² See Marty D. Omoto, *Budget Update # 3: Senior (Aging) Programs*, CALIFORNIA PROGRESS REPORT, Feb. 26, 2009, <http://www.californiaprogressreport.com/site/?q=node/807> [hereinafter Omoto, *Budget Update*]; Marty D. Omoto, *Schwarzenegger Administration Proposes Deep Cuts, Elimination of Medi-Cal Programs*, CALIFORNIA PROGRESS REPORT, Jan. 22, 2010, <http://www.californiaprogressreport.com/site/?q=node/7365>.

³¹³ See Omoto, *Budget Update*, *supra* note 314.

³¹⁴ *Id.*

panding Alzheimer's population is not simply an issue of funding. To adequately protect this growing population, California's judges and lawmakers must understand the importance of the choice of residence decision. For an individual with Alzheimer's, the two components of the choice-of-residence decision—participation in the decision-making process and the actual residence chosen—are critical to that individual's care, health, autonomy, moral personhood, and liberty. California's judicial system must embrace its ability to limit the scope of conservatorships, fulfill its duty to monitor wards and protect them from abuse, and exercise its discretion to consider the consequences of choice-of-residence decisions. The state's lawmakers should strongly consider changes to California's conservatorship system, such as increasing the role of non-physician experts in the conservatorship process, in order to protect the integrity of the choice of residence. California should also promote planning tools, such as advance directives and surrogate decision-makers, and should provide necessary support to caregivers.

When enacting laws or hearing cases regarding individuals with Alzheimer's, California's legislators and judges should also bear in mind the unpredictable and uneven nature of Alzheimer's. California's multi-faceted approach to Alzheimer's generally, and choice of residence in particular, should be situational and flexible. Policies and laws should consider those with Alzheimer's as individuals with vastly differing circumstances, rather than as members of a broad, homogenous group; and lawmakers and judges must tailor their approaches to Alzheimer's and choice of residence to consider not only on an individual's particular circumstances, but also the future medical advances in gerontology and the diagnosis and treatment of the disease. California's policies must be up to date: the state should regularly re-examine its legal and social treatment of individuals with Alzheimer's to ensure that the laws reflect the most recent medical understanding of Alzheimer's.

And most important of all, California lawmakers must remember what is at stake: when individuals with Alzheimer's are denied the right to participate in the important decisions that impact their lives, such as the choice-of-residence decision, those individuals lose their last opportunity to enjoy the liberties that most Americans take for granted.